

React

GIVING DEPTH TO SHORT LIVES

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

Newsletter Summer 2019 Issue 48 www.reactcharity.org

Car Comfort for Harry

Harry was born prematurely and spent the first five months of his life in hospital.

Just days after he was discharged, Harry was rushed back to hospital and needed emergency heart surgery, much to the anguish of his parents, Marlene and David.

Harry is now three years old and lives with complex medical needs, including Chronic Lung Disease and Tracheobronchomalacia, a condition that affects his airways. Harry requires a ventilator to assist with his breathing, especially during the night. He has low muscle tone which means his mobility is limited and he needs additional support with head control and body movement. Harry is a happy child, who thrives in the company of others and loves singing songs.

Due to the level of care Harry requires, his parents take him to weekly hospital and physiotherapy appointments. The continual travel caused great discomfort for Harry and he needed a car seat which can be adjusted to support his head and body. Following a referral from a physiotherapist, React was happy to help.

Harry can now travel safely, much to the relief of his parents. "The car seat has made a huge difference for Harry, thank you so much React for your help!"



Harry

Portable Hoist for Cassie

When Cassie was born her parents were thrilled to bring home a thriving baby and introduce her to older

sister Shannon. However, over time it was apparent Cassie was not meeting the usual developmental milestones and at 17 months old, she was referred by her GP for tests.

Mum Tracie remembers the day like it was yesterday when Cassie was diagnosed with Rett Syndrome, a genetic neurological disorder that causes profound physical and neurological disabilities. "At the time, I had no understanding of what the doctors were telling me and it wasn't until I'd done endless research that I understood what the condition meant". Cassie's devastated parents watched as their beautiful daughter deteriorated and by the age of four, Cassie had lost her ability to walk.

Now aged 14, Cassie needs full time care and has undergone many medical procedures including spinal fusion surgery to straighten her back. A portable hoist was recommended by the occupational therapist involved in Cassie's care who approached React for help. We were delighted to assist and having now recovered from her surgery, the family are making good use of the hoist by taking Cassie out. They even managed a trip to the local swimming pool!

Tracie said "React is a godsend. As Cassie's full time carer, a portable hoist is the only way I can safely move Cassie. React responded to our application in a matter of days, they are amazing".

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.

Can We Help?

RAPID EFFECTIVE ASSISTANCE FOR CHILDREN WITH POTENTIALLY TERMINAL ILLNESS

London Marathon Runner

This April, Jo Taman picked up her running shoes to take part in the London Marathon in aid of React children. Jo's training was relentless but she was somewhat nervous when she approached the start line, fully aware of the enormous challenge ahead.



Jo Taman

Jo continues to raise as much money as she possibly can and, being a popular school music teacher, has organised fundraising music concerts at both the school and the local church.

Well done Jo, everyone at React continues to cheer you on and thanks you for your amazing achievement.

Sainsbury's



Sainsbury's Local combined forces across two of their South West London stores to raise funds for React using a variety of popular initiatives.

On a bright Friday afternoon, dedicated staff were on hand to serve the public delicious cakes and

sweet treats in an extremely busy and bustling cake sale. The stores also raised money from their ethical 'carrier bag donation scheme' and collection tins placed by the tills.

Their hard work throughout the year raised a whopping £3,331.04 for React children and we thank all the staff at Sainsbury's for their fantastic effort.

Spiderwalk



In November, members of the RAG at Sheffield University organised a 'creepy-crawly' half-marathon charity walk through the Peak District.

Participants donned warm clothing, hi-vis jackets and used high beam torches late at night to walk the spooky dark route until 1am. The evening was a great success and students were treated to a drink filled bar, scrumptious barbeque and live music throughout the night.

Thanks to all, a total of £851 was raised for React which will buy essential equipment for children living in South Yorkshire.

Currie Motors

React would like to thank our friends Currie Motors, who visited the React office in February to present a magnificent cheque for £1,750. Vince Ellis (pictured) and Fabiola Caceres were welcomed by staff and one of React's mascots, who were delighted to accept such a generous award. The big hearted donation will go towards the provision of car seats and making a huge difference to React families.



Sift Bakes & Brews



On Christmas morning Sift Bakes & Brews coffee house, opened their doors to the public to serve delicious coffee and cakes for free, in exchange for donations in aid of React.

This generous gesture raised a wonderful £675 for our families and we pass on a big thank you from parents and children who benefitted from such kindness.

Fulwell Golf Club

On Thursday 30th May, Fulwell Golf Club Captain, John Andrews and Ladies Captain, Susanna Gillett will rise to the challenge of "playing as many holes in a day" along with club Secretary, Murray Cook and Assistant Pro, Will Bell.

The day is sure to be energetic for the four experienced golfers and all proceeds raised from the event will go to providing vital equipment for React children.

A tremendous thank you to John and Susanna for choosing React as the club's supported charity.



Susanna & John

Walking with Confidence for Aayan



Aayan

Aayan was born a healthy baby boy and his parents were overjoyed to welcome their son into the world. However, at just three months old, Aayan experienced spasms which worryingly led to rapid seizures. Within months Aayan was diagnosed with Global Developmental Delay and Hypotonia which affects his mobility, cognitive ability and speech.

Aayan, now aged seven, is a happy child who shares a very close bond with his older, protective sister, Yusra. Aayan is unable to move unaided and following an appointment with a Physiotherapist, a walker was recommended for home use.

Aayan's physiotherapist referred the family to React who was delighted to help. The walker enables Aayan to practice his walking, whilst building up his muscle strength and he is gaining a huge amount of confidence. It also provides Aayan with some much needed independence and he can direct the walker where he wants to go, especially handy when "chasing" his big sister!

Aayan's Mother Firdousie, said "We were originally told Aayan would never walk and with React's help, he has proved everyone wrong. Although our son's illness is permanent, by using the walker now, we hope one day Aayan can take steps independently, even if it is only for a short distance".

Safe Sleeping for Charlie

Within a couple of days of her birth, baby Charlie began fitting and stopped breathing. It was a terrifying time for her parents and sadly this was not to be the last time they would witness a seizure.

Charlie was closely monitored and her GP referred her at just one year old to a neurologist. The diagnosis was not good; Charlie was diagnosed with multiple complex conditions including Global Developmental Delay and Epilepsy. She is also undergoing genetic testing due to further symptoms which cause Charlie to collapse without warning.

Now aged seven, Charlie is a strong, resilient little girl who loves music, watching movies and entertaining her two younger brothers. She tries to be independent and whizzes around in her wheelchair; although such bravery has been a cause for concern, especially when Charlie made several attempts to climb out of her bed! This night time behaviour was a serious worry for her parents and they became more and more anxious, spending each night listening for the 'thump' which meant Charlie had tried to escape again.

Charlie's palliative care team was in agreement that a specialist profiling bed, which can be height adjusted to keep Charlie safe and secure, would offer an ideal solution. Thankfully, React was able to help this little lady who now sleeps comfortably and so do her parents!

Mum, Emma told us, "React has been amazing. The safe bed has made a huge difference to Charlie and our family life".



Charlie

Ramping Up Support for Dafydd

Baby Dafydd was born prematurely and admitted to a special care baby unit for observation. Shortly after his admission,

Dafydd's parents received the devastating news their little boy has a range of complex conditions including Hydrocephalus, which causes excess fluid to the brain. Dafydd was also diagnosed with Neo-Natal Meningitis and Epilepsy.

Now aged eleven, Dafydd has profound disabilities and relies on a wheelchair for mobility. He needs round-the-clock care from both parents and requires regular hospital admission due to epileptic seizures. This happy young man enjoys being entertained by his younger brother, whom he often laughs at for getting into mischief!

The reality of Dafydd's physical limitations, coupled with the need to stay close to a hospital due to regular seizures, meant the opportunity for family travel was an almost impossible feat.

Dafydd's family were made aware of React through a social worker, who recommended a folding wheelchair ramp to enable Dafydd to travel easily and provide access to a variety of places.

After a swift application to React, the family can now look forward to a break away in a React mobile home and also have the reassurance that Dafydd will continue to enjoy getting "out and about". Dafydd's Mum Juliet said, "Things have been difficult to manage and we are grateful for everything, thank you so much."



Dafydd

Latest News

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.

The Mercers' Company

React would like to express its appreciation and gratitude to The Mercers' Company for the generous £20,000 award to enable terminally ill children in London greater access to nature and the outdoors.

Richmond Art Society

The Richmond Art Society held a 'Fabulous Winter Art Exhibition' in December and kindly selected React as their chosen charity to receive proceeds from the raffle. The society raised £375 and we wish to send a big thank you to all the artists and organisers involved in the exhibition.

DM Thomas Foundation for Young People

Sincere thanks go to the DM Thomas Foundation for Young People for their generous award of £5,292 to assist with vital specialist and postural equipment for React children.

Hampton School

We are delighted to be chosen by the pupils of Hampton School as a charity partner for the current academic year. We wish the school much success with their upcoming fundraising events in aid of React families.

Radical Departures

A big thank you to all staff at Radical Departures who took part in a 'step count challenge' and raised an impressive £450 to assist our families.

The Worshipful Company of Curriers

We would like to express our continued thanks to The Worshipful Company of Curriers for their ongoing support with funding over the years to families in need of vital equipment. Our sincerest thank you extends to all livery companies who support React's work.

DWF Foundation

React is grateful to the DWF Foundation for their award of £1,816 to provide vital, essential equipment to life-limited children living in Greater Manchester.

Takeda

The production and distribution of the 2019 summer newsletter was supported by a financial grant from Takeda UK Ltd.



React

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

Tel: 020 8940 2575

Email: react@reactcharity.org

Website: www.reactcharity.org

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.