



CAMBRIDGE BRANCH
supporting families throughout East Anglia

[WWW.clapa-cambridge.com](http://www.clapa-cambridge.com)

www.clapa.com (hq)

Registered Charity No: 1108160

Patron: Carol Vorderman MBE

April 2009

Dear Supporters

RAISING FUNDS FOR CLEFT LIP AND PALATE ASSOCIATION (CLAPA), CHARITY THAT SUPPORTS FAMILIES AFFECTED BY A CLEFT THROUGHOUT THE EAST ANGLIAN REGION

I am writing to introduce CLAPA-Cambridge Branch charity and would like to ask you kindly to consider assisting us to continue provide help and assistance to many families and children who have, or are affected by, the little understood deformity of a cleft lip and/or a cleft palate (cleft). Please find attached fully completed application form with supplementary documents for your kind consideration.

CLAPA-Cambridge is the branch of CLAPA, national charity based in London with 26 branches. Our branch is run by volunteers who provide support for new parents, children and adults with the condition, from infancy through to adulthood across the East Anglian Region.

On average, three babies are born in the United Kingdom with a cleft every day, around 90 babies per year are born in the East Anglian Region. CLAPA-Cambridge Branch together with the Cleft Team at Addenbrooke's Hospital, Cambridge is passionate to get all the help and support to the families from the start and our volunteers are dedicated to give them emotional support, minimizing the distress inevitably experienced by parents at the birth of a child with a cleft. CLAPA's support begins before the birth of a child, where the standard 20 week anomaly scan reveals a cleft. Whether the cleft diagnosis is at birth or before, this is always a traumatic time for the parents and we are able to provide comprehensive support through the network of parent contacts and by organizing various annual events where both families and children can get the support by our volunteers or a member of the Cleft Team. Our contacts are parents whose children have a cleft or they may have a cleft themselves, so they can offer support gained through personal experience or medical professionals, Dr Anna Zeffertt, Consultant Clinical Psychologist who is also a leading member of the branch.

We also have an invaluable opportunity to help the cleft medical team at Addenbrookes and other Cleft clinics by purchasing much needed medical equipments that will improve the care for patients with a cleft throughout the East Anglia. The cleft team is very supportive of our work and they always find the time to come to our events and speak to parents and children informally.

Dr Anna Zeffertt said: "CLAPA-Cambridge is doing a fantastic job to bring children with cleft lip and palate problems together who would only otherwise meet each other in the hospital clinic or ward setting. Families get a great deal out of meeting each other and sharing information. It is a good step towards breaking down some of the misconceptions that exist about the condition." The Cleft.Net.East Network based at Addenbrooke's provides 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, pediatricians, a psychologist and nurse specialists".

To give a better description of CLAPA's overall operation, I have included a copy of our current Strategic Review. I do hope that your trustees will appreciate the real difference that their support will make to all these children and families and help us to continue develop CLAPA services and this vitally needed support network. We welcome your support for Harry Potter Day and for a Set of Audio Visual Equipment to be used by speech specialist in Suffolk Area.

If you feel you are able to give a CLAPA-Cambridge any assistance and would like any more information about our work and projects please don't hesitate to either contact myself or Dr Anna Zeffertt, Consultant Clinical Psychologist at the Cleft Team, on the number 01223, 596 092, email; anna.zeffertt@addenbrookes.nhs.uk. We would like to acknowledge any support given on www.clapa-cambridge.com and at our next annual event if you wouldn't have any objection.

On behalf of Cleft Lip and Palate Association please accept my sincere gratitude and a very special thank you for your time while considering our requests.

With kind regards

Yours sincerely

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CLEFT LIP AND PALATE TEAM
Cleft.NET. East Network
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Addenbrooke's Hospital
Hills Road
Cambridge CB2 2QQ
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Tim Clarke
Chairperson
CLAPA Cambridge Branch
(01223) 700 386

Every day in Britain
three children are born
with a cleft lip and/or a
cleft palate.

ONGOING ANNUAL PROJECTS/SUPPORT	Description	Cost (£)
Feeding Services, 'Welcome packs' to newborn babies in the East Anglian Region. (providing for 9 hospitals)	<p>Babies usually have difficulties feeding because the hole in the roof of the mouth makes it hard to suck and the special squeezable bottle and orthodontic teats should make feeding easier. The pack includes 1 squeezable bottle, two orthodontic teats, teddy bear, welcome card, informative leaflets about this condition as well as information about the charity, The packs are well received and distributed by a specialised cleft nurse. This is also our first point of contact to raise the awareness and help the families both emotionally and financially.</p> <p>90 packs pa @£10.0</p>	<p>£1800.00 (for 2 years)</p>
Harry Potter Themed Day	<p>The Cleft Team at Addenbrooke's Hospital (psychologists) in partnership with Changing Faces is organising an excited day for 7 to 11 years old children with a cleft lip and/or palate. This will be an opportunity for children to build up self confidence and self esteem enrich their social skills for managing other people's reactions to and questions about their cleft lip and/or palate, make friends, meet other children, share experiences, and most of all to have lots of fun.</p>	<p>1,400.00 (for 2 year)</p>
Meetings; 'Summer' & 'Winter Wonderland' parties	<p>Each year we have two main events the 'Summer' and 'Winter Wonderland' Parties that are supported by the Cleft Team at Addenbrooke's, who always find the time to come and talk to children and parents informally. Both children and parents get a great deal out of meeting other families and talking to members of the Cleft Team.</p> <p>These events help to break down some misconception that still exist about this condition, build up children's self confidence and self esteem. Children love to see the surgeons outside the 'normal' hospital environment and it builds a lovely relationship between the team and the whole family. We are very keen to raise the profile of the branch and the excellent support and medical care provided by the Team. @ app. £1, 100 per each event</p>	<p>£4,400.00 (for 2 years)</p>
Supporting Mr Per Hall, Consultant Plastic and Reconstructive Surgeon's work with 'Operation Smile' in Ethiopia and India	<p>Supporting Mr Hall and his team member travelling expenses to Ethiopia and India with the charity called 'Operation Smile' that he went in December, 2008 and in May 2009. The charity sends teams of surgeons, nurses, doctors and other medical professionals to 26 countries, to operate on children and adult with a cleft lip or palate, as well as train the local surgeons. We sincerely hope that you will be able to support this work, that many medical professionals selflessly give their time, skill and compassion to with the ever-present goal of helping a child or an adult with a correctable facial deformity</p>	<p>£2,400.00 (for 2 years)</p>

Conferences – For medical professional to attend (Craniofacial and Appearance Research Conference)	Part payment for specific nurses and psychologist to attend Craniofacial or Appearance Research Conferences. We are committed to support part payment for nurses @ £1,000pa and £800 for two psychologists, as there are great benefits to families and children when the staff is better trained.	£3,600 (for 2 years)
CLAPA Network Assistant	Part time, pilot scheme vacancy, with 8 hours a week. The role will be to support the projects of the local CLAPA branch and liaise with the Cleft Service based at Addenbrooke's Hospital, Cambridge.	£3,500.00
ONE OFF ANNUAL PROJECTS		
Information/Toys/Publications	<ul style="list-style-type: none"> - Setting up a small patient library of books that can be looked at in the cleft clinics waiting room @ app. £300 - Toys /puzzles for use in clinical Genetics/cleft clinics for helping children with mild learning difficulties @ app. £300 - medical text on feeding difficulties @ app. £150 	£750.00
DVD's on alveolar bone graft surgery, dvd & photographs of 'Summer' party	<ul style="list-style-type: none"> - DVDs on alveolar bone graft surgery - £1,500 - DVD of Photographs of '2009 Summer Party' - £500 	£2,000
DVD's for late teens, requiring osteotomy surgery	Getting the information across, as well as showing speech before and after the surgery would be very beneficial for both parents and teenagers.	£1, 500.00
2 Set of Audio Visual Equipments; camera, microphone, tripod, a case and a stock of mini dvd @ £1,134.00 each	Addenbrooke's has recently purchased some new cam corders for speech recording. They have now state of the art equipment for the specialists working with the core team but we are also aware that other speech therapists working with the Cleft patients across the network do not have funds for audiovisual equipment. Fifteen years ago CLAPA Stevenage funded the first camera and television set up where Dr Anne Harding Bell used video therapy with considerable effect. The most urgent need for video equipment is currently in Norwich, Stevenage, Kettering and Suffolk where therapist staff are unable to collect suitable quality data or offer families video therapy because they do not have the video equipment. The cost of a complete set of camera equipment is currently about £1,134. This will ensure that the quality of service is more equitable and will also make it possible for clinicians locally to carry out video therapy which may substantially increase the effectiveness of therapy. We will also be able to evaluate video therapy as an intervention.	£2,268.00 for two sets