



# CLAPA Regional Coordinators Project

## Evaluation Interim Report

End of Year One

November 2013

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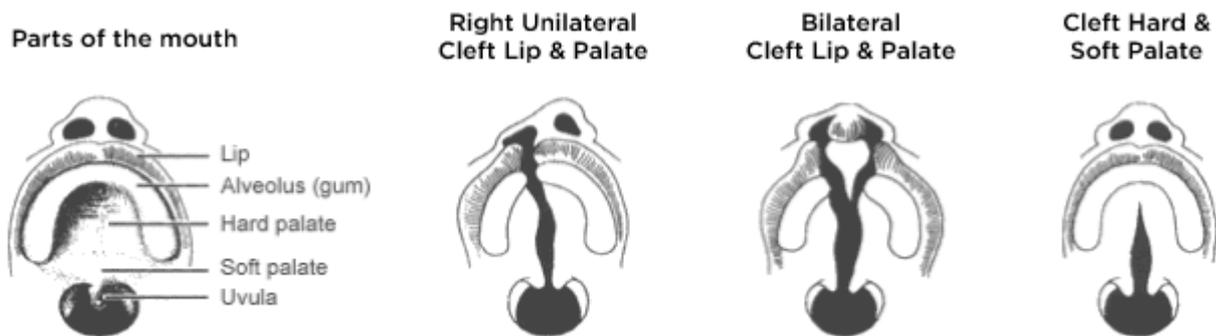
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## Glossary of terms

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.

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

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

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

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

**CLAPA Branch** – CLAPA has branches across the UK, primarily run by volunteers, offering local support to parents, patients and HCPs. Although the East of England Branch is often referred to as the Cambridge Branch, and members focus their efforts mainly on the Cambridge area, support is officially offered to all those affected by cleft across the East of England region.

**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 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 volunteers. Members meet on a monthly 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** - research and/or service provision that is carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. Patient representatives play an active role in shaping the services the benefit from.

## CLAPA Regional Coordinators Project - Evaluation Interim Report (end of Year One, October 2013)

### Executive 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 One (Dec 2012-Nov 2013) are summarised below:

- Volunteers generally reported feeling confident and supported in their role, and believed they were achieving their aims. Volunteers enjoyed attending training days and rated these sessions very highly.
- Children and young people have benefitted from a range of activities and events across the region. Many have also been involved in fundraising and raising awareness of CL/P and CLAPA.
- CLAPA has gained a better understanding of the issues that are important to adults with CL/P and of the support that is needed. CLAPA is currently preparing standardised training for adults who wish to offer support to others affected by CL/P and to raise awareness of the support that is being developed.
- Parents/guardians and family members have enjoyed a number of activities, groups and events. Many had been in touch with a trained parent volunteer for support, with others attending parent support groups. Parents have also benefitted from support and information via the CLAPA Facebook pages.

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

- Continue to collect and incorporate feedback from volunteers, parents, young people and adults.

- Continue to develop the role of the RC in the East of England and transfer this knowledge to other regions.
- Aim to recruit more adults with CL/P as volunteers.
- Hold training days and events more frequently and locally, and advertise more widely.
- Continue making progress toward developing services for young people and adults with CL/P.
- Consider ways of involving siblings, grandparents and ethnic minority groups.
- Continue to forge links with cleft teams, non-specialists HPs, other organisations and researchers.

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

## **Introduction**

### **Background and project rationale**

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

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

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

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

### **Project Outcomes**

The CLAPA Regional Coordinators Project has three key outcomes:

**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 thus far (end of Year One). Supplementary reports will be added throughout the project's duration.

The 2011-2012 pilot project demonstrated that CLAPA are managing to build up a strong volunteering presence in the region. However, the data which CAR and CLAPA were able to collect from parent beneficiaries and young people during the pilot year were limited. In addition, the services which CLAPA offer to adults have been minimal until recently and have therefore been difficult to evaluate.

In response to the findings from the pilot project, Year 1 of the current evaluation has been spent conducting focus groups with children, young people and adults, in order to understand the challenges they face in relation to CL/P and to clarify what type of support they would like to see implemented. Additionally, new measures have been designed by CAR in order to capture data more effectively, and to capture data that is directly relevant to the three key outcomes listed above.

Nonetheless, the RC for the East of England was able to obtain some data from parents, volunteers, young people and adults affected by cleft during Year One. 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 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.

## **Outcome 1**

**“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 been involved in several volunteering activities over the last year. The RC organised and delivered several Training Days for prospective volunteers and encouraged existing volunteers to provide an overview of their personal experience of the role. Parent Contacts have become more active in the region throughout the last year. The RC has also kept in touch with volunteers throughout the year to encourage them to take part in activities and to ensure that volunteers feel supported in their role. The RC has kept in contact with the regional Cleft Team based at Addenbrooke’s Hospital in Cambridge (Cleft.NET.East), and helped to develop the role of Clinic Volunteer, in which volunteers can be present during routine cleft clinics and offer peer support and information to patients attending appointments. The RC has contributed to a review of the way CLAPA Branches operate and supported volunteers to take on new roles within the Branch Committees. Additionally, the RC has supported volunteers to engage in Patient and Public Involvement, allowing them to help shape the delivery of health services.

Throughout Year One of the Regional Coordinators Project, seventeen new people living in the East of England region expressed an interest in volunteering, and nine people went on to complete standardised training (six completed a Volunteer Induction Day and four completed Parent Contact Training; one parent completed both training sessions). The majority of new volunteers were parents of children affected by cleft; a small number were adults who had been born with cleft themselves. Some of the parents also had a cleft themselves.

### Feedback from volunteers

Volunteers who completed standardised training during Year 1 were asked to fill out a Training Feedback Form on the day. Volunteers gave the following reasons for attending training:

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

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

- Meeting like-minded people from around the UK
- Learning about the wide variety of services which CLAPA offers
- Learning about CLAPA’s current strategies and ways of working
- Hearing about the different opportunities that are available to volunteers

- Listening to other people's experiences and having the opportunity to share own experience
- Friendly, informal and relaxed atmosphere

As a direct result of the training, all volunteers indicated that they felt more confident in their role and more able to support others affected by cleft.

When asked which aspects of the training they least enjoyed, very few volunteers chose to comment. However, one suggestion regarding how the training could be improved in the future was made by a number of volunteers:

- The training could be held more frequently and more locally

Following the completion of their training, volunteers have adopted a variety of volunteer roles and participated in a wide range of activities, including the following:

- Branch Committee Member
- Parent Contact
- 'Happy Faces' Coordinator
- Clinic Volunteer
- Adult Volunteer
- Children and Young People's Services Volunteer (e.g. residential weekends)
- Fundraising
- Awareness raising
- Involvement in cleft research

Throughout the year, volunteers were also asked to provide feedback on how they felt they were progressing in their various volunteering roles. Volunteers were asked to indicate on a five-point scale how much they agreed or disagreed with the following statements:

"I am happy in my role as a volunteer"

"I feel confident in my role as a volunteer"

"I feel supported in my role as a volunteer"

"I am achieving my aims as a volunteer"

"I feel that I am developing useful and transferrable new skills"

"I feel able to actively support others affected by cleft"

Almost all of the volunteers indicated that they 'agreed' or 'somewhat agreed' with each of the above statements. No volunteers indicated that they 'disagreed' with any of these statements. Where volunteers indicated that they felt 'neutral' or 'somewhat disagreed', the following explanations were given:

- Time and energy spent on admin and details rather than on action
- Need to have better PC skills and to understand new technologies (e.g. social networking)

Volunteers also indicated that they 'agreed' or 'somewhat agreed' with the statement: "I feel I have access to a local support network", suggesting that as well as being a volunteer for CLAPA they felt that they were also beneficiaries of CLAPA's services.

Existing volunteers from other regions (which do not yet have a RC in post) were also asked about their volunteering experiences with CLAPA. As well as giving many reasons for why they enjoy being a CLAPA volunteer (being able to support others, forming new friendships, promoting awareness, sharing

experiences, and so on), existing volunteers also provided some interesting insights into the aspects that they find more challenging:

*"In my region I feel a bit isolated."*

*"Volunteers need more support locally."*

*"I struggle to be as active as I would like due to other commitments, but if there was a stronger local network I would feel more encouraged and could share the responsibility."*

*"We need someone to communicate what is happening nationally to each of the local branches."*

Some examples of fundraising and awareness raising by volunteers within the region are provided in the Appendices.

### Case studies - Volunteers

A number of volunteers provided case studies specifically for this report. Key quotes from these case studies are provided below.

*"I had been in contact with CLAPA before but only as a purchaser of bottles and teats. The RC contacted me and introduced herself. She was very supportive and my involvement has increased hugely since then."*

*"Before I met the RC I wanted to help others in my situation but didn't have much confidence or know where to start. I have since been trying to set up a Happy Faces group in my area and I have volunteered at my local cleft clinic. I have also put up window displays in the town centre to raise awareness."*

*"The RC is in a great position to promote CLAPA, new groups and the local branches. They should employ more RCs."*

*"It's really good to have someone with more local knowledge. The East of England is a large region and the distances people have to travel can often be underestimated."*

*"Dedicated microsites for Branches on CLAPA's main website would ensure cohesive messages and standardisation of materials/content/branding. The RC could really help with this."*

## **Outcome 1: Summary**

Volunteers who had recently attended a Training Day rated these sessions very highly. Throughout the region, volunteers generally reported feeling confident and supported in their role, and believed they were achieving their aims. Many volunteers felt they were also beneficiaries of CLAPA's services, due to their ongoing contact with the charity. However, others felt that improvements could be made to further develop their experience of being a CLAPA volunteer.

While CLAPA make an effort to host numerous Training Days in various locations across the UK, some volunteers felt these sessions could be held more frequently and more locally within their region. The East of England is still a relatively large area and currently volunteers may have to travel considerable distances

to attend training. The Regional Coordinator is now ideally placed to deliver training in convenient locations across the region.

While a small number of volunteers were adults with CL/P, on the whole CLAPA has far fewer adult volunteers than parent volunteers. Adults with CL/P bring varied and invaluable experiences that most parent volunteers do not have. Some adults may also be parents, offering an especially unique skill set.

Although a recent review of the way CLAPA Branches are run has helped to standardise Branch performance, some volunteers felt that more could be done to ensure that messages, materials and branding were cohesive across Branches.

Existing volunteers based in other regions of the UK made a number of comments regarding the challenges they currently face. Many felt isolated because of a smaller volunteer presence in their local area. For some, this had also led them to becoming less active, because they struggled to cope with the responsibility alone. Others felt they were 'cut off' from National activity. This highlights the need for additional support for volunteers in other regions of the UK, and demonstrates the potential of the Regional Coordinator role.

### **Outcome 1: Key recommendations**

- Endeavour to host more Training Days across different areas of the region.
- Aim to recruit more adult volunteers, including adults who are also parents.
- Consider ways to further standardise the various CLAPA Branches.
- Continue to engage with all volunteers regularly and incorporate their feedback into practice
- Continue to develop the RC role within the East of England and transfer this learning into other regions throughout the UK.

## **Outcome 2**

**“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 been involved in the CLAPA Children and Young People’s Council (CYPC) and has kept in regular contact with the three members who are based in the East of England. The RC has encouraged CYPC members to speak in public about their experiences and raise awareness of CLAPA, and of the issues which affect children and young people with cleft. The RC has also met with the CLAPA Adult Voices Council to gain a better understanding of how CLAPA can better support adults with cleft.

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

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 is currently made up of 13 children and young people from across the UK with varying cleft types, aged 9-17 years. Three members are from the East of England. A summary of the focus group findings is included below. These findings will help to direct CLAPA’s future work in this area.

### **CYPC focus group – summary of findings (18<sup>th</sup> May 2013, Birmingham, UK)**

#### **1) What is important for mental well-being?**

- Self-esteem
- Being happy, a good mental state
- Being confident about your appearance

#### **2) What can prevent you from achieving mental well-being?**

- Bullying
- People thinking you are different from them (in a negative way)
- People not understanding your condition
- Being pestered by people asking the same questions, too much pressure
- Pointing, laughing, staring, avoidance
- People thinking there is something wrong with you mentally
- Additional problems linked to cleft (hearing, speech, eyesight, teeth)

#### **3) What could help to alleviate this?**

- Knowing how to explain to other people what a cleft is (concisely)
- Raising awareness of cleft in schools/in public to ‘normalise’ cleft
- Teaching people how to behave around someone with a facial difference

- Having confidential support from teachers
- Having more public figures/celebrities with cleft
- Emphasising the positives about cleft (being different in a positive way, sharing stories with others, having unique opportunities such as joining the council, learning more about cleft and ways to cope, being a stronger and more positive person with a good sense of humour)
- Meeting other young people who have cleft (giving and receiving peer support)

**4) What could the CLAPA Regional Coordinator do to help achieve this?**

- Support young people with cleft to hold assemblies at their primary/secondary school
- Provide opportunities for young people with cleft to get together locally and regularly
- Make greater use of social networking sites to get more young people involved
- Support young people to make videos/keep a blog about themselves
- Raise CLAPA's profile in the region (it is currently a lesser-known charity)
- Support young people to fundraise/hold events in their local area (organising the venue, coordinating publicity, etc.)
- Encourage schools to include a lesson on visible differences/bullying in PSHE/Citizenship
- Offer knowledge, ideas and support to teachers
- Improved links with the regional CLAPA branches and spread activities across the whole region (e.g. although the South West Branch covers a wide geographical area, most activities are based in Bristol)
- Including a 'what's going on in your local area?' section in the National YP e-newsletter
- Offer talks on cleft/visible differences to the general public and generic health professionals

Throughout the year, many children and young people attended local events hosted by the Regional Coordinator and CLAPA volunteers. Nine children/young people provided feedback about these events. Five of these children/young people had not attended a CLAPA event before. Parents gave the following reasons for attending the events:

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

At the end of the event(s), children/young people believed they had achieved these aims, and listed a number of reasons for why they had enjoyed the event(s):

- Meeting other people with cleft
- Fun activities

When asked about what could be done to make these events better in the future, children/young people suggested:

- More events like this!
- More people joining in

Children/young people were asked to indicate on a five-point visual scale how much they agreed or disagreed with the following statements:

- "I have made friends I can talk to about having a cleft"
- "I can offer help to other children and young people with a cleft"
- "I have learned new ways of coping with problems in a positive way"
- "I feel more confident about myself"

The majority of children/young people indicated that they 'agreed a lot' or 'agreed a little' with each of the above statements. Where children/young people indicated that they felt 'neutral', 'disagreed a little' or 'disagreed a lot' with a statement, no further explanation for this was given. When asked whether they would attend another event like this in the future, seven children/young people circled 'yes', while two circled 'maybe'.

The parents of these children were also asked to provide their own feedback about these events. When asked what they had enjoyed about the event, parents made the following comments:

- Seeing my children enjoy themselves
- Seeing the children exercise and be physically challenged
- Seeing my children interact with other children with cleft
- Seeing siblings (who do not have cleft) interact with other siblings

All parents indicated that their children had enjoyed the event(s), and felt that attending the event(s) had had a positive effect on their children:

*"It was good for him to see other children with the same condition as he hasn't met anyone like this before."*

*"My son has gained confidence from trying new things and talking to other children with the same issues and has made new friends."*

*"This event helped my son to mix with other new children, work as a team and try new challenges and skills."*

*"Our son has thoroughly enjoyed the day, and this will probably have a positive effect on him when he is older."*

*"My other child got to have fun with kids his age and got to enjoy activities too."*

### Case Studies – Children and Young People

A small number of siblings have also approached CLAPA and asked to be involved. One sibling (aged 15) based in the East of England provided a case study for this project. A quote from this case study is provided below. She has undertaken considerable awareness raising and fundraising activities and helped to raise CLAPA's profile within her area. She was recently nominated for a 'Young People of the Year' Award and reached the semi-finals. A report of this is included in the Appendices.

*"I was involved in CLAPA before I got put in contact with the RC, but I was looking for someone from CLAPA who knew about my area and who knew families in my area...so I could meet more people around my age who are in the same position as myself. The amazing work CLAPA do for families and the support they give*

*is outstanding, especially as they are such a small and relatively unknown charity. They do such a great job lifting the confidence of children through events and I want to give something back as a way of saying thank you. I attended the Celebration Event, am starting a youth group for teenagers with cleft and their siblings and have been to the seasonal parties. I found my experience of working with the RC to be positive. The RC was very friendly and easy to talk to, welcoming and helpful. More events around my area are being organised which is leading me to talk to new people. I would like there to be more activities for different age ranges and for CLAPA to involve the siblings of children born with a cleft more. I think the effects the RC has had on CLAPA are amazing, so many new things are happening and being organised. It's given CLAPA a fresh coat of paint for everyone to enjoy."*

One young person who particularly benefitted from the East of England Regional Coordinators Project also provided a case study for this project. Although an active member of CLAPA already, she was encouraged by the RC to run a workshop for children and parents at the Celebration Event, and to give a presentation at the 'Medicine and Me' conference in London, which aims to bring patients and health professionals together to discuss service provision.

*"I was born with a cleft lip and palate myself, and for as long as I can remember CLAPA have provided help and support for both me and my mum...All the way along there has been...a friendly face from CLAPA to make the whole process easier. The Director of Development made it known to the RC that I was around and old enough/willing to help. I was contacted and asked to run a 'How to Cope' workshop for parents and children with clefts...This was very successful and I've had emails from parents saying how their child's confidence has improved. I am also on the CYPC and as one of the older ones I act as a kind of support for the younger teens and children...I enjoy this so much and plan to train as an official volunteer after my 18<sup>th</sup> birthday. I loved every minute of working with the RC. Having an RC is essential because it adds a personal touch to all the work CLAPA does, because each region has its own person attached to it...I could see that if it wasn't for her, the events wouldn't happen with as much success...All the time, CLAPA is growing and offering more and more services, and the RC helps to ensure these services are accessible to everyone who wants or needs them...They need to keep doing what they're doing!...There does need to be more encouraging of older teenagers and adults to meet up, just like there is for young children...teenagers and adults need a different level of peer support. This is something I'd really like to look into starting up myself and will hopefully talk to the RC soon!"*

Another member of the CYPC (age 16) from the East of England recently participated in the BBC Children in Need Rickshaw Challenge. She managed to raise a large sum for Children in Need as well as raising awareness about CL/P and CLAPA. A news article is provided in the Appendices.

### Feedback from adults with CL/P

During Year One, CAR ran two focus groups with adults affected by cleft, in order to explore the kinds of challenges they face in relation to their cleft and to discuss what type(s) of local support may help them to overcome these challenges. The first group was held on 19<sup>th</sup> May 2013, while the second was held on 1<sup>st</sup> June 2013. In total, eleven adults took part in these focus groups. A merged summary of the findings from both focus groups is included below. These findings will help to direct CLAPA's future work in this area.

## **Adult focus groups – summary of findings (May-June 2013, Cambridge and London, UK)**

### **1) What are the main challenges facing adults?**

- Support disappearing after the age of 18 years
- How to get back in touch with cleft services/where to get information from
- HPs (inc. GPs, dentists, etc) not having knowledge about cleft or how to refer patients
- How to approach HPs for information
- Everyone has different problems/needs different information
- Differences between the way services are run at different hospitals/receiving inconsistent messages
- Research not always being put into practice
- People thinking CL/P is just a childhood issue
- People focusing solely on the negative aspects of cleft and not on the positives
- No link between children/young people and adults with CL/P
- Meeting other people who also have CL/P can be uncomfortable for some people
- The general public knowing little about CL/P and 'differences' in general

### **2) What could the Regional Coordinator do to help address these challenges?**

- Raise awareness of the issues that are important to adults
- Provide adults with clear information about how to get back in touch with cleft-related services
- Support adults to approach HPs for more formal advice and referrals
- Help to educate HPs to deliver basic information and refer adult patients appropriately
- Provide a link between different regional hospitals/cleft teams and encourage a homogenised approach to care wherever possible
- Provide a link between the cleft teams and CLAPA
- Provide a link between regional activity and National activity both within and outside of CLAPA
- Work with researchers in the field to provide a link between the evidence base and everyday support
- Consider ways of introducing different levels and types of support for adults with cleft (e.g. developing peer support)
- Encourage adults and CYPs to meet and share advice
- Raise awareness of CL/P in general and of the positives of growing up with the condition

CLAPA Adult Voices was established in September 2010 and currently has nine members aged between 21 and 61. The group have made significant progress over the last year and have played a key part in helping to shape the role of the Regional Coordinator.

CLAPA have already made steps this year to adapt some of their existing services to make them more relevant to adults with cleft. For example, building on the success of the Happy Faces groups for parents and children, CLAPA have recently encouraged adult volunteers to set up similar informal groups for adults with CL/P. Additionally, adult volunteers have been successful in their application for funding to develop Adult Contacts Training. Much like the volunteer Parent Contacts already being recruited, Adult Contacts will be a source of semi-formal peer support for other adults, parents and young people affected by CL/P. Applications have already been received from ten adults, with a further seven expressing an interest in becoming an Adult Contact. The first training day is booked to take place in January. Several more adults with CL/P have also expressed an interest in joining Adult Voices this year.

## Case Studies – Adults

*“The RC has been very supportive and I can’t praise her enough. Without her I would have had nowhere near as much involvement. She is a credit to CLAPA and if every region had a coordinator I am sure the charity’s reach would increase dramatically.”*

*“The RC is totally concerned with her area and what goes on within it. People are starting to connect across the entire region rather than just within their own district or county.”*

*“It’s great to see CLAPA are beginning to offer more support to adults. We have been cut off from services and I myself wasn’t even aware of CLAPA until a year ago.”*

## **Outcome 2 – Summary**

A number of insightful and useful points were raised from each of the focus groups with children, young people and adults affected by cleft.

As with the volunteer Training Days, parents and young people really enjoyed the regional events but felt they could be held more frequently and locally. In addition, they felt more could be done to foster more interest in these events and improve attendance. Parents had also benefitted from seeing their children enjoy the events and commented on the positive effect this had on their children. A number of siblings had also attended the events and parents felt it had been beneficial for them to meet other siblings of children with CL/P. This highlights the importance of local events for all family members and the potential positive impact they can have.

A number of young people from the East of England, including one sibling, had been encouraged to become involved in a number of activities to raise awareness of CL/P and CLAPA, and to tackle some of the issues facing young people with a cleft. They found that this not only had a positive impact on those who benefitted from these activities, but had a positive effect on themselves as well.

For adults, the key challenges are around accessing relevant information about treatment and support after they leave routine cleft care around the age of 18 years. Although support for adults has been lacking in general, CLAPA have made progress towards implementing services which are relevant and helpful for adults with CL/P across the UK. In the future, adults will also be able to offer peer support to others affected by CL/P. In the coming years, the Regional Coordinator(s) will be ideally placed to raise awareness of the issues which are important to adults and of the support that is available to adults on a local and National level.

## **Outcome 2 – Key recommendations**

- Begin to pilot/implement some of the ideas raised in the focus groups across the region.
- Endeavour to host more family events across the region (and encourage volunteers to do the same).
- Continue to raise the profile of events such as these in order to attract more families.
- Begin to host activities for older children and teenagers (and encourage volunteers to do the same).

- Conduct research with siblings and/or wider family members to explore how CLAPA could involve these groups and offer support where necessary.
- Continue to encourage the development of informal groups/activities for adults with cleft across the region.
- Develop and deliver Adult Contacts Training, involving existing adult volunteers where possible.
- Continue to forge links with cleft teams, non-specialists HPs and researchers.
- CAR to develop a measure for use with adults with CL/P to capture their feedback, now that services for adults are being implemented.

## **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.”**

### Overview

While some parents/guardians who have contact with CLAPA go on to become volunteers for the charity, many others are beneficiaries of CLAPA’s services.

Throughout Year One, 14 parents have been supported by Parent Contacts who are based in the East of England via telephone calls or emails. This total is more than for any other region in the UK. The nature of these enquiries varies, although the largest number of enquiries was from parents who had just received an antenatal diagnosis. Support is also provided by Parent Contacts via the CLAPA Facebook pages and occasionally during one-to-one meetings and social gatherings.

On initiation of the RC Project, only one active Happy Faces support group existed in the entire region. Since the RC has been in post, three new Happy Faces groups have been established and are currently active in the East of England. One more regional group is currently being set up.

A new Facebook group specifically for those living in the East of England was set up during Year One of the project. The group currently has 123 active members.

The RC has been involved in organising a number of regional events for parents/guardians and families. However, the East of England includes many rural areas and travelling around some parts of the region can be difficult. To enable parents/guardians to access services more easily, the RC has encouraged parents/guardians to link up and share lifts to events. This has also helped parents/guardians who are less confident to participate in activities and meet others affected by CL/P.

### Feedback from parents/guardians

Throughout the year, many parents attended local events hosted by the Regional Coordinator and CLAPA volunteers. 24 parents provided feedback about these events. Eight of these parents had not attended a CLAPA event before. Parents gave the following reasons for attending the events:

- 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 that CLAPA offers
- To find out how to help others affected by cleft
- To have fun and to meet new people

At the end of the event(s), parents believed they had achieved these aims, and listed a number of reasons for why they had enjoyed the event(s):

- Meeting other families affected by cleft
- Sharing experiences

- Fun activities

When asked if there was anything they did not enjoy, parents commented:

- Needed a bit more time
- Travel

When asked about what could be done to make these events better in the future, parents suggested:

- Icebreaker activities at the beginning of the day
- More activities for smaller children
- More marketing to involve more families
- Option to stay overnight/spread event across two days
- More events like this more often

Parents were asked to indicate on a five-point visual scale how much they agreed or disagreed with the following statements:

Statement	AGREE	SOMEWHAT AGREE	NEUTRAL/NO DIFFERENCE	SOMEWHAT DISAGREE	DISAGREE
"I feel I have access to a local support network"	12	7	5	0	0
"I feel more able to support others affected by cleft"	12	10	1	1	0
"I have gathered information which will help me to address cleft-related issues in a positive way"	13	4	5	1	0
"I would attend an event like this again in the future"	24	0	0	0	0

Parents also left the following additional comments:

*"We met some nice people and have swapped numbers, so will keep in touch for advice and friendship."*

Parents were also asked how they had heard about the events. The majority of parents stated they had heard about them from the Regional Coordinator, or through the region-specific Facebook pages.

#### Case Studies – Parents/guardians

One parent who spoke to a Parent Contact after her child received a diagnosis of CL/P wrote a case study about her experience. A quote is provided below.

*"I remember looking up my local Parent Contact's email address on the CLAPA website. I remember how kind her email was and how quickly she responded to my query about when would be a good time to call. Our actual conversation made me cry...before I spoke to the Parent Contact I understood the practical implications of having a baby born with a cleft...What I didn't know was whether I could cope and how other parents managed. I didn't know anyone else in my position and was utterly afraid of what was to come...I know that talking to the Parent Contact must have given me hope, because I remember my husband saying that I looked happier than I had in days...I remember feeling reassured. The Parent Contact didn't hold back – she didn't pretend it would be easy. However, she made me feel that I could cope and that my daughter would be the happy little girl I'd always imagined her to be...I needed to feel that I could do this – and that is exactly what the Parent Contact made me believe. I still have her phone number in my phone and I find it hugely comforting that I can call her at any time as our cleft journey progresses. I will always be so grateful that she was there when I needed her."*

### **Outcome 3 – Summary**

Parents/guardians enjoyed attending local family events. Meeting other families affected by cleft and sharing experiences and advice was one of the key reasons for parents attending and the most enjoyed aspect of the events. However, the issues of locality and frequency were raised again, with the main comments for improvement focusing on the distance travelled and not having enough time to enjoy the events thoroughly. The RC has made a clear effort to link parents/guardians up to increase attendance and to help with travel. Hosting more events like these in different locations across the region may also encourage more families to attend. The majority of parents had heard about the event through the RC or via the regional Facebook pages, highlighting the potential of (and need for an increase in) regional advertising.

Families also wanted more opportunities to get to know one another and to have activities for smaller children so that parents could network. Some parents/guardians commented that having icebreaking activities at the start of the day, or being more formally introduced to other families by the RC would have made them feel more confident about talking to other parents. This, along with the fact that families attended from across the region, may explain why a minority of parents indicated that the events had made 'no difference' to them having access to a local support network. In contrast, some parents/guardians had swapped numbers with other parents with the intention of keeping in touch for advice and support, which again highlights the potential of these types of events.

A few parents/guardians also indicated that they had not acquired very much information from the events. Although the primary aim of these events may not be to impart information about cleft and cleft services, this is an informal opportunity to notify parents about opportunities within CLAPA and of the support that is available to them locally.

### **Outcome 3 – Key recommendations**

- Continue to support and promote Parent Contacts as a source of peer support.
- Endeavour to host more 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.

- Continue to link local families up to share travel.
- Continue to build upon the success of the Happy Faces groups.
- Introduce families to one another/encourage networking among parents when appropriate.
- Take information leaflets to events/offer information informally where appropriate.

## **Final summary and recommendations**

Psychological adjustment to having a cleft is multifaceted and occurs over time. A wide range of diverse issues may become salient at various times throughout the individual's life. Furthermore, some individuals cope very well with their condition and its treatment, while others find their journey more difficult. It is therefore not only crucial that support is available throughout the lifespan, but that a range of different types of support is available, and at varying levels, from basic information provision through to professional intervention.

The evaluation of the Regional Coordinator's Project throughout Year One has allowed for a better understanding of the issues that are important to children, young people and adults affected by CL/P, and of the support that patients currently value and would like to see implemented in the future. Additionally, clear implications have been raised for the continued development of the services which volunteers help to deliver and which parents/guardians benefit from.

Although this project demanded a new approach to data collection, and therefore required new measures to be designed and developed, the RC was able to collect a reasonable dataset for the evaluation of the first year. Despite some limitations in the amount of quantitative data, a much more robust set of data was collected from children and young people than was collected during the Pilot year. Additionally, qualitative feedback from participants provided a richer understanding of their experiences as a whole. Throughout the coming years, the RC should endeavour to collect more high quality data that can be used to evaluate and evidence the project's outcomes. This may also include feedback from regional cleft teams, local CLAPA Branches and other organisations. In addition, very little data was collected from participants belonging to an ethnic minority group. This may warrant further investigation to ensure CLAPA is able to reach groups such as this who are often neglected within research and practice.

Many positive steps have been taken throughout the initial year of this project and CLAPA continues to grow in strength and numbers, delivering a service which many families and individuals value highly. A number of specific recommendations have been set, including the development and expansion of existing activities across the region, as well as the development of new services for young people and adults with CL/P. A number of topics for future research in this area have also been identified. The key aims for Year Two are to build on the successes of Year One and to implement the recommendations laid out in this report.

NB. The RC for the East of England left CLAPA on 26th September 2013 and a new East of England RC has now been appointed. She started in post on 30th October 2013.

## CLAPA Regional Coordinators Project - Evaluation Interim Report (end of Year One, October 2013)

### Lay summary

Having a baby diagnosed with a cleft lip and/or palate (CL/P) can be an upsetting time for parents. Ongoing treatment can also be stressful, and parents often have concerns about their child's future. Being born with a cleft may also affect the child as they grow up, particularly if they have concerns about their appearance or speech. If not addressed, concerns may continue into adulthood. Additionally, new issues arise during later life stages, such as starting a family and the chance of heritability. Adults may also be unsure how to access information and further treatment. Having access to appropriate support when it is needed is vital in helping people to cope positively with the impact that the cleft might have on their lives. The Cleft Lip and Palate Association (CLAPA) provide support to anyone affected by CL/P in the UK. Although they already provide a valuable service nationally, they have received widespread requests to implement this service on a local level. Following a successful pilot project in 2010-2011, CLAPA received funding from the Big Lottery Fund to employ three Regional Coordinators (East of England, East and West Midlands (known as Central), South East) over the course of four years. The aim of this project is to improve local services for anyone affected by CL/P.

The three key 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 asked to independently evaluate the success of the project throughout its four year duration. The aim of the evaluation is to allow families, young people, adults and volunteers to provide feedback about the local services CLAPA provides, and to supply evidence to current and future funders in order to keep services running.

The key findings of the evaluation at the end of Year One (Dec 2012-Nov 2013) are summarised below:

- Volunteers generally reported feeling confident and supported in their role, and believed they were achieving their aims. Volunteers enjoyed attending training days and rated these sessions very highly.
- Children and young people have benefitted from a range of activities and events across the region. Many have also been involved in fundraising and raising awareness of CL/P and CLAPA.
- CLAPA has gained a better understanding of the issues that are important to adults with CL/P and of the support that is needed. CLAPA is currently designing a training day for adults who wish to offer support to others affected by CL/P (Adults Contacts Training).

- Parents/guardians and family members have also enjoyed a number of activities, groups and events. Many had been in touch with a Parent Contact for support, with others attending Happy Faces groups. Parents have also benefitted from support via the Facebook pages.

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

- Continue to collect and incorporate feedback from volunteers, parents, young people and adults.
- Continue to develop the role of the RC in the East of England and transfer this knowledge to other regions.
- Aim to recruit more adults with CL/P as volunteers.
- Hold training days and events more frequently and locally, and advertise more widely.
- Continue making progress toward developing services for young people and adults with CL/P.
- Consider ways of involving siblings, grandparents and ethnic minority groups.
- Continue to forge links with cleft teams, non-specialists HPs, other organisations and researchers.

**Thank you** to everyone who contributed to the evaluation by participating in focus groups, responding to surveys and providing case stories. Your feedback and support are very much appreciated. For more information about this project or to offer your feedback, please contact [Nicola2.Stock@uwe.ac.uk](mailto:Nicola2.Stock@uwe.ac.uk) or [Claire.Cunniffe@clapa.com](mailto:Claire.Cunniffe@clapa.com).

## Appendix 1: CLAPA CYPC member Eleanor completes the Rickshaw challenge for BBC Children in Need



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### Team Rickshaw 2013: Eleanor

Meet Eleanor, one of the young volunteers who is taking part in The One Show Rickshaw Challenge 2013!

<b>Name</b>	Eleanor
<b>Age</b>	16
<b>From</b>	Upminster, Essex
<b>Cycling Partner</b>	Her father Keith

Sixteen-year-old Eleanor from Upminster, Essex, has been selected as one of the riders for The One Show's Rickshaw Challenge, a 700-mile journey across the UK to raise money for BBC Children in Need.



Now an official ambassador for CLAPA (the Cleft Lip And Palate Association), Eleanor was bullied at school having been born with a severe **bi-lateral cleft lip**. Through the charity, Eleanor received support and counselling to raise her self-confidence and self-image. She will be undertaking the challenge with her father Keith.



Speaking of the challenge, Eleanor said: "Being born with a cleft lip really knocked my confidence, as I felt like no-one really understood. I'm much more confident now, but it's been a long journey. I'm doing the challenge with my dad and am so excited. I'm ecstatic, I genuinely can't wait!"



Both Eleanor and Keith have been training heavily since they were selected for the challenge, and Eleanor is also a keen dancer, having starred in a range of productions. As an ambassador for CLAPA, Eleanor sits on their young council, which meets quarterly to discuss fundraising and events. She also listens to and advises other young people who are affected by similar situations. Currently at sixth form college, Eleanor has hopes to become a speech and language therapist.

**“**  
**I'm ecstatic, I genuinely can't wait!**  
**”**  
**Eleanor**

**CLAPA**  
CLAPA is the only UK-wide voluntary organisation specifically helping those with, and affected by, cleft lip and palate.  
CLAPA was set up in 1979 as a partnership between parents and health professionals. It provides support for new parents, and for people with the condition and their families, from infancy through to adulthood. Branches are run by people who have themselves benefited from the organisation, often working in partnership with local health professionals.



**Team Rickshaw 2013**  
Meet the other riders



**Get fundraising for BBC Children in Need**  
Everything you need to be a hero fundraiser



**Donate**  
Make a difference to a child or young person and donate to BBC Children in Need

## **Appendix 2: CLAPA Fundraiser nominated for a YOPEY** [30 Aug 2013]

Since the age of 9, Jaimee Tuck (15) has gone above and beyond to raise money and awareness for CLAPA. Jaimee's younger sister, Molly (7) was born with a cleft palate. Molly's cleft was diagnosed two days after birth, and the family were soon put in contact with CLAPA. "I had never heard of CLAPA before Molly was born" says Jaimee "which is why I've organised events at my primary school and secondary school, to raise money and awareness."



Jaimee has raised nearly £1000 for CLAPA through various fundraising events. When Jaimee was at primary school, she held a non-uniform day. Jaimee arranged a further non-uniform day at her secondary school and asked a representative from CLAPA to talk at the school assembly. Jaimee has also organised a cake sale. "Although it was a lot of fun, it was hard work, as I spent all weekend baking cakes- I made and decorated more than 200" says Jaimee. Not only has Jaimee been proactive in planning her own fundraising events, she has also helped out at the CLAPA Cambridge parties and set up a young people's group- a chance for people born with a cleft and their siblings to socialise and meet new friends.

In addition to raising money for CLAPA, Jaimee has raised a considerable amount of awareness for the charity. Through the events Jaimee has organised, fellow students (affected by a cleft) have learnt more about CLAPA and gone on to participate in CLAPA events. A local business man chose CLAPA as his sponsored charity at a charity golf day thanks to Jaimee's awareness raising.

"I got involved with supporting CLAPA as a way of saying thank you for the help they gave to my family and it feels good to know that my help will go towards helping others who are in the situation we were in."

Jaimee's sister Molly was born in 2006, and has undergone 6 operations. She had a repair on her palate at 11 months then again at 22 months. Molly has ongoing speech therapy and hearing problems. Since she has some difficulty learning to speak, Jaimee has learnt Makaton so that her and her sister can communicate.

Jaimee's support for her sister and CLAPA have not gone un-noticed as she was recently nominated for a Ferrier Pearce Young People of the Year Award (or YOPEY) by her friend Eleanor Upton-Heath. "Jaimee always put her sister first, and was always there for her" says Eleanor. "Jaimee is a really special teenager and she still manages to be kind, considerate and do brilliantly at school. I would just like her to have a reward for her long and passionate devotion to her little sister, so that she can recognise how special she is to everyone around her."

CLAPA would like to say a big thank you to Jaimee for all the hard work she has put into raising awareness and money for CLAPA and congratulate her on being a role model to other teenagers.



If you have been inspired by Jaimee to organise events for CLAPA please follow this link:

[http://www.clapa.com/get\\_involved/](http://www.clapa.com/get_involved/)

### Appendix 3: Media coverage of volunteers fundraising in the East of England

## Fun day to boost young boy's appeal in Birdbrook

Published on the 05 September 2013

Alex Fitchie has a cleft palate and is about to have his 2nd op. His mum Jessica is holding a fundraising day for the Cleft Lip and Palate Association at the Birdbrook Tavern.

PHOTO: Mum and dad Jessica and Alex Fitchie with son and daughter Alex and Bethany.

**A family are hosting a fun and shopping day at the Birdbrook Tavern to raise money to help a charity close to their hearts.**



The event on September 7 from 11am until 3pm is being staged to raise money for the Cleft Lip and Palate Association (CLAPA).

Alex Fitchie, 6, of Hales Barn Road, Haverhill, has had an operation to repair a soft cleft palate and is due more surgery in October.

His mother Jessica is organising the fun day to donate to the charity which supports families and raise awareness. "Alex's cleft journey is different to most children as he wasn't diagnosed until he was four years old after getting a nasty case of chicken pox," Jessica said. "As a baby Alex found it difficult to breastfeed, which is a classic symptom of cleft palate. I was fobbed off. "Later his speech therapist noticed he was quite nasal. I was advised that he would grow out of it. "But when he was infected with chicken pox Alex had a thorough inspection inside his mouth and the doctor referred him to a specialist."

Alex had an operation in 2011 to repair the hole, however he needs a further operation as air is still escaping. He had tried intensive speech therapy to improve things but it became apparent that more surgery was needed.

The event at the Birdbrook Tavern will offer facepainting, cup cakes, crafts, a raffle and stalls from local businesses. Jessica runs the business Queenie Bee Beauty.

To donate to Alex's appeal for CLAPA go to <http://www.justgiving.com/alexfitchie/new/3>

CLAPA is the only UK-wide voluntary organisation specifically helping those with, and affected by, cleft lip and palate. It is unique. CLAPA was set up in 1979 as a partnership between parents and health professionals. It provides support for new parents, and for people with the condition and their families, from infancy through to adulthood. Branches are run by people who have themselves benefited from the organisation, often working in partnership with local health professionals.

To find your local branch go to <http://www.clapa.com/members>.

Other parents are on hand to talk about issue and lend support.



**Appendix 4:** Media coverage of a skydiving fundraiser in the East of England

## Three Peterborough friends' skydiving for charities

Photo supplied by Anna Ruggiero

Published on the 30 August 2013

### Three Peterborough women are taking the plunge, and supporting their favourite charity by taking part in a skydive.

The girls, Leighan McKearney (33), Emma Iles (33), and Helena Dean (29), all from Peterborough, will be bravely jumping from 13,000 feet above Sibson Airfield, on Sunday, September 1.



The charity parachute jump came after the three women were discussing how to help good causes. Leighan explained: “The idea started one evening with the three of us enjoying a glass of wine. “I had been feeling restless for a while, and wanted to do something different, while helping a good cause. Emma then suggested we all do a skydive, and I jumped at the chance.”

Emma has chosen the Cleft Lip and Palate Association (CLAPA), and she said: “My nephew was born with a cleft lip and palate, and the association were a constant resource of information and support.

“I’m excited and nervous about the jump in equal measures, but I’m sure once I have done it, I will want to jump again, and I’m so pleased to have this opportunity to raise some money for such a worthy cause.”

Helena said: “I’m also a bit of a daredevil, and have wanted to do a skydive for some time now. Doing the jump gives me a great opportunity to live out a dream and support a great charity in the process.”

**Support the girls** on their epic jump by donating via their JustGiving pages:

Leighan: [www.justgiving.com/Leighan-McKearney](http://www.justgiving.com/Leighan-McKearney)

Helena: [www.justgiving.com/helena-dean1](http://www.justgiving.com/helena-dean1)

Emma: [www.justgiving.com/Emma-Iles](http://www.justgiving.com/Emma-Iles)

