Glide-away bed to help Alfie

At the age of eight, when tests were nearing to an end, Alfie began to regress and struggle with certain tasks such as reading and writing. At this point, medical intervention was recommended and eventually Alfie was referred for a CT scan. The examination showed abnormalities in Alfie’s brain, leading to an urgent MRI scan. Specialists diagnosed Alfie with a condition called X-Linked Adrenoleukodystrophy and just 3 months later, Alfie had lost all mobility skills as well as his speech. Alfie’s illness is progressive and now aged nine, his only communication is by tracking, blinking and moving his eyes. Mum, Rachael, told us Alfie is still able to demonstrate his ‘cheeky’ side, and this young man can still make his family smile.

Due to an impossible wait for adapted housing, Alfie’s family converted their dining room into a bedroom. This meant Rachael and Colin were sleeping on a sofa next to Alfie to watch over him throughout the night. Understanding the huge toll the lack of sleep was having on the family, a hospice social worker recommended they obtain a glide-away bed, often used in hospice settings for families staying with patients for a period of time. With the help of this sponsor, the family applied to React.

Rachael told us how the adaptable bed has been an absolute ‘game changer’. It means Alfie’s parents can now sleep comfortably and watch over him as he sleeps.

Jack’s Trike

Born prematurely at 28 weeks, Jack has endured a difficult start to life. Diagnosed shortly after birth with Apert Syndrome, Jack has very limited mobility and although his surgeries have been successful, Jack’s parents Michele and David were acutely aware of their three-year-old’s restricted independence. When Michele spoke to us, she explained: “There was very little he could do and seeing him in the park watching other children play and ride their bikes just broke our hearts.”

Michele and David began to research adaptable trikes and met with a representative from a specialist manufacturer and although impressed, were overwhelmed by how expensive the trikes are. It was during the preparation for one of Jack’s cranial surgeries that a physiotherapist mentioned React. With help on hand, an application was submitted and we were happy to assist.

The trike arrived in time for Jack’s birthday and kept hidden away as a surprise. Michele told us: “Once he realised that the bright green trike was his, he couldn’t stop squealing! It was the happiest we’d ever seen him. He now directs us to the local park and proudly rings his bell when riding past cyclists and pedestrians.”

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.
Queen Ethelburga’s Collegiate

React was thrilled to be voted as charity of the year by Eoforwic House at Queen Ethelburga’s Collegiate. The York-based school carries out a plethora of fundraising initiatives throughout the academic year including gala dinners, bake sales and non-uniform days. We send our sincere thanks to students and staff for their hard work and support.

Pike Anglers Club of Lincoln

On a cold Sunday morning, Clive and fellow members of the Pike Anglers Club, Lincoln, set out on a mission to do what they love most – catching freshwater pike! We are delighted to report that not only were the team successful in catching a few impressive specimens, but their ‘React Fish-in’ raised a much appreciated £222. A big thank you goes out to all 14 anglers who participated.

Durham University

The student fundraising arm of Durham University, known as ‘DUCK’, have chosen React as their Charity of the Year and have been carrying out a whole host of fun activities in aid of our families. From bake sales and karaoke nights to walks and treks, there is no limit to what these eager students will set their sights on and React would like to wish the very best of luck to those participating in this July’s London 10k race.

Gemma Leszczyszyn

This summer, Cambridgeshire-based Gemma plus ten more brave participants will be taking part in the ‘Sandringham 24’, a 24 hour endurance race through the famous Sandringham estate. The team is made up of friends and family of eight year old Ted, a child living with multiple complex needs.

“In March 2021, Ted was diagnosed with Adrenoleukodystrophy and I know first hand how brilliant React was” said Ted’s aunt, Gemma.

“It was Ted’s Mum, Freddie who asked us to direct all race donations to React as a show of support following the provision of a buggy that React provided for Ted last year”.

React sends the very best of luck to the whole team and will be cheering on Team Ted when the big day comes.

Laila’s Car Seat

Life has not been easy for one-year-old Laila. Her Mum, Liga, went into labour prematurely, giving birth at just 23 weeks, and Laila was born weighing just 665 grams. Very soon after, Laila was diagnosed with Microcephaly and Cerebral Palsy.

Laila’s condition remains fragile and she needs to be secure and safe, especially when travelling by car. This is not only to keep her comfortable, but also to ensure her breathing is not compromised. Standard car seats proved unsuitable, and the family were referred to React by the local children’s hospice. Laila’s OT was able to recommend a suitable car seat, which met Laila’s needs perfectly.

Gemma was delighted by the speed in which we were able to respond, and expressed her joy at how quickly the car seat arrived: “Next thing I knew the car seat was in the car”.

Now Laila and her family are able to safely venture out on longer journeys together and visit loved ones.

Storming to Victory!

In April, long term supporters Storm Building gathered up more than 20 colleagues, besides family and friends to take part in a local 5k ParkRun in aid of React families. Donning the iconic yellow React t-shirts, the energetic group stormed to the finish line and raised a fantastic £2,055.87 in the process. It was an unforgettable day and React thanks each and every participant of Team Storm for such a fantastic effort.

The Financial Crime team at NatWest is made up of colleagues from around the UK who kindly chose to support React as part of the bank’s wider ‘Do Good Feel Good’ campaign. Taking place through two different fundraising activities, the team came together to raise a fantastic £1,074.

The first activity involved individual challenges, where more than 25 participants set themselves a target relating to wellbeing and the forfeit was to make a donation if that target wasn’t met. The second, took the form of an all-team fundraising quiz and React sends its thanks to the event organisers and to all who contributed to the campaign.

Natwest Group

Ron Brokenshire

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Identical twins Ruby and Amelia were born in 2018 to Mum, Katie and Dad, Peter. Both appeared to be healthy babies but during routine visits from a Health Visitor, Amelia was found to be developmentally delayed. Alarmingly, Amelia started experiencing seizures and for 3-4 months the family struggled to obtain a diagnosis, until Amelia was admitted to hospital with Bronchitis. It was during this time, Amelia was diagnosed with Rett Syndrome, a rare genetic condition that affects brain development. Her sister Ruby underwent similar tests and devastatingly, was diagnosed as having the same debilitating illness.

Four-year-old Amelia and Ruby communicate using eye movements and Katie told us how they both have very different personalities. “Amelia is very ‘chilled and laidback’, whereas Ruby is very ‘sassy’ and will be the first to let you know if she doesn’t like something!”

Needing double of everything, the family struggled with storage space due to copious amounts of medical equipment, and their two-bedroom bungalow was becoming cluttered and crowded. The family already knew about React and its services having benefitted from previous help, so we were more than happy to help solve their storage problem.

Katie told us how the shed React provided has proved a ‘massive help’ and explained “Time can be very limited with so many frequent hospital visits, so having somewhere to store equipment safely and out of the way is one less thing to worry about.”

With the trike costing £2,225, Rebecca and Jody turned to charitable organisations for funding, without success. Almost a year went by before they heard about React, and they agreed to submit one last application.

Rebecca reported: “We cannot thank you enough, Isla always wanted to ride a bike like her sister, and she is over the moon with her tricycle. It is already benefiting her development as she builds her leg muscles and she has even begun to pedal it herself a little bit. Thank you so much for responding to our application so quickly.”

Isla was just three months old when her parents, Rebeca and Jody, became concerned by their baby’s lack of development. They raised the issue with their GP and shortly after, Isla was diagnosed with Spinal Muscular Atrophy. Now aged five, Isla faces multiple challenges and despite numerous physio sessions she cannot stand unaided. Rebecca, researched children living with SMA and found many were successfully using specialist tricycles, and following a consultation with Isla’s physiotherapist, an assessment was arranged with a manufacturer. The perfect trike was identified and Isla’s parents immediately saw how their daughter was excited by the prospect of some ‘grown up wheels’.

Charlie is described by loved ones as a “Happy Chappy”, despite his traumatic start to life. When Mum, Chloe was in labour, Charlie suffered a significant bleed on his brain, while still in the womb. Charlie was incubated as soon as he was born, and doctors diagnosed HIE, a cerebral palsy-like movement disorder, with severe dystonia and seizures.

Charlie is unable to sit up unaided and has very specific postural needs. He uses a chair provided by healthcare services to support him correctly, but it is not the most comfortable and after sitting in it for prolonged periods of time, Charlie can often become irritated. His parents noted that, whenever he visits the local hospice, he sits nicely in a P-Pod, appearing comfortable and happy.

With the help of Charlie’s OT, Chloe reached out to React, and was over the moon when she heard we could help. Chloe told us, “We were actually quite shocked when we received the call from React, as we did not think we would get any support at all. Charlie loves his P-Pod, and thank you for making the whole process so quick and easy”. 
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 / 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.

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.

DONATE ONLINE TODAY AT www.reactcharity.org