



**DRAVET**  
Syndrome UK

## NEWSLETTER

### JULY 2012

#### DRAVET FAMILIES ANNUAL WEEKEND AWAY

### CONTENTS

2.  
SUPER SIBLINGS

3.  
UPDATES

4.  
FUNDRAISING

#### BOARD OF TRUSTEES

Marie Baker - Chairperson

Amy Thompson Treasurer

Dawn Paterson - Trustee

Emma Williams - Trustee

#### CONTACT DETAILS

32 Wilton Avenue

Hampden Park

Eastbourne

East Sussex BN22 9HZ

07775 347234

[www.dravet.org.uk](http://www.dravet.org.uk)

[marie.b@dravet.org.uk](mailto:marie.b@dravet.org.uk)

Twitter - @dravetuk

Members of The Joint Epilepsy  
Council



Proudly supported by Roald  
Dahl's Marvellous Children's  
Charity



The 25th May saw our fourth annual Dravet families get together. 41 families descended on the Sherwood Forest Center Parcs from all over the country. As always the weekend kicked off with our family meal at Hucks Diner, kindly paid for by The Dean Henshall Memorial Fund. This gave all our families a chance to reconnect with one another and for new families to meet others.

Saturday morning saw our first ever siblings session. DSUK provided funding for all the siblings to join in with a raft building session. After they had built their rafts and set sail on the lake a number of volunteers took them on the pedalos and kayaks. This was such a lovely opportunity for the sibs to get together with others in the same situation and for us at DSUK to let them know how much they are appreciated. All the sibs received one of our children's DSUK tee shirts as a small gift and the sibs that were too young to join in with the raft building received some money for an activity of their choice.



Our annual soft play session was held on Saturday afternoon and once again Hucks were kind enough to open the restaurant early so that our families could have sole use of the soft play area for 2 hours.

The mum's night was held on Saturday evening and the dad's had their night out on the Sunday. With so many families in attendance this year we took over the Country Club and Sports Bar.



Another welcome addition to this year's itinerary was the grandparent's coffee morning. Every year more and more grandparents come along to join in the fun so it was nice for them to be able to get together to share their experiences.

As always the weekend was a huge success and we were so very lucky with the weather. Committee member Rachel Spray did a fantastic job organising the whole weekend and thanks goes to Sheila Henshall, Lucy and all their family and friends for continuously raising money for Dean's Memorial Fund, which provides a small grant for each family to attend the weekend.

## SUPER SIBLINGS

By Martin Baker

Thank you again for all of your “Super Sibling” nominations since the last newsletter. It is great to hear more stories of the amazing brothers and sisters out there in our community. As previously, all of the nominations will be carried forward and considered for the next award.

Ok so let's meet the latest “Dravet Syndrome UK Super Siblings”

### Thomas Bjork Aged 10 is the Brother of Matthew

“Thomas is amazing. When we found out Matthew had Dravet I felt for Thomas not having a ‘normal’ family but he took Matthew into his heart – to watch them rough and tumble brings me such joy. Living with a brother obsessed with Balamory cannot be easy, especially when he insists you watch it with him again and again. When Matthew has a fit at night Thomas always comes to check that he is ok. We try to hide our distress about situations, but if Tom see's I'm upset he always comes over to give me a hug. He was happy for me to go his class to tell his friends about Dravet and also helped on my stall at the school Christmas fair selling carol books for the charity. Tom is a very active young man who is in the local swimming, football and cricket teams. He enjoys playing on his Wii with Skylander as a new favourite. He enjoys Ben 10, Horrible Histories and I'm sure that he must have a soft spot for Peppa Pig!!! ” – Joanne Bjork



*Thomas Bjork*



*Kayla with big sister Jessica*

### Kayla Rose Dickinson Aged 5 is the Sister of Jessica

“Despite being only five Kayla has and continues to be a lovely young girl. She keeps a close eye on her sister, defending her behaviour and ensuring that she is safe. She has alerted us to seizures and tells people that her sister has epilepsy. We have four children, Jess being the eldest and Kayla adores them all, always offering to help with a smile. The bad days are made better by having Kayla around. In her nursery year at school she won an award for always smiling and helping others” – Julie Dickinson

Kayla loves crafts and colouring, dancing on the wii, going in the caravan and caring for Peppa and Suzy her guinea pigs.

I'm sure you will all agree that Thomas and Kayla really are “Super Siblings” and their respective brothers and sisters are very lucky to have them watching out for them. Their families and friends must be very proud as we all are at Dravet Syndrome UK.

As I mentioned the response has been amazing and reading all of the nominations has been inspirational. Please keep them coming in, it's great to hear how all of the brothers and sisters are contributing to enriching the lives of their families.

Please send any new “Super Sibling” nominations on the nomination form, which can be downloaded from the ‘news section’ of our website, to Martin Baker at 32 Wilton Avenue, Eastbourne, East Sussex, BN22 9HZ

Many thanks.

**LOREAL CITIZEN WEEK**

Dravet Syndrome UK were lucky enough to be chosen as one of the charities to support by Loreal during their annual Citizen Week. On Thursday 21st June Chairperson Marie Baker visited the Loreal Offices in Hammersmith, London to take part in a brainstorming session with a number of volunteers who had put their names forward to give advice and share experience and knowledge on how to successfully market the charity, something of particular importance during this economic climate. A number of great ideas came forward, which will be implemented over the following months and we really cannot thank the Loreal volunteers enough for their insightful input; it's always really useful to gain opinions from people who are new to Dravet Syndrome.

The brainstorming session was followed up the following Tuesday when we were invited to attend the Citizen Week Networking Event at the Loreal Offices. This gave us an opportunity to speak directly with a number of Loreal employees about Dravet Syndrome and what we at DSUK do.

Huge thanks to Debbie Blignaut for putting us forward to be involved in Citizen week and to everyone who took time out to work with us.



*Chairperson Marie Baker with Loreal Employees*



**MA HEALTHCARE**

**EPILEPSY IN CHILDREN CONFERENCE**

On Wednesday 20th June Chairperson Marie Baker headed to London to exhibit at the Epilepsy in Children conference, held at the Hallam Conference Centre. To keep costs to a minimum we once again shared a stand with Matthew's Friends and we were delighted that every single delegate we spoke to had some knowledge of Dravet Syndrome; a very different response to that of the same conference last year.

The conference was attended by a range of health professionals including neurologists, consultants, epilepsy nurses and dieticians and it was great to be able to catch up with Dr Elaine Hughes, a member of our Professional Advisory Board.



*Marie Baker - DSUK & Julie Edwards - Matthew's Friends*

Getting out into the professional community is a really important aspect of what DSUK do and it is incredibly rewarding to see how knowledge and understanding of Dravet Syndrome has increased since we first registered as a charity at the beginning of 2009.

**MAILING LIST UPDATES**

In an effort to keep our mailing list as up to date as possible please could all members let us know by emailing Frances at [frances.b@dravet.org.uk](mailto:frances.b@dravet.org.uk) if any of the following changes:

- \* Address & contact phone numbers
- \* Email address
- \* New family members

## TEAM DRAVET CLIMB BEN NEVIS



*Team Dravet ready to set off*

I am absolutely delighted to pass on the news that all 36 members of our Ben Nevis Team Dravet completed the climb of the biggest mountain in the UK. Dravet Mums, Dads, Aunties, Nans, Grandads, Brothers and friends came together on the 30th June in what can only be described as an amazing weekend and a fantastic achievement.

We are busy collecting in all the sponsor money and will be announcing the grand total raised at the beginning of August; so keep an eye on our website, Facebook page and Twitter page for the total, photos and stories of the weekend..

Thanks to everyone who climbed, everyone who sponsored, our fantastic guides at Adventure Nevis and especially Committee member Teresa Finch, who organised the event.

## WILLIAMS WARRIORS DOING IT FOR DRAVET

By Fran Coston

Back in January, shortly after William was diagnosed with Dravet Syndrome, my sister Marg Wakefield suggested we run the Mersey Tunnel 10K. Who would have thought that there would be 44 amazing Warriors also running through it wearing the DSUK tee shirts and raising over £8000 in the process! I seriously doubted my own ability to run for the bus, never mind 10K (6.2 miles)!

Many people came together to support us and we thank each and every one, yet some people who need a special mention

William, for being our inspiration for this fundraising, and all the other children and adults affected by Dravet Syndrome. Lily and Emily for being so understanding without realising it.

Jeff Bird and Kevin Gorry who decided to run wearing the purple morph suits, after realising it would be impractical to run as Peppa Pig (William's favourite TV character). They ran the whole 10K with their hoods up and faces completely covered, and it was hot! The amount of attention they got from running like that was amazing, really got the charity noticed.

Martin Connell, a work colleague of my sister Jane at Liverpool John Moores University, heard about William and his Warriors and joined along with 8 of his work colleagues. He ran the Liverpool Half Marathon in March and the Edinburgh Marathon in May for DSUK too.



*William's Warriors*

Jane Short and Denise Minde, two of my sisters, were chief childminders/crowd control/cheer leaders, therefore allowing myself, Mike and Marg organise and lead William's Warriors. Marg Wakefield for suggesting we run the Tunnel 10K and Cathy Cotgrave, my good friend, who volunteered to run with us and giving us the idea to create a team!

Other fundraising has included the William's Warriors Race Night that raised £1600. This was the brainchild of Becky Mazier and her husband John. In addition to money raised through betting and buying horses, we had fantastic prizes to raffle and auction. Also the charity wristbands were sold throughout the evening. Unknown to us a regular of the pub where the race night was held, Alice Cavanagh, had earlier been an official Olympic Torch bearer. She was allowing people to be photographed holding the torch for a donation of £1, which in turn she donated to our cause!

And finally thanks to St Peter's Catholic Primary School, where I used to teach, who have been selling DSUK wristbands.