

# React

GIVING DEPTH TO SHORT LIVES

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

Newsletter Summer 2021 Issue 52 [www.reactcharity.org](http://www.reactcharity.org)

## Lara's P-Pod

Mum Charlie, experienced a difficult pregnancy and at 33 weeks, doctors picked up something unusual on a routine scan but were unsure what it was. Baby Lara was born weighing just 2lbs and everyone knew straight away she was going to be profoundly disabled. Charlie and husband, Matthew, still had no idea of the extent of their baby daughter's complex condition.

Over the coming months, Lara's health remained a concern but it was not until she was nine months old, she was diagnosed with Titinopathy, an extremely rare neuromuscular condition. "The diagnosis is life-limiting, it was important to make Lara as comfortable as possible," said Charlie. "Following gastrostomy and fundoplication surgery, Lara is gaining weight and is a healthy size, still with all the other complications but, she is a happy toddler." Now aged 22 months, Lara still has difficulty moving her arms and legs and, with scoliosis increasing, a nurse felt she would benefit from a P-Pod, a supportive beanbag chair, which also comes with an activity frame allowing Lara to explore through play.

Charlie said, "The community nurses suggested we approach React and I was amazed at the fast response. When you're living in a crisis, everything is such a blur but it's nice to have someone who can assist immediately and I honestly didn't know how much help React could give me until I needed it. Lara absolutely loves her P-Pod and sits in it every single day." We were delighted to assist this wonderful family and if you know of parents who could do with some help, please get in touch!



Lara

## Malakai's Tablet

Five months into her pregnancy with Malakai, Anne undertook her last prenatal scan and was assured her baby was developing as expected.

Malakai's siblings were desperate to meet him so, at seven months gestation, Anne arranged a 4D scan for the whole family to attend and it was during this family outing that doctors identified a serious problem. Malakai's kidneys were not developing normally and he would be born with Chronic Renal Failure. "It was devastating news but at the same time, thank goodness it was discovered early on as I was able to properly prepare and attend regular checkups for the rest of my pregnancy," said Anne.

Malakai is now an energetic and cheeky five year old boy, but because of his kidney abnormalities he requires dialysis twice a week, for four hours each session. Whilst the hospital provides an entertainment system for children, Malakai has watched every minute of content over and over and was becoming increasingly bored during dialysis sessions. The social worker working at the hospital recommended a touch screen tablet, to keep him entertained and help with his learning whilst receiving treatment.

Unable to source a tablet herself, Anne was referred to React. "I was so impressed at the simplicity of React's application form and it was such a quick process. The tablet has really helped make Malakai's dialysis sessions more enjoyable and is perfect for his virtual school lessons. We really appreciate React's support."



Malakai

## 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](http://www.reactcharity.org) or call 0208 940 2575 for friendly advice and support.

## Takeda UK Ltd

This project to publicise React's work through its newsletter and promote services to healthcare professionals and families throughout the UK, was supported by a financial grant from Takeda UK Ltd. React is sincerely thankful to Takeda for its generosity.



RAPID EFFECTIVE ASSISTANCE FOR CHILDREN WITH POTENTIALLY TERMINAL ILLNESS

## Hertfordshire RAG

React is thrilled to announce it has been chosen as the University of Hertfordshire RAG society's supported charity for the 2020-21 academic year. Whilst coronavirus lockdowns pose major challenges for enthusiastic students keen to get out and fundraise, this has not deterred RAG members who have already taken on an array of fun challenges, whilst keeping Covid safe.



Throughout the year, Herts students have walked, ran, cycled and even skydived their way towards raising a fantastic amount for React families. A huge thanks goes to Izzy and all RAG participants for their determination and commitment.

## Sainsbury's

React is proud to continue its partnership with Sainsbury's stores during the lockdowns, with three branches kindly stationing React collection tins beside checkouts and encouraging local customers to donate and learn about our work.

During what has been an incredibly challenging year for the retail sector, React extends its sincere gratitude to all essential workers for their continued enthusiasm and fundraising for React families.



## Newland House School

During the past academic year, the Head Boy and Girl at Newland House School announced React as their chosen charity for the year and undertook a plethora of fun and games to raise funds. Despite the coronavirus pandemic hitting half way through the year, this did not stop eager pupils who continued to fundraise virtually through socially distanced events. React was presented with an incredible donation of £3,389.69 at the end of 2020 and we would like to say a big thank you to all pupils and staff for their hard work and enthusiasm.



## Rachel Lawrence



Over the past year, face coverings have become a ubiquitous symbol for the fight against the spread of coronavirus and are used in almost all areas of public life. In response to their widespread use, one young fundraiser with a passion for knitting and sewing, created a beautiful array of handmade face masks. The talented Rachel

Lawrence made the generous decision to give them away to family and friends in exchange for donations to React. Rachel's stylish face masks were quickly snapped up and her ingenuity raised an impressive £200. A massive thanks to Rachel who worked so hard to keep us safe and to those who contributed by buying her masks.

## Livery Companies



The Livery Companies of the City of London are ancient guilds dating back hundreds of years, who have a long history of philanthropy and charitable giving. With 110 Companies now in existence, these organisations represent professions from almost all walks of life, with some tracing their origins back to the 12th century.

React would like to send a special thanks to all Livery Companies who have supported families over the past few months, namely the Worshipful Companies of Fan Makers, Curriers, Secretaries & Administrators and Horners, for providing essential equipment to children living in London during the coronavirus pandemic.

## Thank you Charlotte Grobien

For more than 15 years, Charlotte Grobien OBE has dedicated her life to raising money for children's charities via her company 'Give It Away'. By building, developing and selling properties in London, Charlotte donates every penny of profit to good causes and React is honoured to benefit from her kindness. Over the years, Charlotte has provided families with many various pieces of equipment, ranging from simple sensory toys to specialist profiling beds.



Charlotte told us: "I support React because of the enormous impact they have on so many children despite its small size. With the pandemic making React families' lives even more challenging, I recognise how much they need our support."

React sends its most heartfelt thanks to Charlotte for her exceptional work and generosity.

## Clara's P-Pod

Chloe knew something was seriously wrong immediately after giving birth to her baby daughter, Clara. The tiny newborn became increasingly irritable and doctors transferred her to the neo-natal unit for monitoring. Clara had sustained significant brain damage and was now experiencing continuous, life-threatening seizures. Doctors gave Chloe the heart-breaking news that her daughter was unlikely to make it through the night. "We had her baptised that very same day," Chloe told us. "We just didn't know what was going to happen."

Despite the odds stacked against her, Clara is a happy child who celebrated her fourth birthday earlier this year. She lives with multiple complex conditions including Epilepsy and Microcephaly and is Quadriplegic, requiring constant care. Chloe had been looking at acquiring a P-Pod seat for Clara for some time as the specialist seat is known to offer a high level of support but, the family were repeatedly met with rejection from various organisations. With nowhere else to turn, Clara's Occupational Therapist referred the family to React.

"I was over the moon when I heard React could help, you really are an absolute lifesaver and I keep telling anyone with a child like Clara to contact you! Before, Clara just wanted to be in my arms but now, she's totally relaxed and comfortable in her new chair. It has really given her some independence, thank you."



Clara

## Medical Trolley For Karl



Karl

In the winter of 2019 Karl's family were not unduly worried when he began coughing as they suspected it was just a common cold. It was when Karl started to cough up blood, his parents became concerned and rushed him to hospital where, he was diagnosed with Chronic Lung Disease at the age of seven.

Now aged ten, Karl has battled with his health significantly over the past year. He has been dangerously ill and one day, Mum, Maria noticed her son's eyes started to roll which was terrifying to witness. Once again, Karl was rushed into intensive care, where he suffered cardiac arrest and left fighting for life. It was then, his parents were given the devastating news; Karl had contracted Covid-19.

Maria told us, "The entire family thought they had contracted COVID-19, but luckily, after 14 days of isolation, no one had any symptoms." Whilst, Karl was in a coma and gravely ill, his family had no option but to isolate at home. "It was just a nightmare, my only form of communication were updates from the nurses and they were so kind, they would hold a phone to his ear so I could talk and sing to Karl. It was awful not being able to visit and whilst I prayed for his recovery, I was also praying for ours." said Maria.

After eight lengthy months in hospital, Karl was finally able to go home with the help of equipment to aid his breathing. With Karl on a ventilator 24 hours of the day, and requiring numerous medications, his parents identified a medical trolley to store

essentials and a video monitor to keep a close eye on him. The family were also desperate for a dehumidifier, as their home was damp and it was extremely important that the air around Karl was kept clear. Karl's family were eager to get Karl home but without these essential items, discharge was not yet possible.

With the family anxious for Karl to return home, a nurse suggested approaching React. "I cried with happiness when we were told React could help. We just wanted him home and without React's assistance it would not have been possible", said Maria. "We know Karl has a short life and we take every day as it comes but it is amazing we can be with him and that he is home where he belongs. Thank you to React".

## Rhys' Buggy

At just 32 weeks into her pregnancy Vicky went into labour and baby Rhys was born, weighing just two pounds. Despite concerns about a premature birth, doctors thought Rhys would develop normally.

"As parents, we just knew something was wrong," said Vicky, and it was a trip to the GP when Rhys was two that determined just how right Vicky and Garyth were. Almost immediately, Rhys was referred to Great Ormond Street Hospital and after numerous tests, he was diagnosed with Chromosome Deletion Syndrome, Microcephaly and Autism. "We were tested to see if the illness was genetic," said Vicky, "But it wasn't, it's just one of those things."

Now aged 14, Rhys requires constant care yet remains a happy young man who enjoys spending time with his family. "He loves to be out and about but his limited mobility means he can only walk so far," Vicky told us. "We once had a buggy but over time, Rhys grew out of it and now we're pretty much housebound."

When React heard about Rhys through the support of an occupational therapist, we were keen to help. Vicky told us "You are amazing, we just couldn't afford a new buggy, as soon as you add the words 'special needs', the item seems to triple in cost. We really didn't expect the Swift 2 Buggy to be delivered in a couple of days and are over the moon, thank you so much."

It is with thanks to our supporters we can support families like Vicky, Garyth and Rhys.



Rhys

# 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. React will provide basic, essential aid and equipment that is unavailable from any other source.

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.

### Covid-19 Update

Throughout the coronavirus pandemic, React has continued to provide its essential service to families across the UK, providing a rapid response to those in urgent need. We would like to reassure all families, React continues to accept applications and if you think we can help, please do not hesitate to get in touch at [react@reactcharity.org](mailto:react@reactcharity.org).

### Eveson Charitable Trust

React sends its sincerest thanks to the Eveson Charitable Trust, for making an exceptionally generous grant of £12,908, providing specialist equipment to nine seriously ill children.

### Storm Building

Storm Building Ltd has chosen React as its Charity of the Year for the second year running. Last year, Storm raised a magnificent £6,000 for our families during the height of lockdown and we look forward to working with the company to assist many more children in 2021.

### Waitrose

A huge thank you to all Waitrose stores for supporting React through the supermarkets' Community Matters programme. Donations over the past year total £1,904 and have provided essential aid to many families who are caring for a terminally ill child.

### Thank you, Churches

During what has been an extraordinarily difficult year for charities and voluntary groups, React would like to say special thanks to churches and religious organisations who have generously supported our work despite closures across the UK. Your donations are greatly appreciated during these difficult times.

### Neighbourly Community Fund

The Neighbourly Community Fund has provided a lifeline to individuals and organisations throughout the UK who have been adversely affected by the Covid-19 pandemic through its micro-grant scheme. We would like to thank Neighbourly and the Southern Co-op for the £400 award which provided essential equipment for our families.

### React Mobile Homes

After the forced closure of React's mobile holiday homes due to the unprecedented events of last year, we hope to open our doors once again this season providing it is safe to do so. Please visit our website at [www.reactcharity.org](http://www.reactcharity.org) or follow us on Twitter @ReactCharity for further updates.

**React**

Rapid Effective Assistance for Children with potentially Terminal illness

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

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