



DRAVET
Syndrome UK

NEWSLETTER
JANUARY 2012

**DRAVET SYNDROME UK ANNOUNCE SECOND
RESEARCH AWARD**

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Council



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Dravet Syndrome UK are delighted to announce our 2nd research grant. This is our 2nd grant within just 8 months and is entitled 'Genetic heterogeneity of Dravet Syndrome: the pathological roles of SCN2A, SCN1B and GABRG2 in Dravet Syndrome patients negative for SCN1A mutations'. The study, costing £29,950, will take place over 2 years and bring together The Welsh Epilepsy Research Network and The Royal Hospital for Sick Children in Glasgow. Drs. Chung, Thomas, and Zuberi will be working with Professor Mark Rees screening 80 patients who have tested negative for the SCN1A gene, yet still have a clinical diagnosis of Dravet Syndrome. The 80 patients will all have been clinically assessed with a definitive diagnosis of Dravet Syndrome by Dr Zuberi's team and will go on to be tested for the rarer gene causes; SCN2A, SCN1B, GabRG2 and PCDH19.

The 80 patients have already been identified and in all cases where pathogenic mutations are found the referring clinician, in conjunction with Dr Zuberi, will be informed to communicate the results to the parents/guardians. Regional consultants will then be able to access localised genetic counselling teams to begin the information dissemination process with the families involved. Where mutations are found parents will be subsequently tested to discover whether the mutation has arisen de-novo.

The prediction is that the results will help explain more of the biological cause of seizures, learning problems and ataxia in Dravet Syndrome and will also help doctors provide parents with a greater degree of certainty when giving both the diagnosis and prognosis at an early age.

We are absolutely delighted to be in a position to fund this important study and are thrilled to confirm that an update on the project will be delivered by a member of the research team at our Family & Professional's conference in November.

**IN MEMORY
CONNOR LATTER**

The Dravet Syndrome UK community was rocked on New Years Day when we heard the tragic news that Connor Latter had passed away. Connor, son of Sarah Page and Richard Latter, was just 14 years old and in those short years touched many lives in a purely positive way.



Connor Latter

Connor was only diagnosed in the summer of 2011 and I speak for everyone when I say we are all truly grateful for the short time we knew Connor. His smile and general 'coolness' will never be forgotten and our thoughts are with Sarah and Richard.

CONRAD WACE

Conrad Wace, partner to Sheila Henshall, tragically passed away on the 17th August last year aged just 49. Conrad was very well known to us and was a constant source of support since we first registered as a charity at the beginning of 2009. Conrad, along with business partner Henry, helped to set up our first website and when Dean Henshall tragically passed away it was Conrad who took the lead in setting up 'Dean's Fund'. Conrad is dearly missed and we will always remember the helping hand he gave us and the belief he showed in our organisation.



Conrad Wace

FAMILY & PROFESSIONAL CONFERENCE 2012

Saturday 17th November sees Dravet Syndrome UK's second Family & Professional Conference. The one-day conference will take place at The Park Royal Hotel in Warrington, Cheshire from 9am until 4pm. Registration will begin at 8am.

Topics covered will include:

- * Advancements in research
- * Progression in the understanding and treatment of Dravet Syndrome
- * A guide to the medications used in Dravet Syndrome
- * Alternative treatments
- * Education, further education and transition
- * Family experiences
- * Co-morbid conditions

To complement the main presentations we will be holding round table discussions where experts in various fields will be available to provide information and answer questions on relevant topics.

Alongside the speakers we will have a wide variety of stands providing information on products and services that are relevant to both families and professionals working in the field of Dravet Syndrome.

To book a place please contact Marie Baker at marie.b@dravet.org.uk Delegate rates are £10 per person for DSUK family members and £47 per person for professionals. An agenda for the day will be available from the beginning of April.

Accommodation is available at the hotel at a reduced rate for delegates. This rate is £89 for a double room or £79 for a single, and includes breakfast. For further information on The Park Royal Hotel please see their website at www.qhotels.co.uk/hotels/the-park-royal-cheshire

FUNDRAISING BALL

A black tie ball will be held in the evening of the 17th with pre-dinner drinks commencing at 7pm.

With an excellent raffle and auction we can guarantee that it will be a wonderful way to relax and have fun whilst raising money for Dravet Syndrome UK.

Tickets are £60 per person and if you would be interested in a monthly payment scheme please contact Marie Baker at marie.b@dravet.org.uk

SEIZURE ALARMS

Dravet Syndrome UK are delighted to have funded 19 Pulse Oximeter Machines in 2011, 40 machines since we first set up at the end of 2008. These monitors attach to the patient via a sticky probe and monitor the patient's heart rate and oxygen levels. Generally when a person seizes their heart rate will increase and their oxygen levels drop. The pulse oximeter can be pre-set to individual parameters to alarm when the levels exceed or fall below their individual 'norm'.

Although these monitors are of great peace of mind to the families who use them we are fully aware that this form of monitoring is not suitable for all. Particularly those older children/young adults, those who are more mobile or can display challenging behaviour. For this reason we are running a trial on the Emfit Nocturnal Tonic-Clonic Seizure Monitor. We will initially fund 5 of these monitors to families on our membership on a first come first served basis. The monitors will be granted on the condition that the family informs us on the reliability and usage. If the family finds that the monitor is not beneficial to their child then we would ask for it to be returned.

We fully appreciate that those diagnosed with Dravet Syndrome experience a wide variety of seizures so this form of monitoring may not be ideal. It is for this reason we are initially funding them as a trial for 5 families only. If you are interested in being part of this trial programme please contact Marie Baker at marie.b@dravet.org.uk

SUPER SIBLINGS

SIBLING AWARD

We all recognise how simply super our Dravet children's siblings really are but despite that they rarely get the recognition they deserve. At Dravet Syndrome UK we would like to change that and so we are launching our 'Super Sibling Award'. Parents and carers can nominate their child to win our sibling's award and we will choose a winner every 3 months, to coincide with our newsletter. You can nominate them for any reason you like, maybe they've done something extra to help their brother or sister, maybe they've done particularly well at school, maybe they've organised a fundraising event at either work or school or maybe they are just consistently a fabulous sibling. There is no age limit, all they have to do to qualify is to be a super sibling.

The winner each quarter will be picked by Martin Baker and will be awarded with a certificate, a small gift and have a piece written about them in the next quarters newsletter. So go ahead and fill in the 'Super Sibling' nomination form and let's give those brilliant brothers and stupendous sisters the recognition they deserve. Please ensure your nomination forms are returned by Friday 13th April.

SIBLING SUPPORT

Following a request from one of our member's older children we have decided to start up a sibling support forum on Facebook. This will run alongside the current family support forum and will also be a closed, private group.

The group will be moderated by our Chairperson, although the only postings and comments made will be by the siblings themselves. Only siblings over the age of 13 are able to join the group, in line with Facebook rules and two of our older siblings, Jade-Marie Barlow and Alice Williams, will be moderating and taking the lead within the group.

If your child wishes to join our new support forum please contact Marie at marie.b@dravet.org.uk



Alice Williams with Katie Baker



Thomas Lawton



Sigrid Morrison, Hannah Rigler & Katie Baker



Center Parcs 2011

DRAVET FAMILY GATHERING 2012

Our annual Dravet family gathering has been agreed upon for the weekend of Friday 25th May for 3 nights at the Sherwood Forest Center Parcs. We are delighted to once again be able to offer the family grant of £150 per family. This grant comes from The Dean Henshall Memorial Fund, the fund that was set up in Dean's memory to ensure that Dravet children and their families were able to get together and have FUN.

As always we will plan an itinerary of family events, which will be available a little nearer the time. If you need anymore information on booking please do not hesitate to get in touch with us. The trustees and committee members are looking forward to catching up with old friends and meeting new families.

RUNNERS REQUIRED FOR THE 2012

BUPA 10K

We are thrilled to once again be able to offer 8 places in the Bupa10K following the huge fundraising success of the event last year

The Bupa London 10,000 starts and finishes in St. James's Park and uses Green Park as its assembly area.

The race starts on Birdcage Walk and follows an anti-clockwise route around the City of Westminster and the City of London via Parliament Square, Embankment, Blackfriars Bridge, Queen Victoria Street, Cannon Street, Great Tower Street, Crutched Friars, Fenchurch Street, Leadenhall Market, Cornhill, Queen Victoria Street, Puddle Dock, Embankment, Horseguards Avenue, Whitehall and via Trafalgar Square to the Finish in The Mall.

Runners pass many of London's famous sights, including Westminster Abbey, Houses of Parliament, Big Ben, The London Eye, Cleopatra's Needle, Tate Gallery, Millennium Bridge, The Monument, Lloyds of London, Leadenhall Market, Bank of England, Mansion House, St. Paul's Cathedral, Horseguards, Nelson's Column and Admiralty Arch. Buckingham Palace acts as the backdrop to the start and finish.

The run takes place on Sunday 27th May and if you would be interested in joining our team please contact Dawn Paterson at dawn.p@dravet.org.uk

CHRISTMAS RAFFLE

Many thanks to everyone who supported our 2011 Christmas Raffle. The prize of a one week stay at The Manassa bungalow, St Merryn, Near Padstow, Cornwall was drawn by Amy Finch and went to Wendy Easton. Wendy has been a great support to Dravet UK and we wish her and her family a very happy holiday.

GOLF DAY HELPS FUND

RESEARCH

Back in October committee member Annabel Hughes organised and hosted a golf day at Woburn Golf Club. The day was a huge success and raised a total of £15,000, which has been put towards the research project submitted by Dr Chung. To read about the day please go to the news section of our website, www.dravet.org.uk and many thanks to Annabel and everyone who supported, donated, played and helped to host.



Annabel Hughes with twins Rebekah & Henry

PURPLE DAY 2012

Monday 26th March is purple day, which was created in 2008 by Cassidy Megan who was motivated by her own struggles with epilepsy. Cassidy's goal is to get people talking about epilepsy and dispelling the myths. Dravet Syndrome UK are asking people to help us raise awareness of Dravet Syndrome on Purple Day and, if possible, to raise some much needed money to go into our research fund - all monies raised through Purple Day events will go towards research into Dravet Syndrome.

So what can you do? How about asking your children's schools if they will consider a non-uniform day? You could sell purple cakes in the playground (or even our Dravet pins) Coffee mornings are a great way to catch up with friends and raise some cash, or you could organise a bring and buy toy sale with your friends. Its totally up to you, but whatever you do should be fun!

If you would like some of our Dravet Pins, priced at £1 each (plus p&p) please contact Marie Baker at marie.b@dravet.org.uk We can also help you with posters, provide leaflets and collection boxes. Lets make Purple Day great for Dravet this year.

