

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

Newsletter Winter 2019 Issue 49 www.reactcharity.org

Car Seat for Hanná

It was in the A&E emergency room that nine month old Hanná was diagnosed with Epilepsy and Quainat began to worry about her daughter's

condition. For the past couple of months, Hanná had not been 'right' but Quainat believed it would be something her daughter would grow out of. However, this time was different.

Just one month before Hanná's third birthday, Quainat received her daughter's devastating palliative care diagnosis. "I can't begin to explain what it was like. As a mother, I feel like a lot of people don't get it, but React understands the situation of our children."

React heard that the family had already struggled to buy a suitable car seat for Hanná but when she began to rapidly develop Scoliosis, the precious car seat was rendered useless. "It cost us more than our washing machine," Quainat recalled.

Thanks to our supporters, Hanná has a new safe and comfortable car seat and enjoys travelling by car. Quainat told us: "When we sit in the front seats, car journeys feel like girl trips. It's enjoyable and fun, it's not as clinical. It's like a mother-daughter date, and to have that experience just normalises it all."

Following the writing of this newsletter, React received this message, which Quainat has allowed us to share:

'I hope the story is featured in the newsletter. I wanted to tell you Hanná passed away over the weekend. The car seat helped my daughter be comfortable during car journeys. Your help has made a great impact on our lives. Thank you for supporting us, listening to us and holding our hands during some of our most difficult moments.'



Jaxon Scooots!





We live in Cardiff and after Jaxon was born he was transferred to Bristol, so we needed to spend the first few weeks travelling here and there. The first few days were hard for us all. Eventually Jaxon came home but he's got difficulties. He can't really move or sit up - he tries, but it takes a lot of effort. He'd watch his brothers and sisters playing and then they'd leave the room, and you'd see him wanting to follow. We carried him around the whole time just so he could catch up with them. He needs a wheelchair but, because of how small he is, there are none which are suitable. He's three now, and he's really small for his age. We have a 16 month old and they're about the same size.

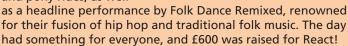
I saw a video of the Scooot online and it looked really good for Jaxon. It would allow him to move by himself and he wouldn't be stationary all the time. We were desperate to find a charity to help us as we couldn't afford the Scooot ourselves. I'd seen posters about React in a physiotherapist's office, and my partner found you online. We put in an application and within days, we had the Scooot. It was so easy; it takes a lot of the stress away. React is a breath of fresh air.

Now, he's always using the Scooot, he loves it. Every morning after breakfast, he's straight in the Scooot and listening to Take That. That's his favourite band (he's even started doing sign language to some of the songs)! The Scooot has given him his independence. We go out as a family and he doesn't have to wait by us the whole time. He can go off with his brothers and sisters and he can enjoy being a kid. We all go to the shopping centre and Jaxon can whizz around with the rest of them! I've really seen his personality come out - he's cheeky and he's got a wicked sense of humour!"

Teddington Village Fair

The Teddington Society held another of their amazing annual village fairs, with profits going to React families.

Those who attended were treated to stalls and pony rides, as well



Thank you to Sheena Harold and the rest of The Teddington Society for kindly choosing to support React.



Natwest Skydive

Across two summer weekends, 19 brave bankers of NatWest

banded together to embark on a sponsored skydive in support of React. None were more fearless than Shivani, who did not let the fact that she is blind stop her from jumping!

Thanks to their incredible efforts, a staggering £11,601 has

been raised to date and we would like to say a special thanks to Sally Schofield and Neil Taylor for leading the teams towards such a lifechanging total.



Sing the Blues and Dance with Soul

On the 28th September, React was thrilled to spend the night singing the blues and dancing with soul!

Held at the Bank of England sports grounds in Roehampton, the evening saw guests transported back to the 80s, enjoying

a hooch bar, a delicious three course dinner, and dancing the night away to a live band.

React sends a huge thanks to all who attended for making the night a roaring success. We hope you all had a fabulous time!



Jurassic Coast Challenge



Over the course of two days in June, Candice and friends, Becky and Karen, embarked upon the Jurassic Coast Challenge.
The trio walked an unbelievable 100km (over 62 miles - the equivalent of doing the London marathon 2.4 times), and climbed a whopping 2,600 meters!

This immense effort raised a wonderful £1,425 for React families, and the charity sincerely thanks Candice, Becky and Karen. We hope you put your feet up afterwards!

London to Brighton Bike Ride

In September, father and son duo Conor and Micheal hopped on their saddles and cycled the full 55 miles from Clapham



Common to Brighton Pier. Overcoming treacherous hills and a nasty puncture halfway through, they made it to the south coast in just over 7 hours, raising £812 for React in the process.

Conor said, "It was an exhausting task but the stunning scenery, team spirit and fantastic cause kept us going up those monstrous hills! It was a fantastic feeling reaching the seafront and we rewarded ourselves with ice cream and beer at the finish line!"

Amdocs' 10K Run

Long-term readers might remember the stunning efforts by Amdocs runners in previous years, who have been running the 10K in aid of React.

This July, they've done it again! In addition to raising their highest amount ever (a huge £1,517) the run was made extra special by the team completing the course in record time! Well done to all the runners and



massive congratulations to Martyn for completing the course in one hour and 27 seconds, beating his 2017 time by four minutes! Thank you all!

A Seat for Malachi

Malachi and his twin sister were only a few months old when they went to their GP for a routine examination. With

the doctor noticing something not quite right with Malachi's development, he was referred to Great Ormond Street Children's Hospital, where he was diagnosed with Vein of Galen Malformation. This is an incredibly rare condition which affects just one in a million children. Abnormal connections are made between the blood vessels in the brain, blocking the flow of oxygen and blood flow to the rest of the body. "We hadn't even heard of it before," Malachi's Mum, Sylvia, said. "It was hard to believe what was happening to us."

To treat the malformation, the family were left with two bitter options - either let Malachi live without intervention, which would eventually lead to multiple organ failure or, risk a surgical procedure which carried a 15% success rate. Rather than watch Malachi's life ebb away, his parents asked the medical team to operate. "We couldn't just sit and watch. At least we had a small chance to do something," Sylvia said.

During the complex operation, Malachi suffered a brain haemorrhage and went into a deep coma. For weeks, the family resisted calls to turn off his life support machine, until one day, Malachi finally woke up.

This gravely ill little boy returned home, but the brain injury has left him with multiple disabilities. He has restricted movement, and is non-verbal; only his hearing remains unaffected. "We were so happy he was home but those first days were really hard. Before the operation he was mobile and about right for his age. The brain injury changed everything. The whole time, we can compare the difference in him just by looking at his sister," said Sylvia. Over the years React have supported Malachi and his family with equipment and respite holidays. "One of the first times he smiled after the coma was on a React holiday," Sylvia told us.



During a recent visit to a local children's hospice, Malachi used a P-Pod - a portable specialist seat that provides comfortable and safe support for those with postural needs. This was a vast improvement to being squashed into the corner of the family's sofa and propped up with cushions.

React was thrilled to provide a P-Pod for Malachi and his mother told us "In the P-Pod he just looks so comfortable and content."

"React were fantastic, very supportive and understanding. I know React deals with a lot of terminally ill children but we feel unique. We're treated as individuals."



Independent Gracie

At her very first scan, Johanna was given the devastating news that there was fluid behind her baby's neck. After

an aminocentesis test to find out more, Johanna learned that her baby had a serious heart condition. The expectant mum was given an idea of what the first few years of her baby's life would be, which included major surgery.

As soon as Gracie was born, the true complexity of her condition became apparent. She was diagnosed with DiGeorge Syndrome, a rare chromosome disorder. At only eight days old, baby Gracie faced her first operation.

Eight years later, Gracie lives with a tracheostomy tube inserted into her windpipe and she requires a suction machine to keep her airways clear. This cumbersome machine is heavy and difficult to transport. Johanna particularly remembers waiting at the school gate with Gracie's two siblings looking out for a teacher who came to help carry the heavy suction machine.

With doctors unable to predict when Gracie will be well enough to have her tracheostomy removed, the family consulted their community nurse about the difficulties of carrying the heavy suction machine whenever they went out. The nurse suggested a portable lightweight machine to allow the family more freedom and referred them to React.

"Honestly, React was brilliant. So simple and easy," Johanna said. "Even the community nurse was surprised at how fast the response was!"

Gracie can now carry her suction machine herself into school and she experiences some independence. Johanna told us, "Despite her condition, it's not holding her back, Gracie is embracing every minute of every day."

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.

VOLID DETAILS

TOOK BETAILS
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 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 f each month/year (delete as appropriate) Starting on (please make this date one month from now) untifurther 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 nay 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.

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 responsilibity to pay any difference.

PLEASE SEND THIS FORM TO THE ADDRESS OPPOSITE.

Latest News

Mid-Surrey Bowls Club

React was delighted to be chosen by Mid-Surrey Bowls Club to benefit from their charity bowls match against the Dennyside Bowling Association. The event raised a tremendous £2,900 which will make a monumental difference to React's families.

Esher Church of England High School

The pupils of Esher Church of England High School kindly selected React to benefit from their house day. Through bake sales, fun games and 'soaking the teacher', £557.21 was raised for React children. Well done and a big thanks to all!

Ella's Choir

Our thanks to Helen Astrid and the members of Ella's Choir whose summer concert raised £372 for React families. We are incredibly grateful to Helen and Ella's Choir for their continued support.

Writtle University College

Writtle RAG Society chose React as one of its charities for the 2018-19 academic year raising a magnificent £1,125.13 through a variety of pub crawls and street collections. Huge thanks to all Writtle students for their support.

Kew Village Market

We would like to express our gratitude to Kew Village Market for raising £932 to purchase a P-Pod seat for one of our families. Our thanks go to the committee for making this award possible.

Hogarth Health Club

Twelve teams battled it out this summer at the Hogarth Health Club's Beach Volleyball tournament in aid of React. Thank you to all the players, staff, and crowds involved who made the day such a success raising almost £300 for terminally ill children.

Well Done George!

A big thank you to eight year old George who raised a fantastic £221.50 in aid of React through a charity bake sale and school triathlon. Our sincere thanks go to George and his family for their kind support.

Waitrose

React would like to extend sincerest thanks to all local Waitrose stores who jointly supported the charity in a region-wide Community Matters scheme this summer. We would like to thank all Waitrose staff and customers for supporting us so generously.



Tel: 020 8940 2575 Email: react@reactcharity.org Website: www.reactcharity.org

Rapid Effective Assistance for Children with potentially Terminal illness

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

St Luke's House 270 Sandycombe Road

Kew, Richmond Surrey TW9 3NP

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.

taid it