

React

GIVING DEPTH TO SHORT LIVES

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

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Cassie's Wet Room

Cassie was born, their world turned upside down. What was meant to be a smooth pregnancy, ended hastily as doctors rushed to deliver Cassie when her heart rate became erratic. Following anxious periods of waiting, numerous MRI scans and tests, Marta and Steve were eventually told Cassie's diagnosis.

Now aged five, Cassie lives with CHARGE syndrome, Hypotonic Cerebral Palsy and significant Developmental Delay. CHARGE syndrome is a rare genetic disorder which impacts on Cassie's growth, feeding, respiration and mobility. Cassie requires 'round-the-clock' care as well as numerous specialist and mobility aids. As she continues to grow, home adaptations have also become increasingly vital for her wellbeing. With the family already in severe financial difficulty struggling to cover the cost of a ceiling track hoist, ramp and lift to help accommodate Cassie's needs, their options had been exhausted when trying to source funding for a wet room for their daughter.

Under extreme pressure to install a wet room to meet Cassie's complex needs, the family turned to React with the assistance of Cassie's Occupational Therapist. "I cried happy tears when we received the good news from React. The wet room is perfect and so much easier for Cassie now. It has everything she needs and will be a massive improvement for Cassie. We can't express how grateful we are to React, this is a perfect present for Cassie."

Welcoming a new born baby into any family is exciting, overwhelming and life-changing. However, when Marta and Steve's daughter



Amelia's Lycra Suit



Although Amelia was born ten weeks prematurely, her doctors were positive and pleased with her progress. One day, when Mum Nasrin was playing with her one year old daughter, Amelia's legs collapsed from underneath her and she began to go floppy but recovered quickly. Nasrin kept a careful watch on her daughter and noticed Amelia's motor skills were deteriorating and unlike most babies, her skills were regressing rather than improving.

Following a number of blood tests, MRI's and spinal scans, doctors are still baffled by Amelia's symptoms. She experiences significant hypotonia (low muscle tone), has little to no head control, cannot roll or sit up and requires maximum support in all activities. Despite this, Amelia is a happy little girl who continues to light up the room with her smile.

To help with her development, Amelia attends regular physiotherapy sessions. After noticing Amelia's back curving and becoming weaker on one side, her Physiotherapist recommended additional support in the form of a Lycra Suit. A Lycra Suit garment can provide stability, support and promote body awareness; improvements which would be highly beneficial to Amelia, assisting her to hold her head up independently, offer support when sitting and help to prevent spinal deformities due to her low muscle tone. Lycra suits are unavailable through local authority funding and, unable to meet the cost herself, Nasrin contacted React.

"React has been so quick and helpful. We are still not sure what Amelia's diagnosis is but with the use of the Lycra Suit, it will help her to improve and feel supported within her own body."

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

React Holidays



Jake

Jake, aged three, lives with Hypoplastic Left Heart Syndrome, a complex cardiac condition which will eventually require a heart transplant. Jake's family enjoyed a stay at one of React's mobile homes in Skegness last year and the family can't wait to go back again:

"With everything we've been through since Jake has been born and the constant hospital appointments and surgeries, I just wanted to let Jake have some normality. He absolutely loved the arcade and seaside and now always asks when we can go back to the 'home in Skegness'."



Jack

Four year old Jack, who lives with an undiagnosed illness, recently visited the React holiday home in Blackpool with his family. Everyone including Jack loved saying hello and having their photos taken with the holiday characters.

"It's so nice to have the help and support. Everyone was very accommodating and welcoming."



Zack

Ten year old Zack and his family love React holidays so much, they've visited every single one of our mobile homes! Their annual holiday gives Zack and his family a well-deserved break from their daily routines.

"Zack's Cystic Fibrosis means he needs to take a lot of medication including 30-40 pills a day along with two inhalers and his nebuliser. He misses a lot of school because of hospital appointments and handling his condition can be very gruelling. It was nice to give Zack and us a well needed break and to give him some fresh air and exercise. We've made a lot of memories at the React mobile homes and taken some wonderful pictures. We really appreciate it."

Richmond May Ball

React was delighted to be one of the benefitting charities at this year's prestigious Richmond May Ball, held on Friday 12th May.

The Richmond May Ball is an annual fundraising event held in the heart of Richmond upon Thames and welcomes over 400 guests to enjoy a champagne reception, a sumptuous three course dinner, entertainment and the chance to bid on an array of luxury prizes. Over the years, the Ball has raised funds for local charities and proceeds from this year will make a huge difference in providing support to React families.

We would like to say a huge thank you to the Richmond May Ball Committee and all who attended for generously supporting React children and choosing us to be part of such a wonderful evening.



Up For A Challenge?



Up for an exciting challenge this year? Motivated to set yourself a goal? React's challenge events are the perfect opportunity to experience a fun-filled day whilst raising money for React families.

React challenge events are tailored to all – whether you like to run, swim, cycle or jump, there's something for everyone. If running is your forte, why not join React at the British 10k? Registration is free and all we ask is that runners raise a minimum sponsorship of £150. Don't miss out on this superb event and contact us today to secure your place!

Alternatively, if you would like to learn more about the different challenges we can arrange, call us on 0208 940 2575 or email Jasmine at react@reactcharity.org. Take on the challenge of a lifetime and raise money for terminally ill children!

Sainsbury's Support

The Sainsbury's West Region team has been hard at work using creative fundraising initiatives to raise funds, having chosen React as their charity of the year 16/17. The team has held bucket collections, store singing, competitions and dress up days including a spooky Halloween Walk, where members of staff dressed as scary ghosts and ghouls.



React is extremely grateful to the Sainsbury's West Region team for their kind support and we can't wait to see what else they have planned this year.



Sporting Bears Motor Club

Sporting Bears Dream Rides

On June 4th, Sporting Bears will offer Dream Rides at Thirlestane Classic car show in aid of React families.

Dream Rides are a wonderful fun-filled activity for all, with the chance to take a ride in a car of your dreams and sample the thrill of a unique and rare experience.

Sporting Bears are a dedicated group of classic car and sports car enthusiasts who raise money through social and touring events around the country. They have been long-time supporters of React for many years, raising funds for families living in Scotland. We are extremely grateful to be working together once again on this superb day.

Light Up For Ella

Ella



Seven year old Ella lives at home with Mum Louise, Dad Richard and little Sister, three year old Lois. Ella is a kind-hearted and gentle little girl who loves listening to music and visiting the seaside.

When Ella was just eleven weeks old, her parents rushed her to hospital after noticing their daughter was experiencing a seizure. After numerous tests, the unthinkable occurred and Ella was diagnosed with 1p36 Microdeletion Syndrome, a disorder which affects her mobility, speech, vision and development. Ella also lives with epilepsy and requires close supervision at all times.

Due to Ella's visual impairment, it is difficult for her to see the world around her and connect with other people and her school has been working hard at finding alternative ways to achieve this. Her Community Nurse recommended the provision of a light panel for home use, a portable piece of equipment which allows objects and shapes to be illuminated, enabling Ella to easily focus and direct her attention on them. The panel also serves as sensory stimulation for Ella and will give her parents the opportunity to continue working with Ella when she is unable to attend school.

Not wanting their daughter to fall behind with the progress she was making, Louise contacted Ella's Community Nurse who helped the family apply to React for the light panel and also requested a video monitor, to alert them of Ella's epilepsy during the night.

"The thing that is amazing about React is that the charity's turnaround is so quick. Everyone is so polite and communication is great. The light panel and video monitor are both a massive improvement on Ella's quality of life and safety and we are so grateful."

Helping Alex

threatening conditions including Microcephaly, Encephalopathy and Cerebral Palsy.

Now aged twelve, Alex experiences up to a dozen seizures every day and he is reliant on his family for all his care needs. Alex responds well to bright colours and sounds, watching the television makes him smile as he is able to concentrate on the shapes, sounds and colours moving in front of him.

His Nurse recommended the family purchase a television for Alex's bedroom to occupy him whilst he spends many days confined to his bed. A television would keep him company when his parents are elsewhere in the house. However, with his parents solely reliant on Danut's wage as a manual worker, purchasing a television would impact on the family budget enormously.

Desperately seeking a way to enable Alex to have a TV in his room, his Nurse referred the family to React and helped them fill out an application form.

"We have never seen anything like React before, you are so prompt. Alex adores the TV and the colours and lights have a calming effect on him. His younger brother is now always pointing out things to Alex on the screen and it has become a good way for them to bond together. Alex is so relaxed and content. Thank you so much."

Six week old Alex was rushed to A&E after experiencing his first seizure. His parents, Mihaela and Danut were panic stricken and daunting news was to follow; Alex was diagnosed with a number of life-



Alex

Car Journeys Made Easy For Kerrie

Parents Anita and David were concerned that their daughter was not meeting the expected milestones. After multiple visits to the hospital, baby Kerrie was finally diagnosed early last year with a rare genetic disorder, Angelman Syndrome.

Angelman Syndrome is a neurological disorder which affects the nervous system. Four year old Kerrie cannot walk, talk or communicate and she experiences uncontrollable movements. As a result of her condition, Kerrie has no awareness of danger and it is imperative someone is with her at all times, to ensure she is safe.

When Kerrie outgrew her car seat, travelling was no longer safe as she cannot differentiate between sitting or standing and she constantly fidgets, becoming very difficult to restrain. With Kerrie no longer safe or comfortable, and with the family reliant on income support, Anita and David worried how they were going to source a specialist car seat to meet Kerrie's needs.

Unable to cover the cost themselves, they consulted Kerrie's medical team, who recommended React.

"I burst into tears when I received the good news from React. I can't tell you how much pressure was lifted off our shoulders and with React's help we can now take Kerrie out and about again safely and comfortably."



Kerrie

Pike Anglers Club

The Pike Anglers Club, based in Hull, held a fundraising 'Fish-In' in aid of React and in memory of a little boy who was assisted by the charity. The anglers had a fun-filled day of fishing and remembering young Ronan whose face features on the trophy given to the angler catching the biggest pike. React would like to thank Clive and the group for their fundraising Fish-In's, raising funds to assist many React children.

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 ____/____/____

Issue no. (If present)

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 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 20-72-17

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

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 **vodafone**

You can donate by Text too! You can now donate between £1 - £10 by texting REAC12 and the amount to 70070. It takes just a few seconds to help so many families.

Fulham College Boys School

React would like to thank Fulham College Boys School for supporting React families by holding a football tournament and dress down day, raising a fantastic £277.43! Well done boys and we look forward to working with you again.

Kew Community Choir

Kew Community Choir gave an incredible performance of 'Joseph and the Amazing Technicolor Dreamcoat' and React families benefitted from their collection. Donations collected through their sell-out shows amounted to a wonderful £369.31. React would like to thank Mary Noyes and the Kew Community Choir for their very kind support.

Erskine Cunningham Hill Trust

React is grateful to the Erskine Cunningham Hill Trust for their generous award of £1,000 which has provided life-limited children living in Scotland with essential equipment that has significantly improved their quality of life.

Eton College

Following a visit from Sister Frances Dominica OBE, React was delighted to receive a kind donation of £277.47 from Eton College through money collected at their Sunday chapel service. We would like to thank the college for their generosity and support of React families.

Worshipful Company Of Curriers

We would like to thank The Worshipful Company of Curriers for their most recent award and support over the years, which has had a huge impact on React families living in London. Thanks must also go to the many livery companies who support React's work through donations made to the Poor Fund.

Masonic Charitable Foundation

Freemasons of Surrey gathered at the Nutfield Masonic Centre to give donations to fifteen charities including React. We are truly grateful to the Masonic Charitable Foundation for their generosity and their award which will benefit many life-limited children.

Cheshire Freemasons Charity

We would like to express our sincere gratitude to the Cheshire Freemasons Charity for their award of £2,000 to provide vital, essential equipment to React families living in Cheshire.

Hodge Foundation

We would like to thank the Hodge Foundation for their support of React's work. The Foundation's most generous award of £5,000 will provide essential educational equipment to life-limited children living in Wales.



React

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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.