



September 2010

Dear Support

www.clapa.com (hq)

Registered Charity No: 1108160

Patron: Carol Vorderman MRF

RAISING FUNDS FOR CLEFT LIP AND PALATE ASSOCIATION (CLAPA), CHARITY THAT SUPPORTS FAMILIES AFFECTED BY A CLEFT IN 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).

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 could be 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 by purchasing much needed medical equipments that will improve the care for patients with a cleft or other children who are treated on D2 Ward. We work closely with the regional Cleft Team based at the Addenbrooke's Hospital who is very supportive of our work and passionate to improve the cleft care. 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, paediatricians, 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 any of the projects listed.

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

Mary Newbold
Treasurer/Web Administrator(Volunteer)

CLAPA- Cambridge Branch
c/o Cleft Team at Addenbrooke's
(01234) 308 101
nm.newbold@ntlworld.com

"How wonderful it is that nobody need wait a single moment before starting to improve the world"
Anne Frank

CLEFT LIP AND PALATE TEAM
Cleft.NET. East Network
Box 46
Addenbrooke's Hospital
Hills Road
Cambridge CB2 2QQ
(01223) 596272 or (01223) 596092

Tim Clarke
Chairperson
CLAPA Cambridge Branch
(01223) 700 386

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

Guwahati, India December 2009 ".....In total we operated on 520 patients on 10 operating tables over 10 days. Personally I did 20 cases, 5 under local anaesthetic in young adults over 15 years of age. The highlight for me was catching up with Kiran, my dancing girl from the Blue Peter show whose lip I did in May. I was able to repair her palate this time. She came to give a goodbye card to myself and to my friend Dr Phil McDonald who was the anaesthetist who looked after her when I was operating. We both were very moved when her father held our hands and said; Thank you, you have changed my daughter's life forever. **That is why we go to help....(Per Hall)**"



(Mr Hall, Kiran and Mr McDonalds
During their trip with Operation Smile)



(One of Mr Hall's patient in uk)



(Operating of Mr Hall at
2009 Summer Gathering)

ONGOING ANNUAL PROJECTS/SUPPORT	Description	Cost (£)
<p>Feeding Services- 'Welcome packs' to every newborn baby born with a cleft throughout the East Anglian Region.</p>	<p>New born baby 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. 90 packs pa @£10.0</p>	<p>£1800.00</p> <p>We have secured enough funds for the next 2 years</p>
<p>Harry Potter Themed Day</p>	<p>The Cleft Team at Addenbrooke's Hospital (clinical 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, share experiences, and most of all to have lots of fun.</p>	<p>700.00</p> <p>We have secured enough funds for this year.</p>
<p>Meetings; 'Summer & Winter Awareness' and 'Support' Gatherings</p>	<p>Each year we have two main events the 'Summer' and 'Winter' gatherings 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. These events help to break down some misconceptions that still exist about this condition, build up children's self confidence and self esteem and help parents to share their experience with each other. Children love to see 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 as well as raise the valuable funds to enable us to continue support many families in East Angila. @ app. £1, 100 per each event</p>	<p>£4,400.00 (for 2 years)</p>
<p>Supporting Mr Per Hall's (Consultant Plastic Surgeon) work with 'Operation Smile' in Ethiopia and India</p>	<p>Supporting Mr Hall travelling expenses to Ethiopia and India with the charity called 'Operation Smile 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 and/or a cleft palate, as well as train the local surgeons. Mr Hall together with other medical volunteers selflessly gives their time, skill and compassion to with the ever-present goal of helping a child or an adult with a cleft in developing countries.</p>	<p>£1,200.00 (for 2 years)</p>

<p>Conferences – For medical professionals to attend (Craniofacial and Appearance Research Conference)</p>	<p>Payment for clinical psychologists or another team member to attend Craniofacial or Appearance Research Conferences as there are great benefits to families and children when the staff is better trained. Unfortunately there is no study leave budget now for medical and allied health professional staff sufficient to cover many of the meetings that the team tries to get to, to keep up to date.</p>	<p>£2,000.00 (for 2 years)</p>
<p>ONE OFF ANNUAL PROJECTS</p>		
<p>Breast Pumps (At the moment there is the 3 for 2 offer from the manufacture, what is very cost effective)</p>	<p>Financing breast pumps so that every mother who wishes to, is able to breast milk feed her baby, as babies usually have difficulties to breast feed. We have financed over 10 breast pumps for the last 6 years. At the moment the Addenbrooke's has 22 breast pumps, so that every mother who wishes to, is able to breast milk feed her baby. This is actually one of the National nursing standards of care. The cleft team has found over the last couple of years that the number of babies with a cleft condition is slowly increasing (probably due to increased population in East Anglia) and they are concern that they won't be able to offer to every mum with a new born baby born with a cleft a breast pump. All breast pumps are out on loan. They keep careful records of pumps and who they are loaned out to and for how long, so that usage can be audited</p>	<p>£1,300.00 We have recently purchased 3 breast pumps with accessories</p>
<p>Desk Top Computer at the Addenbrookes for the Audit IT Team.</p>	<p>The audit IT Cleft team is in a process of developing IT infrastructure and a database. The Computer programmer who has been working closely with the team has been gradually building an electronic system for them to be able to ensure that they identify all patients, who are being actively treated throughout the whole network and count the activity that this produces. For example, when the cleft team goes to outreach clinics they will have a print out of a summary of every intervention that has happened to that child since the database has been running.</p>	<p>£1,200.00- £1500.00</p>
<p>1 Set of a Professional Standard Video Camera with accessories to be used by the SLTs at Addenbrookes</p>	<p>The cleft team has been for years videoing pretty much every stage of the patients surgery and speech outcomes as well as in xray dept. when investigating speech. As technology has moved on they would also like to move towards a system which stores not on tape but on memory cards which can then be uploaded onto a server for easier retrieval and archiving. Many children born with a cleft have either minor or major speech impairment and are regularly monitored by the speech therapists who together with other team member will be able to decide if children need any speech correction surgery or more intense speech therapy.</p>	<p>£1,500.00 We have recently secured enough funds.</p>

<p>2 Sets of Audio Visual Equipment; camera, microphone, tripod, a case and a stock of mini dvd @ £1,300.00 each (approx) for speech recording used by the Speech and Language Therapists (SLTS) in Norwich and Peterborough and North Cambridgeshire cleft outreach clinics.</p>	<p>We were aware that the specialists working with the cleft patients across the network do not have funds for audiovisual equipment and the therapists are unable to offer collect suitable data or offer families video therapy because they don't have the video equipment. Fifteen years ago CLAPA Stevenage funded the first camera and television set up where Dr Anne Harding Bell (Lead Specialist Speech and Language Therapist) used video therapy with considerable effect. 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. They will also be able to evaluate video therapy as an intervention. Children will also be able to use DVDs at home what might encourage more regular practice. Many children born with a cleft have either minor or major speech impairment and are regularly monitored by the speech therapists who together with other team member will be able to decide if children need any speech correction surgery or more intense speech therapy</p>	<p>£2,600.00. for two sets We have recently secured enough funds</p>
<p>A video for 5 years old</p>	<p>This video will help 5 year old patients with cleft lip and/or palates to better understand their 5 year review visit to the multidisciplinary team. Additional money within this donation, should the project cost less, was to go to the purchase of a DVD player that would allow young patients to watch the video at the hospital. The basic plan was to send out DVD's with the letters inviting patients to the appointment, however, a means to view material in clinic or in the waiting room would help greatly. They will meet all the team members - and especially about the moulds that they have done of their teeth, which none like) -</p>	<p>£2,500.00 We have secured enough funds</p>
<p>Financing a speech course at Birmingham</p>	<p>Financing a speech course for a young boy was born with a unilateral cleft lip and palate and grew up with a fistula in the hard palate. Several attempts to close it were unsuccessful. He has had associated hearing problems but appointments were not kept and although he now has hearing aids he is reluctant to wear them. He is a charming and very sociable boy who manages to communicate very well but he has very distinctive speech which a stranger would struggle to understand. Jordan needs more therapy, he needs psychological support and encouragement to wear his hearing aids. The residential course in Birmingham June 4 - 6 could meet all of these needs at least in part and may help the family to re-engage with the reaming aspects of his cleft care. It would be such a benefit to Jordan, his family, the school and all the team if he could have this opportunity.</p>	<p>£400.00</p>