

React

GIVING DEPTH TO SHORT LIVES

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

A Lifetime of Support

There were no major concerns during pregnancy for Summerlyn and Dennestus, who were soon to become parents for the first time. Yet devastatingly, Summerlyn suffered a massive haemorrhage during labour and needed an urgent caesarean section. Following an emergency delivery, newborn Khalid was not breathing and his body was lifeless. Although hospital staff were able to resuscitate him, the moments spent without oxygen caused a catastrophic, irreversible brain injury. Following his traumatic start to life, Khalid, now aged three, lives with a number of severe conditions that affect all aspects of his daily life. Quadriplegic Cerebral Palsy means he has very limited movement and cannot sit or even lie down without

specialist equipment to support him; Epilepsy means he is prone to seizures and must be monitored at all times; whilst Global Developmental Delay means he has learning and communication difficulties. It is a daily struggle for his parents to simply understand Khalid's needs.

Although his loving parents strive to give Khalid the best life possible and provide their "smiling and giggling" boy with all the love and support he needs, there are times when even the most capable of families need a little helping hand. React has supported Khalid and his family on a number of occasions over the past two years, providing specialist seating, a specialist car seat, a fridge freezer and a sofa; all vital pieces of equipment that were beyond the family budget, yet essential to Khalid's care.



Summerlyn said: "I want to say a big thank you to React for supplying the equipment Khalid needs. It's made a huge difference to Khalid's life and for that I cannot say thank you enough. Thank you!"

As a child's health care needs are subject to change over the years, so too can the costly equipment required, placing further financial burden on the family.

Sophie was diagnosed with Aicardi Syndrome at only five months old. Doctors discovered she was missing a vital part of her brain which should connect the left and right hemispheres. The condition is so rare that Sophie is one of just 400 children in the world to be born with it. Now aged seven, Sophie has a number of complex needs; she is mentally and physically disabled requiring 24 hour care from her loving parents, Angela and Lee.

Despite relying solely on Lee's wages as an engineer, the family do their best to provide Sophie with everything she needs. Over the years React has assisted with various essential items, including an adapted buggy, educational equipment, water mattress, washing machine and baby monitor.

"Thank you so much React, for all the help you have provided over the years. You really have made such a huge difference to all of our lives" Angela and Lee Sutherland.



React understands that caring for a child with complex needs is never easy and invariably involves the purchase of costly pieces of equipment. The charity has no limit on the number of times families can apply for support.

Children helping Children

React has received support from a number of schools this year, ranging from Nurseries to Universities and all those in between. The fundraising activities have been as varied as the children's ages and they all have a joint goal in mind; 'Children helping Children!' React would like to thank all the Nurseries, Schools, Colleges and Universities who have raised funds to benefit the lives of seriously ill children. A special thank you must go to Monty's and Windham Nurseries, Kew Green and Kings House Schools and Durham and Sheffield Universities.



React news in Scotland

Supporting Children in Scotland

Over the past five years React's work in Scotland has gone from strength to strength, with the charity responding to over 1,200 requests from families in Scotland in need of essential equipment and support.

This is thanks in no small part to the generosity of individuals and organisations throughout the country, including The Hugh Fraser Foundation, The Robertson Trust, The Barcapel Foundation, The Ecton Trust, The Darroch Charitable Trust, The Gannochy Trust and our friends at Kilsyth Rotaract. This is by no means an exhaustive list of the supporters in Scotland we would like to acknowledge; please know that your support is greatly appreciated and we remain truly grateful for your endorsement of our work.

React would like to give a special mention to Sporting Bears who have supported React's work in Scotland for a number of years through their fabulous 'Dream Rides'.



Access to Learning

Following Rebekkah's birth at only 28 week gestation, she was diagnosed with a variety of severe and permanent disabilities, including Global Developmental Delay and severe Dystonic four-limb Cerebral Palsy.

Now aged eleven, Rebekkah from Dunbartonshire has learning and communication difficulties, which, coupled with her limited mobility, severely reduces the range of

stimulation and activities she can engage in. Despite this, one activity Rebekkah enjoys and benefits from is the use of her computer. Through a specialist switch, Rebekkah is able to activate games, music and colours, providing her with the opportunity to learn and interact with her surroundings. Without this Rebekkah's educational development is seriously compromised.

So when Rebekkah's computer needed replacing, the family turned to React. Rebekkah can now once again access the games, music and photos she so loves.

Her mother, Denise, said:

"Thank you so much. Rebekkah can now play her music and activate her switch games. The touch screen is also so much easier for her to use and she absolutely loves it!"

In The Spotlight

In this edition of the React Newsletter, we would like to shine the spotlight on a very special friend of React, Charlotte Grobien; Founder and Managing Director of Give It Away Ltd.



Having decided to donate all the profits made from setting up a property development company, Charlotte founded Give It Away Ltd.

React came to Charlotte's attention in 2006 during the first of her property developments. Since then Charlotte has become a loyal friend of the charity and many families have benefited from her business acumen and generous heart.

In total Charlotte has raised over £824,000 and has divided the profit between a number of other charities. Her most recent project is the building of three houses in Woking and she tirelessly charges around the country seeking the best deals on furnishings and building materials, ever mindful of profit margins.

Charlotte said: *"With each property development I realise that I am building something much more than just a four-bedroom house. It is the laying of foundations that I know will benefit so many. I am just pleased if I can really make a difference to the lives of children and families in difficulties - that's what motivates me"*

An Evening of Motown

On the 8th October 2011, guests attended React's very first Motown inspired fundraiser for an evening of Dinner, Dance and Divas.

Organised by React's Ladies Committee, this unique event offered a sumptuous three course meal, followed by the chance to win a number of fabulous prizes through a raffle and auction. Guests were entertained with the soulful sounds of the Motown era by the legendary Patrick Alan of the Drifters and his 11 piece band.

React would like to thank all those who attended and for making the evening a resounding success raising an impressive £18,000.



The Sky's the Limit for CIBC Duo

React supporters find a variety of ways to raise vital funds for React's work, but not all are as daring as CIBC employees, Ann-Marie Marfan and Ralda Baher. The brave duo took part in a sponsored skydive and jumped out of a plane at 10,000ft, freefalling at over 120mph! We are delighted that they lived to tell the tale and raised £1,325 for React.

Congratulations Ann-Marie and Ralda for completing this challenge and we hope to see you and more of your colleagues jump next year!

React, The Captain's Choice

React would like to thank Jackie Booth, Lady Captain of Lymm Golf Club, for selecting React as her Charity of the Year in 2011.

Jackie's term of Captaincy will include a number of fundraising events, most notably the annual charity day, which raised over £3,600 towards React's work with terminally ill children. Thank you Jackie and all at Lymm Golf Club for your support.



Picture courtesy of Lymm Life

No Stress

Daniel was diagnosed with Neonatal Marfans Syndrome shortly after his birth and although at first, it was unclear how significantly this congenital abnormality would affect his life, only seven weeks later his mother, Sarah, was given the news that would change her life forever... Daniel was living with the most severe form of the condition and it was unlikely he would live beyond two years of age.



Sarah told us: "At first I tried to remain positive and was feeling quite hopeful that Daniel's diagnosis wouldn't be too bad. So when the doctors told me how serious it was, that's when things got really scary."

With Marfans Syndrome affecting the connective tissue throughout the body, Daniel has extremely floppy joints and increased bone growth. This means even simply holding Sarah's hand can leave him at risk of bone dislocation and his mobility is significantly impaired. Although these features cause Daniel a great deal of difficulty, of greatest concern is Daniel's heart problems. With the lack of connective tissue causing his heart valves to stretch, any form of stress to Daniel could cause his heart to rupture, from which he would almost certainly die.

"As any parent will know, it is an almost impossible task keeping your child happy and calm at all times. But that is what I have to try and do 24 hours a day. It really is so terrifying knowing any form of stress could be potentially fatal for him and, as Daniel is also very young and cannot yet understand the implications of his condition, it is a constant struggle trying to meet his needs" said Sarah.

With Sarah being a single parent caring for both Daniel and his older sister Amber, aged 15, she not only has great physical and emotional strain placed upon her but also finds herself under growing financial pressure. When the family were moved into a new home and it was found to have only bare concrete flooring; completely unsuitable for any child, let alone one with such complex physical needs, Sarah simply did not have the funds needed to purchase new flooring and so turned to React for assistance.

Sarah said: *"I was delighted when React said they would be able to help as although it has taken a while to get to this stage, Daniel is gradually learning how to control his movement and can only really do this on the floor. We now have new laminate in place which is not only much safer for him to be on but importantly, is so much more hygienic and easy to clean. We know it might get harder for Daniel the longer he lives, but we hope, against all odds, that he will be given this chance."*

A Favour for the Family

React provides basic essential equipment to families struggling to meet the healthcare needs of their child. In some cases, this can be the provision of a specialist piece of equipment, in others it can be basic household items. Either way, the impact these items have on a child's comfort and quality of life is immeasurable.



Favour's start to life involved a number of surgical procedures, most notably the removal of a large section of her bowel, which was infected with Necrotising Enterocolitis.

Now aged three, Favour lives with Short Gut Syndrome and Liver Disease meaning she has never been able to eat like other children and is fed via a pump through her nose.

Constant vomiting and diarrhoea makes the washing of Favour's clothing and bedding a never ending cycle. When the family's washing machine was beyond repair, Favour's mother, Ololade, a single parent, contacted React.

Ololade said: *"Thank you so much for providing the washing machine. This item is so important to us and I do not know what I would have done without React's help."*



Are You Sitting Comfortably

Taylor, aged 8, lives with Rett Syndrome, a life threatening neurodevelopmental disorder. She has Epilepsy, Severe Learning Difficulties and Scoliosis (a curvature of the spine).

She requires 24 hour care from her parents, Sandra and Carl, and many items of specialist equipment are needed to ensure her comfort and safety. These include a specialist chair, bed, sleep system and wheelchair.

Taylor's care needs are of paramount importance and you can imagine the family's distress as they watch Taylor's condition deteriorate affecting even the simplest of pleasures. Sandra told us: *"Taylor can't take part in many activities and one of the few things she really loves doing is simply sitting together with the family. She used to sit happily in her wheelchair or specialist seat but as her condition worsens she is unable to sit for long periods and cries out in discomfort and pain."*

The family knew Taylor had been enjoying the use of a P Pod Bean Seat at her school and asked Taylor's Occupational Therapist for advice. The family were put in touch with React, who was delighted to help and provided a P Pod Bean Seat. Additionally, the replacement of the family's old, worn fridge freezer, which is vital for storing Taylor's medication, was an added bonus.

Sandra said: *"We really want to give Taylor the best life possible so were absolutely over the moon when React told us they would be able to help with the fridge and the P Pod Bean Seat. It supports her properly and is so comfortable for her to sit in. We can now enjoy our time together as a family and take it with us wherever we go. It really is just brilliant. Thank you React."*

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 they can. **Thank you.**

YOUR DETAILS

Please complete your name and address details below so that we can reclaim the tax on your donation (see below) and also to keep you in touch with our work.

Your title and full name _____
 Address _____
 _____ Postcode _____
 Email _____
 Signature _____ Date _____

YOUR GIFT TO REACT

Please accept my gift of

£250 £100 £50 £25 £10 Other £

I enclose a cheque/postal order made payable to React OR please debit my MasterCard/VISA/CAF Card/Debit Card (delete as appropriate)

Card number _____ (Security Number) _____
 Start date ____/____/____ Expiry date ____/____/____ Issue no. (if present)

Signature _____ Date _____

REMEMBER TO GIFT AID YOUR DONATION! (SEE BELOW)

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

MAKE A BIG DIFFERENCE WITH A REGULAR GIFT!

If you would like to give regularly to React, why not set up a standing order? It helps enormously to be able to count on regular income and also reduces costs.

Please pay REACT £ _____ each month/year (delete as appropriate)

Starting on _____ (please make this date one month from now) until

further notice and debit my account number

Bank sort code

Name of account holder _____

Signature _____

To the Manager (bank name and address) _____

Postcode _____

Please pay REACT, Account No. 00886556, Barclays Bank, George Street, Richmond, TW9 1JU Sort code 20-72-17

MAKE YOUR DONATION TAX-FREE

REMEMBER TO GIFT AID YOUR DONATION!

I would like React to Gift Aid this donation and all donations I have made since 6 April 2003. I am a UK tax payer and will tell you of any changes in my tax status or address.

giftaid it

The Inland Revenue have asked us to remind you that you must pay an amount of income tax and or capital gains tax at least equal to the tax that REACT reclaims on your donations (currently 25p for each £1 you give).

PLEASE SEND THIS FORM TO THE ADDRESS OPPOSITE.

Tom's Day

On 3rd September 2011 Sandy, Nigel and Cara Griffin held a 5-a-side Football Tournament in memory of their son and brother Tom.



Tom was diagnosed with Malignant Melanoma in October 2008 and sadly passed away 9 months later aged 15. Having benefited from React's support in the past, the family recognise the value of the charity's work and wanted to extend their warmth and understanding by raising funds to help others.

Tom's Day consisted of a 5-a-side Football Tournament and a boys v girls rounders match, won by the girls! An evening BBQ and disco finished a successful day. The event raised a magnificent £600, which was matched by Barclays Bank to make a grand total of £1,200.

The Griffin family sent the following message: "Thank you React for making the most terrible time in our lives a little easier, we hope that our donation does the same for another family."



Tom and his parents

React would like to thank Sandy, Nigel and Cara Griffin for their love, courage and understanding. They truly are a remarkable family and React is honoured to be considered a worthwhile recipient of their fundraising achievements.

950 miles, 7 days, 2 React supporters

On Sat 23rd July, Chris Davies and Phil Stevens set off on their bikes for what would be a monumental challenge in aid of React's work. Starting at Land's End, Chris and Phil faced a gruelling 950 mile bike ride that they hoped would see them arrive at their destination, John O' Groats, in only 7 days. Remarkably, through dedication and perseverance, the boys achieved their goal, arriving in Scotland on Friday 29th, having ridden an average of 135 miles per day, at times until 11pm at night!



So far Chris and Phil have raised almost £3,000 to help React's families with more donations coming through daily. Thank you Chris and Phil for completing this amazing challenge.

Sainsbury's

React is delighted to have been chosen as Sainsbury's Charity Partner of the Year for 2012, in Richmond. We would like to thank the staff and customers who kindly nominated React and eagerly anticipate the outcome of the coming year's fundraising activities.

White Stuff

React would like to give a special mention to the Richmond & Chiswick branches of White Stuff. Since 2008, these two stores have taken on a number of fundraising initiatives in aid of React's work, helping to raise thousands of pounds. We would like to thank all the staff who have made this possible and for continuing to show such dedicated support to React's families.



React provides urgent basic essential aid to families whose child has been diagnosed with a terminal or life-threatening illness. Any donation you make will be used to maintain or improve a child's quality of life in the weeks, months or years left ahead. Thank you.

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

Registered charity no. 802440 (UK) SC038067 (Scotland)