

React

GIVING DEPTH TO SHORT LIVES

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

Newsletter Summer 2018 Issue 46 www.reactcharity.org

Safe Journeys for Phoebe

At just four weeks old, tiny new-born Phoebe was

rushed into hospital when concerned mum Emma noticed she was shaking rapidly. Doctors recognised infantile spasms and Phoebe was admitted to hospital for the next six months where she experienced between 40 to 100 seizures a day.

Now aged two, adorable Phoebe has been diagnosed with Ohtahara Syndrome and West Syndrome, which are very rare types of epilepsy and neurological disorders. She has significant Global Developmental Delay and limited head control but she loves nothing more than playing with her brother Alfie and sister Lilly.

React has worked with Phoebe and her family since her diagnosis, during difficult times when there was no other support: "When Phoebe was in hospital, it was an extremely tough and emotional time for us. Phoebe was vomiting after every seizure which was terrifying and we honestly didn't know what to do. A nurse suggested React, who have helped us so much ever since."

Most recently, the family were finding car journeys with Phoebe very problematic when the slightest bump or turn meant Phoebe's head would droop. During seizures, Emma would urgently pull over and monitor her daughter, only driving again when Phoebe recuperated. The family's nurse recommended purchasing a specialist car seat, which could recline and swivel, allowing Emma easier access to Phoebe as well as providing much better head support. React was delighted to help Phoebe's family once again, alleviating the stress of car journeys and ensuring Phoebe's safety.



Phoebe

A Good Night's Rest

Catherine and Jackie had no idea that the birth of their much wanted baby would be so traumatic. Their new-born son struggled to breathe his first breath for 20 harrowing minutes and they were given devastating news that he was unlikely to survive his first night.

Defying doctors predictions, Jack is now seven years old and lives with Cerebral Palsy and Epilepsy. He is entirely reliant on his parents and Jack's complex condition means he is at risk of his oxygen levels dropping whilst sleeping. Catherine and Jackie have spent every night wide awake terrified for their son's safety. When Jack relapsed and was admitted to hospital after a prolonged seizure, the family were desperate for help and the lack of sleep was having a detrimental effect on them all.

Jack's Nurse recommended a SATS Monitor which would sound an alarm if Jack's oxygen dropped to a dangerous level. In total despair and anxious about going home, Jack's Nurse referred the family to React:

"Leaving the hospital without a monitor was absolutely terrifying but React provided one so quickly. The turnaround time was incredible and it's been an absolute godsend for us, giving us such reassurance and more sleep at night."



Jack

Can We Help?

Do you know a child who could benefit from React's help? For rapid, effective assistance our application form is available to download www.reactcharity.org or call **0208 940 2575** for friendly advice and support.

RAPID EFFECTIVE ASSISTANCE FOR CHILDREN WITH POTENTIALLY TERMINAL ILLNESS

Moor Mead FC

React would like to thank the players and parents of Moor Mead FC's U11s for generously supporting React families by holding a fundraising collection.



Sponsored by Twickenham Studios, the team raised £744.84 by offering face painting to rugby fans on a busy match day which was attended by React's very own mascots, Ricky & Rachel.

Thank you to all involved for enthusiastically raising a superb amount for React families.

Kew House School Quiz

React would like to thank Kew House School for hosting a Quiz Night in aid of React children.

Parents and teachers gathered to take part in the school quiz and had a fun-filled time whilst raising money for React families. At the school's assembly on 23rd March, React was delighted to accept a cheque for an outstanding £5,000.



Thank you to all those involved in the Quiz Night at Kew House School, this wonderful sum will make a huge impact on React families.

Join Us For 'A Night in the Sahara'

React is delighted to announce its Patron, Baroness van Dedem will be hosting 'A Night in the Sahara' in the grounds of her home, Trumpeters House on Saturday 22nd September 2018.

Transforming Trumpeters gardens into a vibrant and colourful paradise, guests will be immersed into a night of



desert delights. A delicious three course dinner with wine and entertainment throughout the evening including a live auction, luxurious raffle and dancing to a live band awaits you.

This enchanting evening will welcome over 250 guests and local celebrities in what is sure to be a memorable night.

For more information on the event and to secure your tickets to 'A Night in the Sahara', please call 0208 940 2575 or email react@reactcharity.org.

Ella's Choir

If you've been in the Richmond area recently, you may have heard the harmonious sounds of Ella's Choir, a dedicated group of singers organised by the Helen Astrid Singing Academy.



The Choir meets every Thursday evening and performs around town, in aid of React.

Conductor Helen says: "The aim of the choir is to help spread the word of React and provide an opportunity for individuals to come along and enjoy a good sing. New members are always welcome."

We would like to say a huge thank you to Helen and all involved in Ella's Choir for the wonderful support shown to React families and we look forward to many more superb performances.

Cottenden Country Fair

React benefitted from the generous support of the Cottenden Country Fair which took place in Stonegate Village Hall, East Sussex.

With the sun shining and a fabulous array of stalls, goodies and yummy treats to eat, the fair was a huge success with everyone having a fantastic time and raising an astounding £556.62 for React children.



React would like to express our sincerest gratitude to Lily for her hard work on the day and also to the fabulous organisers Sally-Ann, Bonnie & Charlotte for kindly choosing to support React, helping to assist children living with life-shortening illnesses.

Thank You Charlotte

On the 15th January, React was thrilled to receive a very generous donation of £15,000 from the charity's dedicated supporter Charlotte Grobien OBE. Her company 'Give It Away' renovates buildings, and donates all profits to charities. Charlotte has made an immeasurable difference to the lives of many and React would like to say a huge thank you for her truly invaluable support.



Better Bath Times

Four year old Ted is described by his parents as the 'happiest boy you'll ever meet' and in spite of his health, Ted's contagious smile never disappears.

Diagnosed at birth with Spina Bifida, Hydrocephalus and a Gene Mutation, Ted is blind, epileptic and paralysed from the waist down. Bath times are Ted's favourite part of the day and he loves the water. However, the bulky bath seat provided by the local authority was too big for the family's bath tub and left Ted dangling above the water.

Ted's Mum has given up work to care for him and the family's finances are stretched. Wanting to give their son his love of bath times back, Ted's Physiotherapist helped the family apply to React for a Splashy Seat:

"React is my favourite charity and I tell everyone about it. The understanding and sympathy of the team is so nice and instead of years on a waiting list, they're there every time Ted needs something."

Without the strain on Mum and Dad, and finally a supportive bath seat, Ted can now enjoy as many baths as he wants!



Ted

Huzaifah's New Suit

Huzaifah was a contented, happy baby who was achieving all his milestones. It was when he was just six months old mum Sehrish knew something wasn't quite right: "His eyes were beginning to roll into the back of his head and he wasn't holding his head up or interacting with toys, it was a complete worry" said Sehrish. Huzaifah was admitted to hospital for a gruelling two weeks of tests, and it was then the family were given the devastating news. Huzaifah has an extremely rare metabolic disease and only eight children in the UK are known to have the same condition.

Considered a fairly new discovery, the symptoms of AADC Deficiency are similar to those of Parkinson's disease and now aged four, Huzaifah finds it difficult to support his body and head. Over the years, Huzaifah has benefitted greatly from the use of a Lycra suit, which improves body awareness and stability, even getting to the point where he can now roll over and hold his head up himself. So when their son outgrew the suit, Sehrish was determined to find another and applied to React.

"Without his Lycra suit, I don't think Huzaifah would be sitting up or rolling over right now. He's improved so much physically because of it and it's made a huge difference to his life."



Huzaifah

For children living with a life-threatening condition, a simple cold or chest infection can be serious. Six year old Audrey who lives with a very rare chromosome disorder, Trisomy 9 Mosaicism needed to be immediately hospitalised when a simple cold led to respiratory difficulties and requiring an emergency tracheostomy.

On leaving hospital, the family were handed a bulky suction machine to use for clearing Audrey's airways. The machine was heavy and extremely noisy, giving off a loud and harsh vacuum sound each time it was used. Adding to the copious amount of equipment Audrey already needed, a simple trip to the shop became a mammoth task for the family and affected Audrey, who loves visiting new places.

Seeing first-hand the complications the family were experiencing, Audrey's Doctor recommended approaching React for a lighter, compact suction machine.

"The new suction machine has been such a big relief, it's lighter and noise free, easily fitting in Audrey's backpack when we go out."

Freedom for Audrey



Audrey

Support for Louie

There is only one thing that six year old Louie loves more than watching Toy Story, and that is relaxing in his new Symmetrikit Chair! Louie uses it every day and it allows him to spend time with siblings in the living room rather than confined to his bed or wheelchair.

Young Mum Natalie was just 21 years old when she gave birth and, when baby Louie's feet and legs started to stiffen, the family knew something wasn't quite right. Spending his first ever Christmas in intensive care followed by months as an inpatient, Louie was diagnosed with SMARD, a progressive motor neuron disease. "It's not what you imagine, being a young Mum with a child who has a life-limiting illness but we have grown together and he has changed me so much" said Natalie.

Louie requires a tracheostomy, ventilator and 24 hour monitoring and when he began to experience seizures lasting up to five terrifying hours, his Physiotherapist recommended a more supportive seating system.

"Louie adores his new chair and it's so much easier to handle. He's now on level with his siblings and it allows him to be involved so much more. He loves to paint on his new seat tray and it's just made his life a lot more comfortable. React really does 'react' fast and has helped so much."



Louie

Your Gift Is Urgently Needed

React is a unique charity responding to the needs of children in the UK who are living with potentially terminal illness. Our aim is to help families give their children the best quality of life possible in the short time they have left. Whatever you can give will help. **Thank you.**

Please complete your name and address details below to enable us to reclaim the tax on your donation and keep you in touch with our work.

YOUR DETAILS

Your title and full name _____

Address _____

Postcode _____

Email _____ Date _____

Please remove me from your database

YOUR GIFT TO REACT

Please accept my gift of

£250 £100 £50 £25 £10 Other £

I enclose a cheque 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 ____/____/____

Signature _____ Date _____

If you would prefer to transfer directly to the charity bank account, please see React's bank details below.

MAKE A BIG DIFFERENCE WITH A REGULAR GIFT!

By making a regular gift you will ensure more children live with comfort, dignity, and the opportunity to participate in life as fully as possible.

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 _____

Bank Details

Please pay REACT Account Number: 00886556; Barclays Bank, George Street, Richmond, TW9 1JU; Sort Code 20-72-33

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 in the past four years. I am a UK tax payer and will tell you of any changes in my tax status or address.

giftaid it

The Inland Revenue has asked us to remind you if you pay less Income Tax/ or Capital Gains Tax than the amount Gift Aid claimed on all your donations in that tax year, it is your responsibility to pay any difference.

PLEASE SEND THIS FORM TO THE ADDRESS OPPOSITE.

Latest News

JustTextGiving™ by 

You can donate by Text too! You can now donate between £1 - £10 by texting REACT12 and the amount to 70070. It takes just a few seconds to help so many families.

GC Gibson Charitable Trust

Thanks go to the GC Gibson Charitable Trust for their support of React's work. The Trust's most recent award of £2,500 has had a significant impact on providing aid to React families.

London Letterbox Marketing

React would like to say a big thank you to London Letterbox Marketing for helping to spread the word by delivering React newsletters door to door. Thank you to Zeena and the London Letterbox Marketing team for your support.

Sherburn House Community Grants Fund

Receiving an astounding award of £2,945, React is grateful to the Sherburn House Charity Community Grants Fund managed by County Durham Community Foundation, for supporting life-limited children living in North East England.

Crerar Hotels Trust

Through an award of £2,000, The Crerar Hotels Trust has provided aid to low-income families living in Scotland and we are extremely appreciative of the Trust's generosity.

Arsenal Foundation

React would like to say a thank you to The Arsenal Foundation for their grant of £2,500 to assist terminally ill children and the Foundation has also very kindly donated tickets to an Arsenal loving React family.

Warwickshire Masonic Charitable Association

We would like to express our appreciation to the Warwickshire Masonic Charitable Association for their kind award of £500, to assist children living in Warwickshire.

Barclays Migration

React's sort code has now changed to 20-72-33. We would be most grateful to supporters who have an existing standing order to update their bank at their earliest convenience. Thank you.

Takeda

The production and distribution of this newsletter was kindly funded by a grant from Takeda UK Ltd. Takeda has had no input or editorial control of the content.



Thank you Takeda UK Ltd for supporting React so generously.

React

Rapid Effective Assistance for Children with potentially Terminal illness

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

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

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