

# React

GIVING DEPTH TO SHORT LIVES

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

## A Little Joy for Joe

When a newborn is diagnosed with a serious illness at birth, a family's life is turned upside down. It takes a long time to adjust to the adaptations necessary at home and in life, and to the ups and downs of medical treatments and prognoses. Joe's mother Toni, told us about his difficult start in life and how the purchase of an innovative piece of equipment, funded by React, will make a difference.

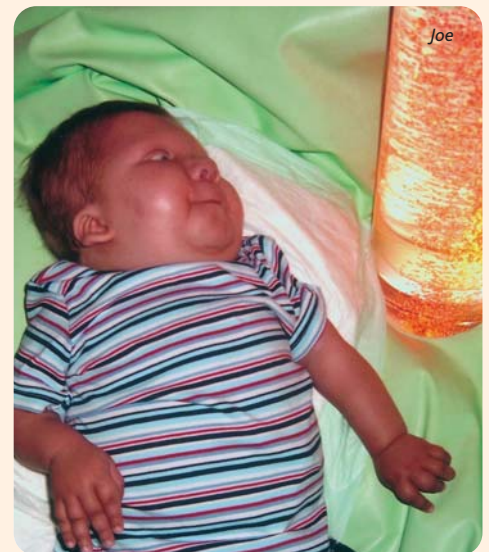
WHEN JOE WAS BORN, he was diagnosed with Noonan's Syndrome and spent the first five and a half months of his life in hospital. This rare and severe illness affects many aspects of a child's health including the brain, heart, lungs, stomach and skin. When Joe was just 10 months old he was rushed to hospital after a prolonged seizure that left him with brain damage. "The doctors told me that Joe would probably not survive more than another three weeks," Toni told us. She was advised to make the 'necessary arrangements' and could only wait, then hope, as the weeks turned into months.

Now, at nearly two years old, Joe has exceeded everybody's expectations and is leaving palliative care. He has very limited movement in his body and is almost blind, but responds

well to the lights and sounds at his local sensory room. However, at nearly a thousand pounds, buying similar equipment for use at home seemed impossible. Toni contacted React and, with funding made possible through donations and fundraising, Joe will soon have his very own 'sensory centre' with a bubble tube and fibre-optic ropes that he can enjoy any time of the day or night. Toni wrote to say how much this equipment means to Joe: "I would like to say a BIG 'thank you' to everyone who has made this possible. I could never have afforded the sensory centre for Joe myself, and words cannot say how grateful I am. We are looking forward to many hours of fun and beneficial playtime at home. All those who are involved with Joe agree that this equipment will be a great help and bring a little joy into his very difficult life. Thank you!"

### The Radio Station with a Big Heart

Heart FM is a valued supporter of the work of React, helping us to provide essential specialist equipment for life-limited children living in Birmingham. We are extremely appreciative to them for making the choice to support us, and if the radio is on in the React office it's probably Heart!



Joe

## Getting Away

IMANI IS ELEVEN YEARS OLD and has a blood clotting disorder called Sickle Cell Anaemia. At the age of five, she suffered a stroke which left her paralysed down her left side. As a result she needed to use a wheelchair and, being left-handed, had to learn to write again. Sadly, another stroke two years later lost Imani her ability to speak and she now communicates through sign language. Imani's mum told us, "Imani has regular blood transfusions which, we hope, will reduce the chance of another stroke. There are no guarantees though." Imani and her mum are currently waiting to be re-housed as their current home is not wheelchair-friendly.

For those like Imani who are unable to benefit from our mobile home holidays, React can consider funding a holiday within the UK in special accommodation - in this case, an adapted chalet in North Wales. "We had a fantastic time" said her mum. "The chalet had plenty of space which made it easy for Imani to get around. It was a lovely break away from all her hospital appointments."



Imani

## Volunteer for React!

THANKS to the amazing support of GlaxoSmithKline, React is now able to steam ahead with our Volunteer Regional Network Programme to promote and raise awareness of our work across the UK.



Volunteering with React is an opportunity to be part of something special and will make a real difference to the lives of children with potentially terminal illnesses and to the families who care for them.

Event fundraising is a great way to get out into the community, meet new people, learn new skills or add that extra touch to your work experience.

Whether you can spare two hours or two hundred, we have a volunteering opportunity for you. No matter what size the gesture, be assured that it is with your fantastic efforts that we continue growing and reaching more children and families in your local community.

For all enquiries regarding volunteering or being a voluntary representative contact us on 020 8940 2575 or email [react@reactcharity.org](mailto:react@reactcharity.org)

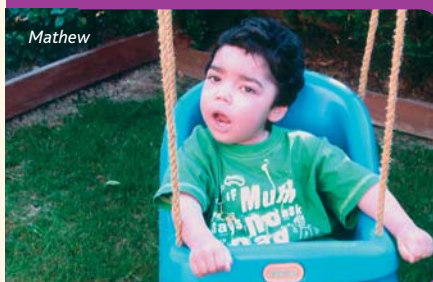
## Fit for Purpose

MORE NEWS OF ATHLETES taking part in sporting activities on behalf of React: thank you to a team of 17 who completed this year's British 10k on the 1st July, raising £4,253.90 for React. Special thanks must go to Michael Webster, who took part for the second time and at 65 years old was our oldest participant; and to the 10 runners from Athena Medical PR team.

If you feel inspired to run, cycle, jump, row, walk or do anything active at all, please do think of doing it for React! We have a choice of runs available throughout the year at various UK locations – to find out more, call the React office.



## Walking Alone



LIKE MANY CHILDREN who benefit from React's help, Mathew has physical disabilities but is as mentally alert as any boy of his age. His teachers consider him to be particularly bright for his three years but Mathew's condition means he must use a communication book to express himself. Living with dystonic quadriplegia, cerebral palsy and severe epilepsy, Mathew's mobility is very limited; however he was able to move around by holding on to a walking frame at his local specialist school.

The school physiotherapist knew that a walker adapted just for Mathew would not only allow him to walk on his own but help keep his posture in line, minimising the onset of scoliosis. Mathew lives with his foster parents and 11 year-old Liam, another boy with severe disabilities. Ray and Jackie both gave up their jobs to look after the boys who need round-the-clock care, so had no means of raising the £1,500 cost of a specially made orthotic walking frame. Thanks to React Mathew is expecting the delivery of his walker any day now and will soon be experiencing some of the freedom that most children take for granted. Jackie told us, "We had not heard about React and have been thrilled that everything has been organised so quickly. Unlike the ones at his school this frame will allow Mathew to walk without having to hold on. It will make a huge difference to him."

## One in a Million

SOPHIE WAS FIVE MONTHS OLD when she was diagnosed with Aicardi Syndrome. Doctor's discovered she was missing a vital part of her brain which should connect the left and right hemispheres. "The condition is so rare that Sophie is one of only around 400 children in the world to have it", Sophie's mother Angela told us. "Sophie cannot sit up unaided and has to use a special wheelchair at all times. Unfortunately, her chair was too bulky to fit into the car, so attending all her hospital appointments became a real problem." The solution offered by Sophie's physiotherapist was to purchase a lighter buggy which would give the family some flexibility when taking her out.

After receiving the go-ahead from React to place an order, Angela wrote: "Thank you for making this purchase possible - the speed of your response saved us a lot of time and stress. We truly are grateful as it will make life so much easier for us as a family."



### We need your help!

Sadly we cannot help all the families who ask us for help due to insufficient funds. Please help families like these by making a donation, however large or small. Call us on 020 8940 2575 or complete the form on the back of this newsletter.



Sister Frances Dominica receives the 'Woman of the Year' award, October 2007.



REACT PATRON Sister Frances Dominica is the Founder of the World's First Children's Hospice Helen and Douglas House.

*"There can be few more devastating experiences in life than being told that your child has a life-shortening condition for which*

*there is little or no chance of cure. Your world threatens to spin out of control, dreams are shattered, assumptions are denied. You search for even just one 'expert' who can tell you it isn't true, that your child can get well. And then the reality dawns, sometimes very slowly, sometimes with alarming rapidity, that normality as you once knew it will never be the same again, and you adjust to a different kind of normality which itself is constantly changing.*

*"In the short-term it seems like everyone wants to help in some way but, as time goes by, you can often feel very alone. We live in a culture of the expert, and so the next door neighbour, the colleague at work, the friend at school, have been deskilled. People are embarrassed or afraid of saying or doing the wrong thing, and out of a sense of inadequacy rather than unkindness, they are tempted to cross to the other side of the road. The people at the centre of the tragedy experience loneliness as they have never known it before. This year Helen House celebrates its 25th anniversary and there are now over 40 children's hospice services in the UK.*

*I know that for many families, React has been a lifeline, helping to ensure that children can live at home in comfort and dignity when without React the cost of caring would be an impossible burden for many parents. For so many families, the lack of bureaucratic wrangling to get a wheelchair fixed or to obtain a specialist new bed, isn't just a breath of fresh air but a feeling that somebody cares – and acts quickly! Thank you to all of you who continue to support this unique and important charity."*

Sister Frances Dominica, OBE

## New: Holidays for Families in Northern Ireland

MANY FAMILIES with a seriously ill child find it difficult to take a break from the routines of care and appointments, let alone go on holiday. React's mobile holiday homes are purchased and maintained entirely through donations, and they offer families an invaluable opportunity to enjoy a break they may not otherwise be able to afford.



Thanks to The Presidents Club Charitable Trust, React is finally able to fulfil it's wish of providing the same opportunity to families in Northern Ireland. React has benefited from the support of The Presidents Club Charitable Trust for more than twelve years and this summer the Trust donated funds to purchase our eighth mobile home, this time at the Sandilands Holiday Park located on the beautiful Kilkeel coast. We look forward to booking families into this charming resort!

## Looking Out For Georgina

WHEN GEORGINA WAS BORN thirteen weeks early she weighed less than two pounds and was immediately placed on a ventilator. After nearly six months, her family was delighted when she was allowed to go home, but the problems with her breathing worsened and she was re-admitted for emergency surgery. Still only weighing as much as a newborn, Georgina had three unsuccessful procedures to clear cysts from her windpipe before doctors finally decided she would need a tracheostomy- a tube through the wall of her throat. Her father Paul told us, "Georgina was lucky to be alive but being on the ventilator for so long has left her with chronic lung disease. We have to be so careful, as the slightest cold virus could quickly turn into pneumonia."

Georgina needs someone with her day and night to watch her breathing and adjust her tracheal tube, so the high-sided cot her parents had bought for her needed replacing with one that would allow easier access. Also, as Georgina was learning to crawl, her parents were constantly aware how vulnerable she was to infection: "We started putting down rugs for her to crawl on but she soon reached the edge!" The family wanted to replace their old living room carpet with a new one to minimise the risk to Georgina. Within a day of receiving this request we were able to purchase both items at just over £400. When a child's safety is at stake it is so important that there is a fast and efficient way to obtain items like these, which is why React responds to such requests immediately.



L-R: Sam (mother), Georgina & Jordan (also Paul, father, behind the camera)

## BBC Radio 4 Appeal

DONATIONS flowed in from all over the country following the React Charity Appeal on BBC Radio 4. On 5th August our Patron, Sister Frances Dominica, visited Broadcasting House in London to speak to the nation about why React is so important to so many families. This Appeal raises over a million pounds every year for charities so we were delighted to have the opportunity to reach such a huge listening audience.

The response exceeded even our expectations and we are pleased to announce that the total amount raised so far from the appeal is a fantastic £26,000! A huge thank you to everyone who sent donations and, of course, to BBC Radio 4.



