

React

GIVING DEPTH TO SHORT LIVES

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



Rosa

Getting Mobile

Rosa is seven and has a regressive condition causing lack of head control, developmental delay, visual impairment and abnormal muscle tone. Rosa cannot walk, talk, sit or crawl.

Rosa lives at home with Mum Amy, Dad Gareth and brother Ithan. They are a very active family and love nothing more than long walks and outdoor activities together, something they have also found hugely beneficial to Rosa who enjoys the change of scenery. However, Rosa is a full time wheelchair user and her family are finding more and more frequently that they cannot visit places they like as there is no suitable access. Mum and Dad have been carrying Rosa wherever possible but as she continues to grow this is no longer a realistic option.

The local authority provided a wheelchair for daily use, but it could not cope with all terrains and Rosa's Physiotherapist thought the Advance Mobility Pushchair with specialised support would suit her better. This would allow Rosa to access a wider environment and spend quality time with her family away from home. The pushchair is also tailored to meet Rosa's needs, ensuring she is supported correctly and comfortable whilst travelling. An application was made to React and the family were overjoyed at the swift response, providing this very special piece of equipment which has made life so much easier for them.

A Good Night's Sleep for the Family

Little Mason is two years old and lives with Mum Laura, Dad Tony and brother Alfie, aged four. Mason is a happy little boy who is always smiling and loves nothing more than playing with his big brother.

But for Mason, life can be complicated. He has a rare diagnosis of Osteopathia Striata with Cranial Sclerosis and has been fitted with a tracheostomy tube to enable him to breathe.

Mason's condition causes secretions into his small lungs, which could prove fatal and he needs suctioning 24 hours a day. Whilst the local authority were able to provide the family with a suction machine, it was heavy and difficult to manoeuvre, making time away from home a struggle for the family. Additionally, the machine is very loud and frightening for Mason as he struggles to understand what is happening.

Laura explained "The machine wakes the whole house at night and whilst we know the treatment is essential, we wish there was a quieter option. Mason requires a lot of suctioning at night and I am finding it very difficult to get the boys settled. Their father works shifts so cannot always be around to put them to bed and is often very tired himself".

The family were desperate to find a solution which would cause less distress during this treatment so spoke with Mason's Community Children's Nurse. She put them in touch with React who were delighted to provide a Medela Suction Pump which is far lighter, quieter and much easier to use.



Mason

Pink Pimms Party

On 23rd June a perfect Pink Pimm's Party was thrown at Pitcher & Piano, Richmond, in celebration of Charlotte Grobrien OBE's wonderful support of React families. Through her company 'Give It Away', Charlotte raises funds by developing and building properties. Charlotte has been a keen supporter of React for a number of years and we were delighted to celebrate with her during another busy and successful year. Thank you so much Charlotte for all that you do for React families.



Charlotte and mascots Ricky and Rachel



CIBC Balloon Release

React is extremely grateful to CIBC for choosing to support our families once again this year. The CIBC Children's Foundation supports three charities each year, raising vital funds through a number of fundraising activities; so far the bank has held a Charity Breakfast, Softball Competition, Balloon Release (pictured) and Bake Off. React families will also benefit from CIBC's well-renowned Miracle Day, where the bank donates trading fees and commissions to the selected charities. We express our sincerest thanks to the whole team for their continuing support.

Ladies Lunch

Kind hearted ladies gathered to enjoy a fine three course meal at the Bulls Head in Barnes to raise funds for React families. As well as the wining and dining, entertainment consisted of a raffle with a range of exquisite prizes and a speech from Guest of Honour and Former Bond Girl Valerie Leon, who summarised, 'As a former Bond Girl I see a comparison: James Bond fights for a better world where there is justice and equality and React fights for a better world for terminally ill children'. Thank you to all the Ladies who so kindly organised the event and all the attendees for their support.

Rhiannon and Valerie Leon



React Runners

This summer an array of athletic souls laced up their running shoes and hit the streets of London and Surrey in aid of React families. We are very grateful to our runners in the British 10K, Richmond Half Marathon and Super Hero Run, who tested themselves in the summer sun and raised a fantastic amount for React families whilst doing so.

React always has a number of challenge events for YOU to get involved with. If you would like to run, swim, trek, cycle or skydive for React then please do get in touch – react@reactcharity.org.



Mike Miller and DJB



Olly

Chelcie and Billy were already proud parents to two beautiful girls, Lily Mae and Lacie when they discovered they would be having their very first little boy. The couple were elated and could not wait to meet their new arrival, however, during Chelcie's pregnancy the family were dealt a crushing blow; their son had a very complex brain malformation and their little boy's chances of survival were extremely low.

In 2014 baby Liam was born and against all odds, has now celebrated his first birthday. He is blind, experiences frequent, severe seizures and has no independent mobility. "We are so proud of our little prince" said Chelcie, "He is such a brave little boy and surprises us each and every day".

Liam cannot sit independently and in order to support his posture as he continues to grow, his Physiotherapist recommended a P-pod Bean Seat. The chair would be specially adapted to Liam's needs and, unlike some specialist seating, will provide comfort, allowing him to feel very much part of the family when relaxing at home. His parents simply could not cover the cost of this seat on their own, so approached React who were delighted to help. Hearing the charity would provide Liam's new P-pod Seat Chelcie wrote "When we received your letter we were all so happy! Thank you so much for everything you have done – we don't know what we would do without you".



Journeys Made Easy

When Oscar was born he was not breathing and his family knew immediately something was very wrong. It was not until a few months later a full diagnosis was made, Doctors confirmed that Oscar has a rare illness, CHARGE Syndrome, causing heart defects and delayed growth and development. For Oscar the condition has led to scoliosis and vertebral abnormalities along with the fitting of a tracheostomy and a tube inserted into his stomach for feeding.

Although he has been in and out of hospital throughout his entire life, Oscar is a very happy little boy living with Mum Amber, Dad Mark, big sister Lily-Rose and his five year old brother Oliver. Oscar celebrates his third birthday this year.

The family were in desperate need of a suitable car seat for Oscar to transport him safely to vital hospital appointments so Oscar's Physiotherapist put them in touch with React. Amber, was overjoyed by React's fast response and to hear that they would receive the requested seat; a specialist model to provide the support Oscar needed along with suitable harnessing to keep him safe.

Supporting Jake

Jake lives with Lesch-Nyan syndrome; a degenerative, metabolic condition which causes profound and multiple disabilities which, for Jake, has included renal complications, severe movement disorder, self-harming behaviours and the insertion of a gastrostomy tube for feeding. There is no cure for Jake's diagnosis and treatment is purely supportive.

As a result of his condition, Jake requires a high level of postural support, particularly throughout the night. Both of Jake's hips have become dislocated and it is vital he is correctly supported to prevent further deterioration especially as he grows taller and heavier. During a visit to his local hospice the family met with Jake's Physiotherapist who suggested that a specialist sleep system would be the best solution, trialling Jake in one which met his needs.

The recommended sleep system can be placed either on the floor in the family living room whilst Jake is relaxing in the evening or on top of his bed at night. It is extremely lightweight so can be easily transported around the home or even when travelling to stay with extended family. Crucially, it is also tailor made to meet Jake's exact needs, supporting him where he needs it most.

Jake requires 24 hour care, his mother was left with no option but to leave her job as an Office Clerk when Jake was ten years old as his needs were simply too great. Although Jake's father is in full time employment their finances are stretched and at £595 the sleep system was simply out of their reach. Fortunately, with the help of Jake's Physiotherapist, an application was made to React who were delighted to assist.



Your Gift Is Urgently Needed

React aims to give children with life-limiting illnesses the best quality of life possible in the short time they have left. Whatever you can give will make a difference to a family struggling to give their child the best they can. **Thank you.**

YOUR DETAILS

Please complete your name and address details below so that we can reclaim the tax on your donation (see below) and also to keep you in touch with our work.

Your title and full name

Address

Postcode

Email

Signature

Date

YOUR GIFT TO REACT

Please accept my gift of

☐ £250 ☐ £100 ☐ £50 ☐ £25 ☐ £10 Other £

I enclose a cheque/postal order 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 use the following details: Account Name: React, Account No: 00886556, Sort Code: 20-72-17

REMEMBER TO GIFT AID YOUR DONATION! (SEE BELOW)

MAKE A BIG DIFFERENCE WITH A REGULAR GIFT!

If you would like to give regularly to React, why not set up a standing order? It helps enormously to be able to count on regular income and also reduces costs.

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

Please pay REACT Account No. 00886556; Barclays Bank, George Street, Richmond, TW9 1JU; Sort Code 20-72-17

REMEMBER TO GIFT AID YOUR DONATION! (SEE BELOW)

Make Your Donation Tax-Free

☐ I would like React to Gift Aid this donation and all donations I have made since 6 April 2003. I am a UK tax payer and will tell you of any changes in my tax status or address. *giftaid it*

The Inland Revenue have asked us to remind you that you must pay an amount of income tax and or capital gains tax at least equal to the tax that REACT reclaims on your donations (currently 25p for each £1 you give).

PLEASE SEND THIS FORM TO THE ADDRESS OPPOSITE.

Latest News

JustTextGiving™ by **vodafone**

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.

Row, Row, Row Your Boat!

React is thrilled to be chosen as one of Barclays Bank's charities. The good spirited South West London team are fundraising through a number of exciting activities, the highlight of which so far has been a bold and brave 'Row the Thames' event. On 2nd and 3rd July, a number of Barclays staff traded their keyboards and calculators for oars to row the equivalent of the length of the Thames on rowing machines.

A tough test was completed in good time by the athletic group, who have already raised over £3,500 this year in aid of React families.



Bathrooms by Design

React was delighted to be chosen to benefit from the generosity of local store 'Bathrooms by Design'. In July, the charity received an extremely generous donation of £2,684.05, raised by the sales team's tireless efforts. We would like to say a big thank you to everyone at the store for their hard work

Fly Georgiou Fly!

In August, courageous Georgiou jumped out of a plane flying at 10,000 feet in the London sky! His plummet to earth raised almost £1,000 for React families and the whole team are very excited as to what his next adventure may be! We extend a huge thank you (and congratulations!) to Georgiou and everyone who kindly sponsored him.

Canon Golf Day

The team at Canon UK has held an annual Golf Day in aid of React children for a number of years. This year, the weather proved kind to the philanthropic bunch and with a record number of golfers and a fabulous £790 was raised. We would like to thank Elliot and Andrew for their hard work and successful organisational endeavours, which made the day a roaring success once again.

React

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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. Any donation you make will be used to maintain or improve a child's quality of life in the weeks, months or years left ahead. Thank you.

