

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

Newsletter Winter 2021 Issue 53 www.reactcharity.org

# Baylie's Specialist Chair

Kerrie was monitored closely during pregnancy as her previous two babies were born very small. When it came to baby Baylie, the many

scans were nothing new for Kerrie and husband David but, at a 24 week scan, doctors detected something seriously wrong. Baylie's brain had somehow incurred significant brain damage, seemingly out of nowhere. "Baylie was our rainbow baby after a miscarriage and we couldn't quite believe what was happening. The doctors couldn't tell us if Baylie would survive or not, so we chose not to buy any more baby stuff and prepared ourselves that she would die."

Miraculously, Baylie is now eleven years old, she is Quadriplegic and she has intractable Epilepsy and Dumping Syndrome, a condition which causes issues with digesting food. Although she is unable to speak and requires constant care, she is a bubbly and sociable young lady who has a passion for fashion. "We can't go shopping anywhere without Baylie wanting a new handbag, she absolutely loves them," said Kerrie.

Baylie is reliant on specialist seating and the family were able to source something suitable second-hand. However, as Baylie grew, she became uncomfortable in her chair and her parents found it difficult to move her from room to room. Kerrie had lost her job during the COVID pandemic and David was on furlough so, they had no idea how they could afford a suitable replacement.

Baylie's Social Worker and Physiotherapist discussed approaching React after hearing the family were considering taking out a huge loan. "It was absolutely amazing news to hear that React was going to buy a specialist chair for us and Baylie goes in it every single day when she gets home from school and she doesn't leave it until bedtime. She actually cried the first time we took her out of it and she insisted on sleeping with her new chair next to the bed. It goes everywhere with us."



# Support for Rania

At three months old, Rania developed a cough and a rash on her legs, which unbeknown to parents Naima and Zaman, was the beginning of a terrible nightmare.



This tiny baby stopped breastfeeding and was losing a terrifying amount of weight. Naima and Zaman rushed their little girl to hospital, with no idea what was happening. Rania spent months in and out of hospital, as doctors tried to pinpoint exactly what was wrong although, test after test came back seemingly fine.

It was not until doctors carried out a genetic test on both parents, they discovered Rania had an extremely rare auto-immune disorder. "They've only discovered this disorder about five years ago and Rania is one of just nine children living with this illness," said Zaman.

Rania began a lengthy process of multiple hospital treatments including a bone marrow transplant. The family were required to stay in Newcastle, a staggering 300 miles from the family home. Zaman recollects the extremely stressful time, "I had to stop working and it affected our finances so much." A Healthcare Worker supporting the family noticed their struggles and referred them to React, asking for help towards the additional costs of travelling during Rania's long inpatient stay.

Rania, now aged two, has spent most of her short life in hospital with Naima and Zaman by her side. React is always pleased to be able to help and alleviate some of the stress during a very difficult time.

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.

# Sacred Heart High School

Earlier this year, the Year 10 students of Sacred Heart High School, Hammersmith, went head to head in aid of good causes in the school's annual First Give competition.

First Give is a scheme where each class in the year group select a charity and put together a presentation arguing why their charity should be the recipient of a £1,000 award. Led by Ebere, class 10S nominated React as their chosen charity and after much research, hard work and enthusiasm, put together an inspiring presentation which won over judges and secured victory for React.

A huge thank you to the students of 10S for capturing React's work so compassionately.

# Pandora and Harrison's Wedding

One of the joys of relaxing the lockdown rules, is the return of weddings and family gatherings. With so many having to postpone or cancel, due to the fight against coronavirus, React supporters Pandora and Harrison were delighted to finally tie the knot this summer.



This wonderful young couple made the selfless decision to ask their guests to donate to React in lieu of wedding gifts.

"We feel so incredibly lucky to be able to celebrate with our nearest and dearest on our wedding day that there is truly nothing else we could wish for and, React is a charity who is close to our hearts"

Their generous request led to a phenomenal £3,936 raised for React families, and this has been used to assist those who have been hit hardest by the effects of the pandemic. We send our sincerest thanks to Pandora, Harrison and to all those who donated and we wish the happy couple all the best for a very happy life together.



Multinational company Consilient Health is dedicated to providing valuable products in areas such as women's health and we were

delighted when its local office chose to support React families earlier in the year. The new partnership was kickstarted by a very generous £1,000 donation and we look forward to working with the company throughout the forthcoming year.

Karen from Consilient Health said "We are delighted to be supporting React, especially when the money is put to such rapid use providing equipment for some of the most vulnerable children in the country. For such a small charity, the scope of their impact is remarkable."

React sends a massive thanks to everyone at Consilient Health on behalf of the families helped.

# Thank You Letters from Families

React appreciates the feedback received from families and medical professionals who have taken the time to write and express their gratitude for the work that we do. We are delighted to share some recent quotes with our readers, which shows the difference our work makes to the lives of terminally ill children:

"Thank you so very much for providing a specialist bed for my daughter. As well as this massively improving her everyday life, it will also make a huge difference to me, especially following my recent chemotherapy treatment. React is truly appreciated in my family."

"We would like to take this opportunity to say thank you so much for providing a mobile hoist. You have no idea how much you have helped us as a family and it is going to make life so much easier for us all!"

"I would like to thank React for the speed in which everything was processed. Without this car seat we would not have been able to get Micah out and about – before, even simple journeys to nursery were a nightmare. We cannot thank you enough".

#### **Brentford Dock Residents**



Despite being forced apart from each other for so long, the community bond felt by the residents of Brentford Dock became even stronger during the most recent lockdown, as neighbours and friends got their heads together to create a

community soup delivery scheme open to all residents.

Each month, the Events Team cook up delicious homemade soup, bread and cakes for hungry residents which are delivered to their door, in exchange for donations to React. The scheme has so far delivered to an impressive 600 flats and raised £561. Its success resulted in its continuation even after lockdown restrictions. Thank you to Leigh, Ann and the Events Team for all your hard work and incredibly selfless community mindset, which has meant so much to so many.

#### React Mobile Homes

Following the unprecedented pandemic last year and a nationwide lockdown, it was with a heavy heart that, React was forced to close its mobile homes during the holiday season. With careful monitoring and adherence to government advice, the decision was made to reopen our holiday homes in May and we were delighted to welcome React families back to what proved to be a very successful and fully booked summer season.

Families were once again able to enjoy a week-long respite break in our homes based at holiday sites around the UK and we very much look forward to welcoming everyone back again in 2022.



## Sensory Toys for Logan

Little Logan was delivered at 37 weeks following a routine scan although his worried Mum and Dad did not expect their son to be born with Hydrocephalus, a large build-up of excess fluid on the brain. "It all happened so quick, one minute we're marvelling at the scan images on a screen and the next we're told the baby has to come out now! The nurses were phenomenal and really helped us," said Mum, Leigh.

Logan remained in hospital for eight long weeks before he could go home and endless hospital visits ensued. He underwent seven major surgeries on his brain, during the following weeks. A Community Liaison Nurse recommended sensory toys for use in the home, so that Logan could enjoy time playing with older brother Lucas. After the family contacted React we were all too pleased to provide a bubble tube and some tactile toys for the brothers to bond. "Once we got them, he just loved looking at the bright lights and the bubble tube was his absolute favourite thing. It honestly provided him with so much enjoyment throughout his short life and we have many happy memories as a family," said Leigh.

On Monday 19th June 2021 baby Logan lost his fight for life aged just six months old. "He was such a happy baby and he loved smiling and showing off his two little front teeth. It was amazing to know that there were people out there who could help us during such a difficult time and my partner Colin and I are grateful to each and everyone of them."





# Poppy's Feeding Aids

First time parents Amelie and Thomas realised something was not quite right when their daughter Poppy failed to reach expected milestones. When Poppy was 18 months old her GP referred the family to a Paediatrician, where Poppy underwent multiple genetic testing.

Just shy of her third birthday, Poppy was diagnosed with Rett Syndrome, a rare, genetic disorder which mainly affects females. "Sometimes we can go a while without Poppy needing to visit the hospital and then all of a sudden, she will need to visit about twelve times in a month," Amelie told us.

Five year old Poppy was becoming increasingly frustrated during mealtimes as she struggled to hold her spoon. An Occupational Therapist recommended feeding aids with specialised utensils but with household bills piling up, it was just another expense the family could ill afford.

"We were so pleased when React could help. Poppy lost a lot of muscle mass during the pandemic as we were unable to attend therapy and physio. I still help her lift her arm but she loves gripping the cutlery and aiming it towards her mouth. To be honest, I did not want to ask for help, it's difficult for families to admit they're stretched but the Occupational Therapist was encouraging and React were great."

# Aiden's Car Seat

Seven year old Aiden had a tough start to life, and his Mum, Tiffany recalls the traumatic birth: "Aiden's heartbeat suddenly dropped and I needed an emergency C-section. Once Aiden was born, it took a whole eight minutes to get him breathing. He was rushed off to the neo-natal unit and we were warned he may not make it through the night."

Consultants diagnosed Aiden at just one week old with Cerebral Palsy and Neonatal Hypoxic Ischemic Encephalopathy, a brain injury. This tiny baby remained in hospital for two and a half lengthy months with Mum, Tiffany and Dad, Waheed by his side, leaving extended family to care for Aiden's two siblings, Kahleil and Jasmine. Over the years, Aiden has been in and out of hospital multiple times for various tests and treatments.

Following a growth spurt, his parents struggled to get Aiden in and out of the car. "He would arch his back and fight against being placed in the seat," Tiffany told us. Aiden's Occupational Therapist recommended a specialised, supportive car seat with a swivel base and when we heard the Local Authority was unable to assist, we were only too happy to help. The big smile on Aiden's face shows just how much he loves his new seat and he's ready to ride!



#### **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.

VOLIR 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 f500
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) until further notice and debit my account number  Bank sort code Name of account holder
Signature
To the Manager (bank name and address)
Postcode
Pank Dotails

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.

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

#### **Warwickshire Masonic Charitable Association Ltd.**

React would like to thank the Warwickshire Masonic Charitable Association Ltd, for its generous award of £1,000 towards the charity's work in Warwickshire. The Freemasons kindness and support is very much appreciated by us all.

#### Leaving a Lasting Legacy

Remembering React in your will can make a real and lasting difference to the lives of terminally ill children. We would like to sincerely thank all of those who have chosen to leave a gift in their will and if you would like to do the same, please do not hesitate to contact us.

#### **Peter Sowerby Foundation**

We would like to express our gratitude to the Peter Sowerby Foundation, for supporting React's project in Yorkshire and awarding a most generous £5,532 for children diagnosed with a neurological illness.

#### Berwyn Consultants Ltd.

React is extremely grateful to Berwyn Consultants Ltd. for its very kind donation of £1,000 earlier this year. Deborah and Brian Dunk have been long-term supporters of React for many years and we are so thankful for their kindness.

#### The Worshipful Company of Curriers

The Worshipful Company of Curriers very kindly awarded £1,500 towards React's work in London and we thank the Trustees of the Curriers Company Charitable Fund for their continued and invaluable support.

#### **React Fundraising**

There are so many fun and creative ways to fundraise over the festive period, from a simple office Christmas jumper day, to a winter bake-off or even setting up a stall at your local fair. If you would like to make a difference to the life of a React child this festive season, get in touch: Tel 020 8940 2575, or email react@reactcharity.org.



Rapid Effective Assistance for Children with potentially Terminal illness

Registered charity no 802440 (UK) SC038067 (Scotland) St Luke's House 270 Sandycombe Road Kew, Richmond Surrey TW9 3NP

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



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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