

React

GIVING DEPTH TO SHORT LIVES

Please pass this newsletter on to a friend to help even more children

Smiles on Wheels

Like all prospective parents, young mum Josie was looking forward to the birth of her first child. Throughout her pregnancy there was nothing to suggest her baby would not be healthy. One can only imagine her shock and devastation when things started to go tragically wrong during delivery. Dennis was born with Cerebral Palsy affecting each of his four limbs. In addition, he has West's Syndrome causing severe epileptic fits, respiratory problems and delayed visual maturation.

Dennis is now nearly 2 and the local services work hard to provide him with the special care he needs. His Occupational Therapist had identified a suitable buggy to ensure his spine was correctly supported and help prevent scoliosis. Unfortunately, Dennis is too young to receive the support of the Wheelchair Department and his sponsor approached React. Josie told us "I took Dennis out for the first time in his new buggy yesterday and although it was a bit daunting taking him out in a specialist pushchair, I know that it is the best piece of equipment for his needs and I am so thankful to React and all its supporters for helping us".



Dennis

Where are your Pennies?

THANK YOU TO GREGGS for sponsoring our 'Small Change, Big Difference' collection boxes again this year.

Keep your box by the phone or front door, use it as a swear box at work or ask your friends for donations instead of a bottle of wine at your next dinner party or birthday bash.

However you choose to use your collection box, the pennies really do add up and help us to continue to make a

difference to the lives of the special children for whom we care.

If you have a full box at home please follow the instructions on the back – and don't forget to get in touch for your replacement.

To receive a React collection box please call: 020 8940 2575 or email: react@reactcharity.org



Bubble Trouble



Gashow

WHEN GASHOW'S MUM ASKED US to provide a specialist swing and bubble tube we didn't hesitate to help. Gashow, aged two, visits the local children's hospice and loves using the many specialist toys and facilities. React agreed Gashow would benefit from some stimulation at home and we think this picture shows she agrees!

Inside this issue

- Sister Frances Dominica, OBE
- Angie Best
- React's Children



Summer 2007

Dear Supporter,

Discovering that your child has an illness so serious that he or she may not reach adulthood must be one of the most difficult things any parent has to face.

In some cases, a child's health will deteriorate over years and instead of becoming more independent, they may gradually become less and less mobile or less able to communicate. For other children, the changes are sudden and parents find themselves having to give up work and become full-time carers. Looking after a child with a life-shortening condition is an emotional and physical challenge, but for many it is a financial struggle too.

For parents like these the importance of React cannot be underestimated. With such busy lives, applying for financial support can be a daunting prospect – something which React has been very conscious of since it was founded in 1989.

React works closely with medical professionals to ensure each request, if granted, will benefit the child and family. Applications range from requests for vacuum cleaners and washing machines through to ceiling hoists and specialist beds. Every referral is treated as 'urgent' and responded to immediately.

May I take this opportunity to thank you for taking an interest in React and the vital service it provides. We can only make a difference with your continued help and support.

Yours very sincerely,

Sister Frances Dominica, OBE
Patron of React and Founder of Helen and Douglas House, Oxford.



Caspari's Managing Director Keith Entwisle presents React's Patron Sister Frances Dominica with a donation

React remains grateful to all its supporters and never fails to recognise the tremendous support received from a wide range of fundraisers



GlaxoSmithKline supports many charitable organisations throughout the year and we are delighted they have chosen to assist the development of a Regional Network Support programme. A network of regional volunteers will increase React's profile; raising awareness in areas where we are not currently well known, as well as introducing React to more families who will benefit from our help. If you would like to become a Voluntary Regional Co-ordinator for your area, please call us now.



Caspari has supported React for almost 15 years and its Managing Director, Keith Entwisle, is a valued member of the trustee board. "React plays such an important role in supporting the families of terminally ill children. Caspari has been working alongside the charity for many years and it is to React's credit that it attracts the support of hundreds of our retail customers and their customers each year. I am delighted to be part of such a wonderful organisation"

Home Sweet Home

LENNON IS A DELIGHTFUL much loved little boy who lives in Edinburgh's Royal Hospital for Sick Children. Needing 24 hour care, the local authority is working frantically hard trying to put a care package in place which will enable him to live at home with his mum Natasha. Natasha told us, "Lennon was born nearly 2 years ago and has spent all of his short life in hospital care."

As is often the case, there were no outward signs that something was wrong during Natasha's pregnancy. After 31 weeks with no problems it came as a huge shock to find herself in terrible pain and to be told that she would need an immediate caesarean.

Medical staff who attended the birth instantly knew Lennon was unwell. Within hours Natasha was told that her beloved first born, and first grandchild to the family, had serious medical complications. Lennon was born with Toffs, Lung and Heart Disease, a curved spine and talipeze of the feet. His little throat was floppy making a flap of skin fall inwards covering his wind pipe. A tracheostomy was fitted to enable him to breathe and the medical team began the long fight to save his life.

Lennon has numerous difficulties and challenges to face. He has no anus and waste is removed via a stoma. It will be sometime before he can walk, although there is hope that this may be achieved eventually. Born with only one kidney, there are concerns that this may become infected and extensive, evasive heart surgery is required.

Natasha remains bright and optimistic. Before Lennon's birth she worked full time as a youth worker and has managed to retain some independence by continuing to work part-time, juggling the daily visits to be by Lennon's side. Although Lennon's dad, grandparents and family have their own busy

working lives, a rota ensures someone is constantly with Lennon, assisting his care and giving him much love and attention. Natasha told us, "It can sometimes be exhausting when I receive a call during the night telling me that Lennon has taken a bad turn, having to charge up to the hospital and then going to work the next day." Thankfully, Lennon continues to pull through each crisis that comes his way and Natasha is looking forward to him eventually being at home.

"It will be a little daunting though. I've lived in my flat for just two years and much of that time has been taken up with Lennon's care. There has been little time to concentrate on 'home improvements' and it's embarrassing to know that care workers will invade my home 24 hours a day. Even getting up in the night to wander to the loo will mean getting dressed and privacy will be a thing of the past."

React has been working with Natasha and Lennon for the past year, providing travel expenses, cot and tumble dryer. We look forward to the day when he finally can come home.



Rachel Gets Connected

WHEN RACHEL WAS SIX she started to experience seizures and her parents noticed changes in her behaviour. Within a year Rachel developed considerable learning difficulties and now aged 9 she attends a 'special needs' school. Although still undiagnosed Rachel's doctors accept that her condition is neurological and progressive, something which will be a huge challenge for her to come to terms with in the future. Although the family live in Northern Ireland, future care will involve trips to Great Ormond Street Children's Hospital in London.

Due to the changes in Rachel's health, she has gradually been socially excluded from her friends and her self esteem has deteriorated. Her Community Nurse felt that access to a computer would not only assist with her learning but also help her to achieve a level of independence and provide a form of contact with her old and new school friends. Her school identified a suitable computer and software package and React was more than happy to help.



Rachel

Precious Relief

GRETA, AGED ONE, lives with severe Cerebral Palsy secondary to Hypoxic Ischaemic Encephalopathy. She has no effective swallow and poor muscle tone makes it difficult to position Greta comfortably in her cot. React was delighted to provide a variable high cot with a pressure relieving mattress to help with the stiffness of her limbs.



Greta

Washing Made Easy



THIS BEAUTIFUL LITTLE GIRL IS BOUDICCA aged three who lives in Somerset. Tragically Boudicca has been diagnosed with a brain-stem tumour which has only been partly removed by surgery. Her doctors can only offer temporary treatments which they hope will give her as much time as possible with her parents and three siblings. Just before Boudicca's most recent course of treatment the family's washing machine broke down – an extra expense her parents could not have foreseen. After an urgent call

to React a replacement was made within a couple of days. Boudicca's mother wrote to thank us: "I would like to thank everyone at React for our new washing machine. It is a massive help at a time when finding money for a large and vital item like this can be a real struggle."

Sleep Tight

JAMES, NOW AGED THREE, sustained a head injury after a fall at his nursery when he was just 9 months old. On visiting the local hospital it was discovered he is a severe haemophiliac and what should have been a straightforward recovery became a fight for life.



James now requires 24 hour nursing to care to cater for his complex medical needs. He breathes through a tracheostomy and is fed via a feeding tube fitted into his stomach. Despite all his difficulties James is a sociable little boy who always has a ready smile for visitors.

Having successfully trialled a night time positioning system, James' Occupational Therapist set out to find funding for this exceptional but expensive piece of equipment. James' mum wrote, "Please pass on all our thanks for your extremely generous gift. It will really help keep James' posture as good as possible while he sleeps. He is such a special little boy and really deserves it".



Travelling in Style

MOST DRIVERS ARE AWARE of the new laws which prevent us from carrying passengers under the age of 12 without suitable safety restraints and seats. For React children it has been a necessity rather than a requirement and we receive many requests each day to provide adequate seating in all shapes and sizes. Recognising the fact that Jack had many 'growth'

years ahead of him, his parents and care professionals identified a specialist car seat that would be suitable for many years. Just £665.33 made this family's life more bearable. "Thank you very much for funding Jack's car seat. He is now able to enjoy being in the car and he doesn't bang his head when he's lifted out of the car because of the turntable".

A big thank you to all our supporters for helping children like Jack.

A Special Tribute to a Very Special Boy

Dear React,

I am very sorry it has taken so long to get back to you with regards to the award received towards Ben's headstone. I can only apologise but as you can imagine it has been a very difficult time for us all. We are trying to get our lives back on track now and have accepted that Ben has gone and is not coming back. We have lots of brilliant memories of Ben and also photo's which I am sending to you. This is how he was all the time and he would be very proud of himself to know that his photograph was used. Once again we thank you for your kind award at such a difficult time, it is very much appreciated.



Yours faithfully,

Mrs. Tracey Smith

React's DIY

AMELIE HAS CHARGE SYNDROME, a rare genetic disorder that results in a variety of medical difficulties. It was quickly evident that the family home needed extensive adaptations to care for her needs and although the local authority funded the building works, the family were left with bare walls and floors. React was happy to step in and provide carpet and paint to help ease some of their financial concerns. Amelie's mum told us, "Your generous help has assisted us in completing the internal adaptation to give Amelie her own bedroom for all her equipment and needs".



Can we help?

DO YOU KNOW a child who could benefit from React's help? For rapid, effective assistance please call for friendly advice and support: 020 8940 2575

Recent Events...

A New Year Celebration of Music and Art

Concert & Exhibition, 12th January 2007

IT WAS A COLD BUT BRIGHT AFTERNOON when the audience who had assembled in St Luke's House were treated to a wonderful feast of music.

React has local resident and committed supporter Pat Mowbray to thank for bringing together a group of extremely talented musicians who created a fantastic programme. Highlights included The Caledonian Quintet's rendition of Dvorak, Shostakovich's Waltz No 2 as performed by Trio Sine Nomine, Gudrun Edwards and Sally Mays' delightful Spanish Dance. The evening concluded with the epic Dichterliebe beautifully sung by Mark Wilde, a world class Opera Singer, accompanied by Orlando Jopling, a young conductor who has recently made his debut with the English Chamber Orchestra, London Mozart Players and Sinfonia Viva.

The concert was followed by refreshments in Kew Studio where the twelve resident artists exhibited their range of work. Guests were greeted by fantastic displays of mosaics, textiles and painting.

Thank you to Pat Mowbray and all the talented artists who participated and helped to raise nearly £1,000.

Murder for Dinner

React's Murder Mystery Evening, 25th January 2007

THE 25TH JANUARY WAS BURNS NIGHT, but for those with an aversion to Scottish poetry and haggis there was a more palatable way to spend the evening if you were lucky enough to get a table at the Thames Rowing Club in Putney!



The highlight of the evening was agreed by many to be the death of Lord Saville, and it took some serious detective work between courses to establish whodunnit!

Fortunately, no peers were harmed during the night's events, as this was in fact a Murder Mystery Evening led by Charles Halford and a cast of fellow actors who generously provided their thespian services for free. A full house of over 120 diners deliberated over the dastardly deed and in the process raised £4,000. Needless to say it wasn't the butler, nor on this occasion the amorous groundsman in the kilt!

Thank you to the cast for putting on such a show and also to Judy Burdett and Kim Bach-Nielsen for their hard work in making the event such a roaring success.

Blow a Kiss for Valentine's

Alternative Valentine Event, 7th February 2007

ANGIE BEST hosted a star studded Valentine themed evening with flowing drinks and fabulous entertainment at The Depot in Mortlake.

Guests were greeted with champagne cocktails before being escorted into an intimate dining room. After dinner all were thrilled by performances from international opera star Jeffery Black and pop sensation Hayley Evetts of Pop Idol fame. Fuelled by the wine, it was not long before groups took to their feet and danced to Jeffery's seductive tones of some Rat Pack classics.

React want to say a huge thank you to Angie Best for her continued support and to all those who contributed to a truly unique and memorable event.



Angie Best, Hayley Evetts sharing a kiss with Jeffery Black

Pyjama Day



Kew Montessori Nursery

Kew Montessori Nursery Fundraising, 1st March 2007

ONE THURSDAY MORNING Kew Montessori Nursery pupils made the walk to school still in their pyjamas! All 42 children were celebrating the 10th anniversary of World Book Day and supporting React. They raised £230 in sponsorship.

Susan Vick, Head Teacher, said: "The day gives us an awareness of children all round the world and we were delighted to be able to support our local children's charity at the same time."

React staff were only too happy to join in the fun and came to work in their pyjamas too!

If you're a school or nursery who would like to fundraise for React call Kate on 020 8940 2575 for more information.

St Luke's House, 270 Sandycombe Road, Kew, Richmond, Surrey TW9 3NP Tel: 020 8940 2575 Fax: 020 8940 2050

Email: react@reactcharity.org Website: www.reactcharity.org

Rapid Effective Assistance for Children with potentially Terminal illness. Registered charity no. 802440/SCO38067

Your Gift Is Urgently Needed

React aims to give children with life-limiting illness the best quality of life possible in the short time they have left. Whatever you can give will make a difference to a family struggling to give their child the best care they can. **Thank you.**

£100 £50 £25 £10 other £

I enclose a cheque/postal order made payable to (REACT) or please debit my MasterCard/VISA/CAF Card/Switch/Delta (delete as appropriate)

Card no.

Security Code (last 3 digit number on the back of your card)

Start date ____ / ____ Expiry date ____ / ____ Issue no. (Switch/Delta only)

Your title and full name _____

Address _____

Postcode _____

Email _____

Signature _____

Date _____

Please send me details of how I may make provision for React in my will.

Please send me details of how I may make a regular gift.

I would like React to Gift Aid this donation and all donations I have made since 6 April 2000. I am a UK tax payer and will tell you of any changes in my tax status or address.

Please remove me from your database.

Date ____ / ____ / ____

Note: If you would like to make a regular donation by direct debit or standing order, please telephone React on 020 8940 2575.

PLEASE RETURN THIS FORM TO:

React, St Luke's House, 270 Sandycombe Road,
Kew, Richmond, Surrey TW9 3NP

We need your help!

EVERY DAY REACT IS HONOURED to work with wonderful children and parents like those featured in this newsletter. If you would like to help by donating urgently needed funds or becoming a React volunteer, please call us on 020 8940 2575 or email us react@reactcharity.org

The Gannochy Trust

THE GANNOCHY TRUST remains one of our most ardent supporters of our work in Scotland. We are extremely grateful that they have chosen to commit to our three year Adolescence Project and help Scottish teenagers.



Adam

A Special Thank You

REACT VALUES THE WORK OF ALL ITS SUPPORTERS but would like to give special thanks to: Athena Medical PR, First Direct Bank, Virgin Money, The Crown Pub in Richmond, Our Lady of Grace & St. Edward, the Church of St. Elizabeth of Portugal, Wisley Golf Club and Kew College.

The Freemasons' Grand Charity

THE FREEMASONS' GRAND CHARITY has supported the work of React since 2000, enabling us to reach out to even more children throughout England and Wales. Their most recent donation of £2,000 was received in March of this year and we are truly thankful for their ongoing generosity.

The John Ellerman Foundation

THE JOHN ELLERMAN FOUNDATION continues to provide support costs for our Family Liaison Officer, ensuring we provide a single point of contact for families, queries and support. The position is unique as it also provides direct liaison with medical professionals enabling us to deal with requests in the minimum time possible. Thank you.

Give it Away

REACT ARE DELIGHTED to have benefited from the inspiring and ground breaking support of Give It Away.

Charlotte Grobien is the company's Founder and Managing Director. Having sold her previous company she decided to use her business skills to benefit charitable organisations. Give It Away has redeveloped three properties and is giving all its profits to charity. Charlotte handpicked each of the recipients, selecting React to be one of only ten charities that will benefit.

Charlotte was delighted to visit Luke and his family whom React has supported over the years.



Charlotte and Luke