

React

GIVING DEPTH TO SHORT LIVES

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

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EyeGaze for Muhammad

his older brother," she remembers, "I couldn't put my finger on it but something felt different."

For the first two years of his life, Muhammad suffered from many colds but on one occasion, his parents noticed him grunting and falling over. "We just knew something was wrong," said Mum, Sumerah. The family rushed to hospital, where Muhammad's condition worsened. "I thought he'd fallen asleep on me, but he'd collapsed," said Sumerah. Muhammad was incubated and a ventilator fitted. Numerous tests revealed Muhammad had Leigh's Disease - a progressive condition affecting the nervous system. Muhammad remained in hospital for the next two years. During this time, he caught another infection and collapsed once again, this time falling into a six week coma. "When he woke up, he couldn't speak, there was just no response at all from him," said Sumerah.

Now aged nine, Muhammad is unable to walk or talk, but he can communicate by smiling and crying. He is not well enough to attend school, and Sumerah teaches him what she can at home. At their local hospice, Muhammad trialled an EyeGaze - a specialist computer that can be controlled through users' eye movements. "We honestly didn't know if he'd respond to it," Sumerah said. To her surprise and delight, Muhammad could use the EyeGaze to identify shapes, colours and numbers. "We had no idea how much he was picking up! The EyeGaze showed us that, for all this time Muhammad has been absorbing and learning," said Sumerah.

With the help of a paediatric consultant, Sumerah made an application to React. We are delighted to report, Muhammad can now communicate with his family using this technology. "He is such a happy, smiley boy and he just loves the EyeGaze. I am so grateful to React, thank you!"



Muhammad

P-Pod for Louisa

Louisa was born prematurely at just 30 weeks, and she experienced a brain bleed whilst still in the womb. With her family hoping for the best but fearing the worst, they soon realised Louisa was not reaching key milestones and after nine months, they received a diagnosis. Louisa had Cerebral Palsy and Epilepsy. "It was a crazy time," said Mum, Marilia. "We knew the bleed was severe so it didn't take us by surprise, but it was still hard to hear."

Now aged five, Louisa is unable to speak but she can walk a few steps with the support of a specialist walker. Her complex condition includes uncontrollable muscle spasms and her family tried to source a comfortable seating solution for her. Turning to Louisa's Occupational Therapist, a specialist seat called a P-Pod was recommended as the most suitable option. This is a supportive bean bag consisting of a custom moulding that offers comfort and security for children like Louisa. "The P-Pod is amazing. It feels like when we come in straight from work and relax on the sofa - Louisa always wants to chill out in her P-Pod," Marilia said.

When Louisa began to outgrow her P-Pod, her parents tried to re-mould it to make it last as long as possible. Eventually, towards the end of last year, it was clear the seat had reached its limit. Marilia said: "When I heard the charity was able to assist, especially so quickly, I felt so grateful. The new P-Pod has been a godsend for us, thank you so much!"



Louisa



Takeda UK Ltd

This initiative for the production and distribution of the 2020 Summer Newsletter was supported by a financial grant from Takeda UK Ltd. React would like to sincerely thank Takeda for its generous support.

RAPID EFFECTIVE ASSISTANCE FOR CHILDREN WITH POTENTIALLY TERMINAL ILLNESS

Blue Watch

Firefighters Lee and Mike of the London Fire Brigade participated in the growing phenomenon Rough Runner – a 5km obstacle race inspired by the bizarre and hilarious challenges of game shows like Takeshi's Castle and Total Wipeout. Lee and Mike battled their way over giant inflatables, big bouncy balls and the legendary "Travelator", raising a fantastic £440 for React in the process. Well done guys and thank you for your support!



Ulster Bank

React was honoured to be chosen by Tina Campbell, at the Ulster Bank's Sports and Social, as the event's benefitting charity. Tina's daughter, Jessica, was assisted by React in 2017 and Tina has continued to stay in touch following Jessica's unexpected death that same year. Attended by 150 guests, the dinner-dance featured a raffle, auction and live music, raising an incredible £1,987.50. Our sincere thanks go to Tina and the team at Ulster Bank for their amazing support.



Oskar and Karolina

Oskar and his mum Karolina organised their very own charity bake sale, hosted by a local convenience store where they sold a wide array of delicious homemade treats, raising a wonderful £305.27.

Oskar lives with Chronic Kidney Disease and React has been delighted

to support the family since they first approached the charity in 2016. We are incredibly grateful to Oskar and Karolina for taking the time to raise funds for React and send a big heartfelt thank you to you both.



Hampton School

Hampton School selected React as local Charity of the Year and we were delighted to introduce students to React's work. React's Chair, Rupert Wiles, was warmly welcomed at a school assembly and was impressed by the compassion and understanding displayed by all students.

Throughout the academic year, students engaged with an eclectic mix of fundraising activities including sporting events, dress-up days, fairs and quizzes, raising an impressive £2,975.55. Thank you to all staff and students of Hampton School for enthusiastically supporting our work.



Sporting Bears Dream Rides

Sporting Bears are a dedicated group of classic car enthusiasts who give up their time to raise money for children's charities, by giving members of the public the chance to take part in their spine-tingling 'Dream Rides'. At the NEC Classic Car Show, classics like Ferraris and Aston Martins gave exciting rides on public roads (all abiding by speed limits, of course), providing a memorable and exhilarating experience to petrolheads in exchange for a donation to React. The weekend raised a fantastic £3,531 and we would like to say a huge thanks to Dick, Pat, Caroline and Mike for welcoming us and making this donation possible.



St Luke's Church

Always looking for ways to bring the community together, the Social Committee at St Luke's Church earlier hosted a fun-filled bingo night in aid of React. It was a 'full house' as 57 eager participants entered an evening of games, along with a buffet supper followed by ice creams, prizes galore, and a well stocked bar!



Buggy for Josh

Robyn and her partner were excitedly preparing for the arrival of their first child, making the home ready for their new baby boy. However, eleven weeks before her planned due date, Robyn went into labour and baby Josh was born with fetal hydrops - a life-threatening swelling caused by a build-up of fluid in his lungs. Immediately, he was rushed to the paediatric intensive care unit.

The first year of Josh's life has been spent undergoing ten operations - including two open heart surgeries. "We're still not totally sure what's wrong with him, he's still undiagnosed," said Robyn. "It's so difficult - you just don't expect this when you're pregnant." Every time Josh seemed to be making progress, he ended up back on a ventilator and eventually a tracheostomy was fitted. Even now, little one year old Josh must travel with oxygen tanks and a ventilator wherever he goes, 24 hours a day.

With the amount of equipment necessary to keep him safe, Josh's parents soon realised a buggy they had lovingly bought in preparation for his arrival, wasn't suitable. With mounting costs from Josh's stays in hospital throwing the family's finances into disarray, Josh's parents were unable to afford a more suitable buggy. After speaking to their social worker, Robyn made an application to React for a more robust buggy capable of carrying Josh's oxygen tanks and ventilator, which we were delighted to provide. Now back at home, Josh can go out with his mum safely, to baby classes and beyond! "The buggy holds everything beautifully. I can see his ventilator and his oxygen machine, it makes life so much easier."

"We couldn't believe the speed of React. Thank you so much for all your help to allow our special boy to come home from hospital," said Robyn.



Josh

Hoist for Dakota

Dakota's mum, Sarah, knew right from the beginning something was not quite right after delivering her newborn baby. Soon after birth, a blood test revealed Dakota has Duchenne Muscular Dystrophy - a progressive, life-shortening genetic disorder where his muscles will deteriorate over time. Progressive conditions often rob children of the abilities they once had, and Dakota's family know his illness will continue to progress.

Now aged ten, Dakota's illness has taken away his ability to walk, and, for the past two years he has used a wheelchair. Dakota is a happy young man who loves to go to school, sing with his friends and play games on his PlayStation with his older brother. He loves sports, and plays Powerchair football at his local club. Despite all the outdoor activities Dakota loves to be part of, travelling is difficult as Dakota is now too heavy for his parents to lift him. With his grandparents living six hours away, family visits and outdoor trips were limited.

Sarah was made aware of React through her local hospice, and the family applied for a mobile hoist. "We were so pleased at how fast React reacted! When we heard we'd been awarded the hoist we were really excited - I thought we'd be waiting ages!" Sarah told us. As well as making everyday life easier, the hoist means Dakota can travel across country and visit his grandparents. "The hoist lets us have family time together before Dakota's condition deteriorates. We are so grateful for this amazing help to our family. Thank you!"



Dakota

Washing Machine for Maryam

Maryam appeared to be a small but healthy baby but, at just six months old, tests revealed Maryam had Schwartz-Jampel Syndrome, a genetic disorder which affects bone and muscle development.

Now aged four, Maryam is dependent upon a tracheostomy and she is tube fed. She is particularly prone to infections, which severely affects her struggling respiratory system. Her family know just how dangerous it can be for Maryam to catch a cold and, to prevent risk, were advised to wash their clothes separately.

When the household washing machine broke down, the family turned to React. Dad, Shakil, told us, "I'm a self employed driver and when you've got all this going on, there's a lot of financial difficulties. React is brilliant. In times of need, the help they give makes such a difference." We were delighted to help thanks to the compassion of our wonderful supporters.



Maryam

DO YOU KNOW A CHILD WHO COULD BENEFIT FROM REACT'S HELP?

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

£500 £250 £100 £50 £25 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.

Harrodian School

A great day was had by all at the Harrodian School Summer Fair, raising £2,000 for React. We send big thanks to all at the school for its support.

Fulwell Golf Club

Fulwell Golf Club raised a magnificent £19,251.08 for React's families. Thank you so much for this overwhelming contribution to our work, and providing vital aid and equipment to so many. We thank you for your incredible and valuable support.

Storm Building Ltd



React is pleased to announce a 2020 charity partnership with Storm Building Ltd, which kicked off at the beginning of the year with a very kind £1,000 donation, followed by a further fantastic donation of £2,000 during the Covid-19 lockdown. We look forward to working with Storm throughout the year and thank all the Directors and staff for choosing to support us.

Lbox Communications

React would like to thank the team at Lbox Communications for once again agreeing to distribute our newsletters free of charge and raise valuable awareness to our work.

Jack and Jill School

Following the conclusion of the Jack and Jill School Charity of the Year partnership, React was presented with an amazing cheque for £6,308 at the school's Christmas Carol Concert. Thank you to all who raised this magnificent sum which will do so much for so many. Our sincere thanks go to all.

The Worshipful Company of Curriers

We would like to send our thanks to The Worshipful Company of Curriers for their most recent award. As kind supporters of React for many years, The Worshipful Company of Curriers has made a substantial difference to families in need of essential equipment. We are grateful once again to them and to all livery companies who support React's work.

Millennium Stadium Charitable Trust



We would like to express our sincere gratitude to the Millennium Stadium Charitable Trust for their support of React's work in Wales. The Trust's most generous award of £6,835 will provide more terminally ill children with aid and equipment essential to their care.

React

Rapid Effective Assistance for Children with potentially Terminal illness

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

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Email: react@reactcharity.org

Website: www.reactcharity.org



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.