



NEWSLETTER

APRIL 2012

FAMILY & PROFESSIONAL CONFERENCE 2012 UPDATE

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FUND

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Council



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Since announcing the Dravet Syndrome UK second Family & Professional Conference, which is being held on Saturday 17th November in Warrington, Cheshire, over half the delegate places have been snapped up. It proves to be an informative day of presentations and round table discussions focusing specifically on Dravet Syndrome and we are absolutely delighted that Dr Charlotte Dravet will also be making a presentation.

Places can be booked directly on our website or contact Marie Baker at marie.b@dravet.org.uk for a delegate booking form. Delegate rates are £10 per person for Dravet Syndrome UK Family Members or £47 for professionals.

The itinerary will be announced in early May .

BLACK TIE BALL

Following on from the conference will be a black tie fundraising ball. Once again tickets are selling fast and Dr Charlotte Dravet will be our guest of honour at this event. Tickets are £60 each and can be booked individually or as a table of 10.

The ball will be one of the biggest fundraising events of the year for Dravet Syndrome UK and already half the tables have been snapped up To book tickets please contact Marie Baker at marie.b@dravet.org.uk

HOTEL & FAMILY INFORMATION

The Park Royal Hotel have offered our delegates reduced room rates for the weekend of the conference and ball at a cost of:

£79 per night bed and breakfast for a single room and £89 per night bed & breakfast for a double room for those staying one night

£72 per night bed and breakfast for a single room and £82 per night bed & breakfast for a double room for those staying two nights

Rooms must be booked directly with the hotel. The Park Royal Hotel, Stretton Road, Stretton, Warrington, Cheshire, WA4 4NS - 01925 730 706

For those families staying the Friday night we will be organising an informal get together in the Red Library, situated in the main bar area. Further details to be confirmed.

SUPER SIBLINGS

By Martin Baker

What a response we have had since the last newsletter to our request to hear about the “Super Siblings” out there. As we suspected there are many brothers and sisters doing amazing things, not just for their brothers and sisters with Dravet but for their families in general.

It has been a near on impossible task to choose from all of the amazing nominations we have had so far and as a result of the great response, Dravet Syndrome UK are pleased to tell you the brief stories of the following three “Dravet Syndrome UK Super Siblings”

Oliver Bell Aged 9 is Brother to Jack

“All of our children’s siblings are special and have to deal with issues that no young child should, but I would like to nominate Oliver as a super sibling as he is such a wonderful big brother to Jack. He never complains if plans change due to an unexpected seizure, he lets everyone know that he has a special little brother and that if Jack has a seizure just to let Oliver know because he knows what to do to help his brother. He shows such compassion and caring to Jack and doesn’t show any resentment whatsoever, even though some days must be so tough when we’ve been up all night and we’re a bit grumpy to say the least! Oliver is a wonderful brother and son, the best we could ask for!” – Catherine Bell

Oliver loves playing on his scooter and BMX and is a big fan of street dance, He loves Diversity and is in a crew himself called Fired. Who knows, we may be seeing Oliver and his crew in Street Dance 3!



Oliver Bell



Heidi Martin with little sister Tessa

Heidi Martin Aged 4 is Sister to Tessa

“Heidi is a great big sister, She helps to look after Tessa and plays with her. She takes ambulances, hospital stays and doctors appointments in her stride. She is never jealous and never complains. Tessa adores her and ‘Heidi’ was one her first words and thankfully one she has never lost following a seizure” – Keren Martin

Heidi loves reading and any kind of art activity and like most girls her age she likes Hello Kitty, Barbie and anything to do with Disney Princesses. She even helps out in her Mummy’s vegetable garden.

Thomas Bonwick Aged 4 is Brother to Jake

“Thomas is only 4 years old and is really helpful. When Jake is having a seizure Thomas sings JLS to Jake which helps him come out of his seizure (that’s what we tell Thomas anyway). He reads to Jake and helps him on his K Walker. Thomas loves Jake so much even though Jake is often the centre of attention due to his condition and for all these reasons I think he is a super sibling” – Kerry Bonwick.

Thomas loves dancing and singing to JLS and also is a big fan of Spiderman, Ben 10 and Batman. Perhaps Thomas might be onto something with the JLS songs to help with seizures. Dravet Syndrome UK should look into some research!



Thomas Bonwick with little brother Jake in the background

I'm sure you will all agree that Oliver, Heidi and Thomas 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 are we all 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.

All of the nominations we have had to date will automatically be considered for the next set of awards and please send any new "Super Sibling" nominations to Martin Baker at 32 Wilton Avenue, Eastbourne, East Sussex, BN22 9HZ (forms can be requested from Marie Baker at marie.b@dravet.org.uk).

Many thanks.

Martin

NORTH WEALD SPONSORED WALK

On Tuesday 5th June, an additional bank holiday for 2012 to commemorate the Queen's Diamond Jubilee, Kylie Brown and her family will be hosting a sponsored walk in aid of Dravet Syndrome UK. The walk will begin and end at The North Weald Village Hall in Essex and will take approximately 40 minutes at a slow pace. Registration costs £15 per adult and £7.50 per child, which includes your sponsor pack and tee-shirt. Kylie has done a wonderful job organising this walk with her Parish Council and the Council have agreed to put on a sponsored fun bike ride, also raising money for Dravet Syndrome UK.

If you would like to join Kylie and her family on the walk please contact Marie Baker at marie.b@dravet.org.uk

SIMON TUCKER LIMITED

CHARITY OF THE YEAR

Many thanks to Simon Tucker Limited, who have chosen Dravet Syndrome UK to support as their charity of the year. Alongside regular donations the architectural design company based in Polegate, East Sussex have very kindly donated a pulse oximeter machine to us to kick start their year's support. Anyone wishing to be the recipient of this monitor should get in contact with Marie Baker.

TEAM DRAVET SET TO SCALE BEN NEVIS

On 30th June a group of 40 intrepid (yet slightly scared) people will be climbing Ben Nevis in an effort to raise £10,000 as Dravet Syndrome UK's first year's commitment to assisting with funding a research administrator to work alongside Dr Sameer Zuberi's team in Yorkhill Hospital, Glasgow.

This particular Team Dravet consists of parents and friends (and an incredibly reluctant charity chair) of those diagnosed with Dravet Syndrome so the challenge is an extremely personal one.

Ben Nevis stands at 4,408 feet and is the highest mountain in the British Isles. Lots of Team Dravet have Justgiving pages set up for sponsorship and donations at www.justgiving.com/dravetsyndromeuk so have a read through some of their stories and please, if you can, donate a few pounds to help us reach our goal.



PURPLE DAY 2012

Monday 26th March saw people all around the world coming together to raise awareness of epilepsy and within our Dravet community many events took place to raise both awareness of the devastating effects of Dravet Syndrome, along with money to go directly to research into Dravet Syndrome. Here's a few photos of some of the events that took place but see our website for more Purple Day pictures and stories.



James Coward & friend Gabriel on Purple clothes Day at school



Rebekah Hughes and Committee Member Mum Annabel selling purple cakes and wristbands



Purple Day display at The Queen Elizabeth Hospital in Gateshead arranged by Laurence Scott, Grandad to Ella-Rose Hare



James Coward and Mum Angela selling purple cakes

Huge thanks must go to the following people Angela Coward, The Khlar Foundation, Annabel Hughes, Keren Martin, The Whitehouse, Family, The South Downs Community Special School, Laurence Scott and The Hare Family. We are still receiving purple day money so will announce the final amount raised for the research fund on our website but so far we have exceeded £2000. Many, many thanks to everyone who got involved this year.

DEAN HENSHALL MEMORIAL FUND BOOST

At the beginning of 2011 we were contacted by Vivienne Thompson, Dean's Aunt, to let us know that Dravet Syndrome UK had been chosen as her workplace charity of the year. Viv works on Ward 9 Orthopedic Unit at Bournemouth Hospital and Sister Karen Lees was a huge support in agreeing Dean's Fund to be the recipient of the Ward's fundraising endeavours for the year. Events throughout the year included lots of raffles, tombolas, jumble sales and car boot sales. There was a teddy bears picnic in the summer that was very successful and after a visit to the ward by a Bournemouth football player, they were given a signed shirt that was promptly sold for £100! There was even a 'guess the weight' of a cake made by a staff member and 'guess the name' of a very large cuddly dog that was donated to the cause! Special thanks must go to Karen Lees, Yvonne Gorton and of course Vivienne Thompson who put in so much time, effort and organisation to make the fundraising a success. However, ward 9 would not have been as successful if they didn't have the support of ALL staff members, the patients and the visitors. A huge thank you to everyone involved for the amazing £706 raised for Dean's Fund.

The Dean Henshall Memorial Fund is used to provide small grants enabling families to attend The Dravet Syndrome UK annual weekend away. This year's weekend away is coming up in just 5 weeks and thanks to Dean's fund 40 families have received grants of £150 each.