

# React

GIVING DEPTH TO SHORT LIVES

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

Newsletter Winter 2020 Issue 51 [www.reactcharity.org](http://www.reactcharity.org)

## Help for Michalina



Michalina

Reflecting back to when her daughter was a newborn, Sandra remembers the troubles her family experienced. "All Michalina wanted to do was to be fed or held 24/7. I just couldn't put her down without her crying. She was feeding and vomiting constantly, and it was such a difficult time." Sandra tried everything to pacify her baby and as a first time mum wondered if she was doing something wrong. She tried numerous feeding routines, but the issue continued.

Eventually, after numerous GP appointments and hospital referrals, six month old Michalina was diagnosed with Aicardi-Goutières syndrome, a disorder which affects the brain and immune system. Mum, Sandra and Dad, Michal were devastated to find they are carriers of the deadly gene, although no-one in their family had heard of the illness before. "It was the most daunting and scary experience. When we first heard of Aicardi-Goutières syndrome we had no idea what it meant, Michal and I started to blame ourselves for what was happening."

Now, aged nine, Michalina is a sweet little girl who loves nothing more than cuddles with her family. Her feeding has improved over time and Sandra has switched her daughter's diet to a blended one. "She can eat anything we eat which is great, as long as its blended and I'm always creating batches of food and use a blender almost everyday," said Sandra.

When Sandra's blender suddenly stopped working she was panic-stricken as the kitchen appliance was a lifeline for Michalina. "React was simply amazing. Within a few days of

Michalina's dietitian making a referral, I heard React could help and I burst out crying. I couldn't really take it in, I was so grateful. The blender blends to such a fine consistency and there is no risk of Michalina's tube being blocked, which gives us huge peace of mind. We're so thankful and it's so nice to know there is an organisation out there willing to help."

## Toby's Rover

When Toby's Mother, Nerys, was expecting her first child she felt something was not quite right and, when comparing pregnancies, a friend shared how her baby was always moving around but, baby Toby just seemed to stay in the same position. Midwife checks found nothing unusual but when Toby was born, he was whisked away immediately for tests. Nerys told us, "It took a year to get Toby's diagnosis, a rare mutation in the DYNC1H1 gene". Now, aged five, Toby requires 24/7 care and he has significant scoliosis of the spine. He cannot hold his head up and his airways are severely restricted, requiring a tracheostomy.

Due to the pandemic, Nerys is currently caring for Toby alone. Toby's dad Nigel works in a pub and moved in with relatives when the pubs reopened to protect any risk to his vulnerable son. The family live in a rural area and the local lanes and footpaths are very uneven. Toby loves being outdoors, the first time he smiled was out on a walk. However, journeys in the buggy can be uncomfortable for him as his buggy bobs up and down on the bumpy paths and Nerys was using rolled up towels to keep Toby supported.

After speaking with Toby's Occupational Therapist, an application was made to React for an all-terrain medical stroller, ideal for moving over rough ground. "The response was so quick!

Since we've been on lockdown, we had not left the house, and with this stroller we'll be able to access the fields and farmland behind where we live without coming into contact with anyone else," said Nerys. The buggy's moulded seating ensures Toby is well supported, the buggy also accommodates his emergency kit, suction machine, and oxygen cylinder which must be carried with him at all times.

"We name every piece of Toby's equipment and his absolute favourite is his stroller 'Rover'. He loves it and smiles each time we go for a stroll. Even dog Buddy, is so excited to see the buggy come out as he knows it is time for walkies! The buggy has given us back some freedom, we're so very grateful!" Nerys, told us. It is thanks to our supporters we can help families like Nerys, Nigel and Toby, make the lockdown a little easier.



Toby

RAPID EFFECTIVE ASSISTANCE FOR CHILDREN WITH POTENTIALLY TERMINAL ILLNESS

## NatWest



After raising thousands of pounds for React families last year, the team at NatWest Richmond continues to support React children, and have teamed up during the pandemic with local designer Mary Spiteri who has donated an exclusive handmade hat to raffle and raise funds for React children. The gorgeous piece is on display at the branch, giving hopeful customers

the chance to win a fabulous bespoke made hat. The piece is worth more than £500 and NatWest are hoping to raise over double by the end of the year. We send our sincere thanks to Mary and all at NatWest for your wonderful support!



## Pike Anglers Club

Members of the Pike Anglers Club love nothing more than catching some fine specimens. This year, has thrown a number of challenges their way, from stormy weather, flash flooding and the coronavirus pandemic. Many planned fishing events were sadly cancelled.

This turn of events did not deter Clive and his fellow members of PAC's Lincoln region, who made the generous decision to donate their entry fee to React, despite cancellations. Additionally, President Phil Turton made a further donation from funds collected by members of the Ashfield Angling Club totalling £740. React sends a huge thanks to Clive, Phil and everyone at PAC.

## Canon UK



Each year, staff at Canon get together for their Charity Golf Day where they have kindly supported React for many years. Sadly, this year's competition was unable to take place but several members of the team came together to make donations to React during the weekend in which the event would have happened. A huge thanks to Elliot Kutner, Andrew Garrod and everyone who donated – your support is truly appreciated during these difficult times.

## Anton's Great Adventure

Ten year old Anton was inspired to help families caring for terminally ill children at home through the pandemic and, after learning about React, decided to embark on a great adventure to raise funds for React families. Accompanied by his dad and uncle, Anton set off from Exmoor and over the course of two days, completed an entire marathon-length walk across the famous "Two Moors Way", whilst battling the relentless wind and rain caused by Storm Alex.



Anton's epic journey has raised an incredible £8,575.44 (including Gift Aid), and continues to rise. We send our huge thanks to Anton and his family for taking on such an enormous challenge!



<https://youtu.be/7gA6KDaznZw>

## Stevenage Ladies Choir

The Stevenage Ladies Choir is a group with a passion for performance whilst raising money for good causes. Like so many other events this year, the group was devastated when their charity concert was cancelled due to coronavirus restrictions. Refusing to let the virus stop them, they banded together over the internet and made a charity single in aid of React. The song, 'As Long As I Have Music', was recorded during isolation and every harmony was recorded individually. The single raised a fantastic £1,067.39 and we highly recommend checking out their tremendous effort on Youtube. Thank you to all for your support.

## Special Thanks to All Our Supporters

So many of us have been adversely affected by Covid-19 over the past months, especially React's families who continue to shield from the virus into the New Year. Throughout the pandemic, React has continued to do all it can to make the lives of seriously ill children a little bit easier, and this would not be possible without the generosity of its wonderful supporters. We would like to take this opportunity to thank everyone who has thought of React during these difficult times by making donations and lending a helping hand. It's been a tough year and yet, together we have achieved so much for so many.

## P-Pod for Joshua

Soon-to-be new parents Lynsey and Jon were excited to be expecting twins and start a new family together. However, when Lynsey went into labour at just 26 weeks, they began to panic, and shortly after twins Joshua and Amelia were born, little Joshua was diagnosed with Meningitis.

Just two days into the devastating diagnosis, the family suffered another blow when Joshua was diagnosed with Hydrocephalus, 'water on the brain' requiring a shunt to be inserted immediately. "We didn't know what to do. We didn't think he was going to make it," Lynsey told us.

Throughout his short life, Joshua has been in and out of hospital, and he spent Christmas at Alder Hey Children's Hospital. Now aged four, Joshua lives with numerous conditions, including Epilepsy, and he is registered blind. Joshua continues to require intensive medical care and suffered a cardiac arrest just a few weeks ago.

With Joshua unable to walk, roll over, or even sit up, his parents find it hard to keep him comfortable at home with his twin, Amelia, and younger sister, Emily. After researching online, Lynsey found a P-Pod, a specialist seat which will support Joshua, and discussed where she could obtain one with Joshua's Occupational Therapist.

"I just thought I can't afford that. I've got three kids," Lynsey said. With the Local Authority also unable to help, the family found themselves not knowing where to turn until their OT recommended React.

We were delighted to provide the P-Pod for Joshua and Lynsey said: "He loves it. He's really happy, he even sleeps in it. It's elevated so his sisters can't creep up on him without me knowing! They absolutely love him, they're all over him like a rash!"

"It makes such a difference, thank you once again."



Joshua

## Josie-Mae's Sensors



Josie-Mae

It was when she was three months old that Josie-Mae experienced her first seizure. Over the next few months, Josie-Mae experienced multiple life-threatening seizures that required emergency treatment. Yet, doctors, were still unable to offer a diagnosis. Mum, Lyz, said "Each seizure knocked me back further and further". It took another nine months to receive a diagnosis, a rare condition called Dravet Syndrome.

It was at Christmas when Josie was just 13 months old, that things became much worse. For the first time, Josie-Mae experienced a seizure during the night. "It looked like she was asleep" said Lyz, "and the monitor showed that Josie-Mae's oxygen levels were dropping fast. Her heart rate was rising rapidly and I knew this was different". Josie-Mae was rushed to hospital where she stopped breathing and although she was allowed home for Christmas Day, Josie-Mae was admitted again on Boxing Day to the hospital's high dependency unit.

Lyz said "Josie-Mae's gene mutation is something they've never seen before, she is a mystery. The hardest part is the not knowing if or when she'll have another seizure, and nothing takes away that worry." Despite her condition, Josie-Mae is a happy little girl who loves to dance and play in the garden but, due to the coronavirus pandemic, the family has been isolating for months. Lyz has given up paid employment to care for her daughter and finances are tight. Lyz had already purchased a seizure monitor but the costs of the sensors meant that things would become increasingly more difficult. "They cost the same as a couple of weeks' worth of food shopping" said Lyz.

With the support of Josie-Mae's Epilepsy nurse, an application was made to React and we were delighted to supply the essential seizure sensors. Lyz told us: "I felt really overwhelmed when I heard you would help, I'm just so, so appreciative".

## Unum

The team at Unum made an extremely generous donation of £2,181 to provide much needed educational equipment for three React children earlier in the year. Frankie from Unum told us: "We are all so pleased we could help provide families with the equipment needed to enable children to communicate and obtain greater independence. We are delighted to be able to support React." Thank you Frankie, Susan and all at Unum for your kindness.



## Chris Bray

Backgammon expert and long term supporter of React, Chris Bray, gave online backgammon lectures during lockdown and kindly asked attendees to donate to React. We thank Chris and his audience for their support and generosity and many thanks to all who participated.

## 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.

OR COLLEAGUE SO MORE PEOPLE CAN HELP REACT CHILDREN

# 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.

### Kew House School

Kew House School made a truly generous donation of £1,890 to provide a specialist tricycle for a local React child. Thank you to all pupils, staff and parents at Kew House School for your kindness.

### Help for Health

React gives huge thanks to Help for Health for their generous award to benefit children living in East Riding.

### Wantsum Cork Lodge

React would like to say a huge thank you to Wantsum Cork Lodge for their generous donation of £500 made during the height of lockdown. Stay safe everyone and thank you for your generosity.

### Sainsbury's

Sainsbury's Local on Friars Stile Road has raised a fantastic £577.44 from collecting boxes at the tills and we welcome requests from all shopkeepers to do the same. Much can be raised from the donation of spare change!

### Adam Downing

Inspired by the birth of his son to do something to help those caring for a gravely ill child, Adam took on a '3 month sober' challenge and raised £535.25 for React. Thank you Adam for your commitment.

### Community Foundation Tyne & Wear and Northumberland

Our sincere thanks go to the Community Foundation Tyne & Wear and Northumberland for their generous award of £4,000. The Foundation's support will provide gravely ill children living in the North East with essential equipment that is unavailable from any other source.

### Catholic Women's League

React sends its sincere gratitude to all at the Southwark branch of the Catholic Women's League for their generous donation of £200 to help React families during lockdown.

### Astound Commerce

A huge thanks to the team at Astound Commerce for their £335 donation. Many thanks to all and thank you for choosing to support React families.

**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.

St Luke's House  
270 Sandycombe Road  
Kew, Richmond  
Surrey TW9 3NP

Tel: 020 8940 2575

Email: [react@reactcharity.org](mailto:react@reactcharity.org)

Website: [www.reactcharity.org](http://www.reactcharity.org)

