

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

Summer 2024 Issue 58

React
GIVING DEPTH TO SHORT LIVES

Sam →

Every child's first day of school is memorable but for Sam and his family it is remembered for different reasons.



Greater Independence for Sam

Although he seemed slightly developmentally behind for the first five years of his life, Sam's illness remained undiagnosed.

Then on his first day of school, while running with the other children, Sam had a fall resulting in a nasty gash on his head. Sam's parents urged doctors to look closer and divulged a range of symptoms. More tests and many hospital visits later Sam was finally diagnosed with Duchenne Muscular Dystrophy. Sam's family had not heard of the illness and it was only after researching online that his parents noted "That's Sam". Duchenne Muscular Dystrophy affects everyone differently but for Sam, it means he struggles with balance, impaired movement, and he fatigues easily. Due to the progressive nature of his illness Sam's symptoms are likely to worsen over time but with the help of his amazing support network everyone is working to slow down this deterioration.

Facing the characteristic muscle weakness, a passing comment about never being able to ride a bike was made to a physiotherapist during a house call. The physiotherapist revealed that there is a way Sam can safely join his family on bike rides and how the pedalling movement would be beneficial for Sam's cardiovascular and muscular endurance and an application to React for a specialist trike was made.

Upon receiving the news that Sam would be able to ride a bike for the first time, the family later told us they were overwhelmed and were quick to send a lovely picture of Sam enjoying his brand new trike.

"With the aid of specialist equipment, Sam could improve his strength"

Sam's dad, Stephen

Aroob

Aroob's holiday

At only six months old, Aroob's parents knew that something wasn't quite right with their beautiful baby.

Their older daughters were walking by nine months, but Aroob was still unable to hold her head up. The family's GP made a hospital referral and it took several years before Aroob was diagnosed with a rare neurological condition, Haxe 1, affecting less than 20 children in the UK. Due to her illness, Aroob is PEG-fed and she requires a catheter. She is unable to walk and now aged 13, relies on her family for all her care.

Heartbreakingly, Aroob's brother passed away last year at just five years old with the same rare condition. The local children's hospice put the family in touch with React and we were delighted to help with a much-needed break in one of our mobile homes. Aroob's Dad Haroon said "We got to see Edinburgh and Glasgow which was a dream come true for Aroob. Thank you for your help and we will never forget your kindness during these very difficult times. React charity is doing a wonderful job supporting children like Aroob in bringing joy and happiness to their lives".

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.





Laila

Laila's P-Pod

Born at just 23 weeks, Laila entered the world in a critical condition and, at just five months old, she was diagnosed with Cerebral Palsy, Chronic Lung Disease, Microcephaly, Epilepsy and she suffers with severe sight loss.

Doctors had their doubts as to how Laila's development would progress but now aged two, this plucky young lady surprises her Mum, Liga, every single day.

Laila wriggles a lot and it is difficult for Mum to keep hold of her daughter safely but, having grown out of the usual safe seating options, Laila had nowhere to relax. A physiotherapist suggested she may be suited to a P-Pod. This expensive equipment is unaffordable for Laila's family, so they reached out to React for help. Liga said "These are scary times, but we are keeping Laila as safe as we can and will make sure that she is happy".

"Keeping Laila safe and happy is what matters"

Laila's mum, Liga

"An absolute godsend"

Rosa's mum, Charlotte

Rosa's Car Seat

At just nine months old Rosa stopped meeting baby milestones, not rolling over nor putting weight on her feet.

She was just 18 months old when she experienced her first seizure. This was the first of many prolonged episodes requiring hospital admission that resulted in further investigation. With her first MRI coming back clear the family were shocked when the second showed a loss of brain cells. Rosa had a progressive neurological disorder, BPAN. This illness means Rosa will only progress so far developmentally before regressing in her teenage years and losing acquired skills over time. Learning that her beautiful daughter is living with an illness which will gradually get worse, Rosa's mum told React "Hearing the diagnosis felt like the world had ended".

Slowly coming to terms with the grief associated with such a diagnosis, Rosa's mum, Charlotte, joined a mother's group through Rosa's specialist school. It was here that Charlotte first heard of React when explaining Rosa's need for a specialist car seat with a swivel function. With support from Rosa's occupational therapist an application was made and Rosa can now travel with the rest of her family in safety with Charlotte recently stating "It has been a godsend".



Rosa



Edgware & Hendon Reform Synagogue

React was honoured to be selected as a benefitting charity of Edgware and Hendon Synagogue's High Holy Day appeal. The High Holy Days are an important time of giving in the Jewish calendar, in which charities are chosen to receive donations from the congregation's charitable contributions made over the year. React was chosen under the 'Tikkun Olam' category - meaning 'repair the world' - and the Synagogue's generous donation of £3,674.86 was used to help our families in London.



Maia's Marathon

A huge shoutout goes to Maia Platts, who proudly represented React at this year's London Marathon. After a long and grueling race past the iconic sites of the capital, Maia triumphantly crossed the finish line and raised over £2,000 for React families in the process. Thank you Maia, for your monumental effort and helping us provide more vital equipment for React families.

Ali's Relief

Once a lively and happy young boy, the adjustment to Ali's demanding care needs has been difficult for his family.

Before he became ill, mum Asmin described her son as having a quirky and noisy personality but at just three years old Ali suffered the first of many seizures. Following numerous consultations with doctors, Ali was finally diagnosed with Batten's disease, a degenerative condition where children regress, losing the skills they once had. Ali's condition deteriorated so badly he eventually lost the ability to walk.

Coming to terms with Ali's illness remains a daily battle for the family, who are a close and devoted family unit. Everyone is determined to keep seven year old Ali as happy and as comfortable as possible whilst the illness continues to ravage his small body.

On hearing about the work React does, Asmin applied for a P-Pod seat and a wheelchair powerpack, to ease pushing Ali around town. Asmin told us "Your help has made a huge difference to our son's life, he can sit comfortably with us and we can now visit family and friends, which means the world to us. Thank you for understanding and making this possible".



Kew House School

React entered its seventh year of its partnership with Kew House School this year, and the hard-working pupils, parents and staff have helped the charity assist many families throughout our time working together. We would like to send our heartfelt thanks to the Friends of Kew House Committee, for once again staging a highly successful Charity Quiz Night and raising an incredible £6,500 for React.



Jaida

Comfort for Jaida

When Jaida-Fox came into the world, she was a healthy young baby who seemed to be developing normally.

Her clean bill of health would be short lived. During the first few months of her life, Jaida's mum, Faye, became concerned that her baby slept almost continually and barely moved on the rare occasions she was awake.

Faye voiced her worries at a routine check-up and Jaida was promptly assessed by the genetics team at a local hospital. To the family's shock, it was soon discovered Jaida has an exceptionally rare neurological condition, which is so rare, doctors cannot even give it a name.

Jaida's parents have had to accept the uncertainty of their beloved daughter's illness, the symptoms of which are wide-ranging. Whilst the family always try to make the most of life, Jaida struggles immensely with her mobility. Her parents applied to React requesting a P-Pod along with a suitable portable chair which we were delighted to provide. Faye told us *"We are over the moon, these specialist chairs have made such an incredible difference. Jaida would live in her P-Pod if she could and the portable chair has enabled her to relax, especially when we were on the beach during our holiday in Skegness. It was a very quick and stress-free application process too!"*

Global-e

Global-e

React is thrilled to be chosen as the charity partner for Global-e's London office. Global-e is an international company specialising in cross-border sales, who decided to support React after being impressed by the speed at which the charity helps its families. The partnership was kicked off with a very generous £10,000 donation and we look forward to working with Global-e to reach out to as many children as possible.

Pike Anglers Club

A group of nine admirable anglers from the Lincoln Pike Anglers Club took to the lake earlier in the pike-fishing season, to participate in their annual Fish-In, in aid of React families. A fun day was had by all with many impressive specimens caught, including the largest ever catch during one of the group's charity fishing events. A respectable £230 was raised for React and we send a big thanks to Clive and all the fab fishermen for your kindness and support.



Happy Birthday Bee!

It doesn't get much more exhilarating than jumping out of an aeroplane from a height of 10,000 feet - but that is exactly what sisters Bee and Tia did, to mark Bee's 40th birthday in style. Not only did they take the brave plunge, they did so in aid of React and between them, raised an impressive £2,242.07. React sends its thanks to Bee and Tia for your bravery and to all those who donated to their fundraising campaign.



Dear Friend,

Thank you for taking the time to read about our important work.

Our work has been relied upon by families for many years. React's rapid service responds to all requests within a 48 hour time frame, a fact which we are proud to uphold.

This commitment is only made possible because of people like you and without your generosity, we would not be able to make such a difference to the lives of those most in need.

The stories detailed within this newsletter are a testament to your support and we want to thank each and every one of you, for your kindness and compassion.

Sadly we are not able to reach all those who need our assistance and ask for your helping hand to expand our good work.

With sincere thanks,

The React Team

Latest News

Give A Little Love

Waitrose's 'Give A Little Love' campaign has raised millions for causes across the UK and abroad, and React thanks all Waitrose stores who have kindly supported React as part of their contribution. The £2,250 raised will make a truly impactful difference to our families' lives.

Richmond and Kew Quilters

The patchworkers of the Richmond and Kew Quilters have supported React families for many years, and it is with a heavy heart that the group recently announced their closure. A final donation of £498.45 was made to React and the charity sends its gratitude to all for their compassion and creativity over the years.

St Richard Reynolds Catholic College

React thanks the hard-working and creative students of St Richard Reynolds Catholic College, who came together to raise £311.02 for React families during their Lenten fundraising programme.

The Worshipful Company of Fan Makers

Founded in the early 18th century, the Worshipful Company of Fan Makers is an ancient company steeped in history. Charity is at the heart of everything they do and, React sends its sincere thanks to the Liverymen for their recent generous donation of £3,500.

Pride of Surrey Chapter

The Freemasons of the Pride of Surrey Chapter chose React as their charity for 2023/24, and have made generous donations in support of React's work. We send a big thanks to the Chapter for showing such invaluable kindness.

Kentown Wizard Foundation

React sends a special thanks to the Kentown Wizard Foundation, for funding the purchase of three new mobile homes. The new homes, located in Great Yarmouth (Norfolk), Porthcawl (South Wales) and Eyemouth (Scotland), opened for the start of the 2024 holiday season and we are immensely grateful for the Foundation's generous support.

Squires Garden Centres

React thanks the team at Squires following the end of their 'Charity of the Year' partnership, whose customers raised a much-appreciated £446.12.

Twickenham-upon-Thames Rotary Club

A big thank you goes to the members of the Rotary Club of Twickenham-upon-Thames, for their generous £500 donation used to provide essential aid to React children. If you are a member of a Rotary Club and would like to make a difference to a terminally ill child's quality of life, please consider nominating React as your club's supported charity.

Kew Village Market

React was thrilled to accept a generous £1,160 cheque at a recent Village Market day, which was used to purchase a wheelchair powerpack. We send our heartfelt thanks to the Committee and to all those who regularly attend and support this fabulous community-led market.

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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.



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

