



NEWSLETTER May 2014

Charity update

As always it's been very busy here at Dravet Syndrome UK. Our amazing team of volunteers have been getting ready for our Centre Parcs family gathering in June, organising pre-trial clinical Epidiolex meetings across the UK for the medical professionals involved to speak directly to our UK DS families, updating our [Understanding Dravet Syndrome leaflet](#) and preparing for International Dravet Syndrome Awareness Day.

It is always good to change and move things forward, and DSUK are going through a period of transition where we have said goodbye to some, and welcomed new, and to that end, we're very sad to announce Vice Chair and Trustee, Galia Wilson, Trustee, Scott Liddle and Committee Members Rachel Spray and Peter Baker are stepping down from their roles at DSUK, but thankfully not saying goodbye to the charity so we will still be seeing them and we would like to take this opportunity to thank them for all their hard work, and time they have given freely for the charity.

On a happier note we're delighted to welcome Annabel Hughes as a Trustee, joining Acting Chairperson Emma Williams and Trustees Teresa Finch and Dawn Paterson. Annabel has been a Committee Member of DSUK and is one of our fantastic fundraisers. Annabel has twins, Rebekah and Henry and lives in Norfolk along with her husband, Haydn. Rebekah has Dravet Syndrome and Annabel first started learning about the syndrome when she attended the IDEA league (now Dravet.org) global conference in Chicago, 2007. Emma Bangar has also joined us to provide the charity with dedicated administration and marketing support.

We would also like to announce, and thank, Derek Amson, dad to Riley with Dravet Syndrome, and Stella Bradley, mum to Elise with Dravet Syndrome, who have both very kindly volunteered to act as moderators on the Dravet private family forum moving forwards. Stella will be taking over from Scott Liddle with regards to adding new members to the forum. The 'Scott Dravet' account will be changed over to 'Stella Dravet' in the next few days. Please note new members must first send a friend request via facebook to 'Stella Dravet' before they can be added.

Centre Parcs family gathering 13th – 16th June

We are really excited about our upcoming Centre Parcs weekend on the 13th-16th June. The event takes place at Centre Parcs in the beautiful Sherwood Forest in Nottinghamshire www.centerparcs.co.uk/villages/sherwood/index.jsp

This year we have thirty-six families attending. The weekend will start with the family meal on Friday night to welcome all the families. Parents and their children will get their main course, dessert and soft drinks paid for thanks to a funding grant from Jeans for Genes charity.



Our sibling event this year is Laser Combat followed by lunch at Hucks on Saturday morning and is already fully booked. We also have a mum and a dad's night out and lots of family meet ups throughout the weekend, so a busy schedule for all!

It's not too late for you to join us and each family attending will receive a £150 towards the cost of the accommodation. If you would like to join us please e-mail Rachel rachel.s@dravet.org.uk

International Dravet Syndrome Awareness Day 23rd June

Dravet Syndrome UK is joining forces with Dravet Syndrome groups and charities around the world on 23rd June in order to celebrate our first International Dravet Syndrome Awareness Day.

If you have an event planned, please let us know. Whether it's a cake sale, charity run or a quiz, we can publicise your events. We have many items available to support your event, including running vests, T-shirts, wristbands, key rings, bookmarks, lapel pin badges and posters. If you need any ideas or inspiration on what to do we have lots of [fundraising ideas](#) on the website.



Your fundraising really does help us help our families dealing with Dravet Syndrome on a daily basis.

Adult Assistance Fund

The Adult Assistant Fund is for families whose children are aged 16 and over. The fund can be used for anything that will improve the lives of the Dravet adult in these families. For guidance on the types of things we fund please visit our website www.dravet.org.uk

The limit on each application is a maximum of £1 000 per family, per year, we look at each individual case to assess the needs and see whether or not they are being met elsewhere. As with all assistance programmes we do not means test but we do require a letter of diagnosis as proof of the condition. The Adult Assistance Fund is a rolling programme and applications are accepted and reviewed at any time.

Marie McLeish, from Glasgow, has been one of the latest families to benefit from our Adult Assistance Fund. Marie needed decking in her garden to provide a calm and safe seating area for her daughter Amanda with Dravet. The Adult Assistance Fund gave Marie £400 towards the cost of this project which covered the materials from Jewson's and the joinery work to construct the decking.



Helen Lamont has also benefited from the fund. Her son Matthew had lived happily in the same residential home for seven years. However, in 2012, there were lots of changes and he started to find it very difficult to cope, so in the summer of 2013 Helen applied to the DSUK Adult Assistance Fund for a grant so Matthew could have a special holiday. This application was successful and Matthew was delighted to hear he was going to Disneyland Paris for a holiday.

Helen says:

“The look on Matthews face when I told him he was going to Disneyland Paris for four days with his two most favourite friends in the world as his carers was unbelievable....I would like to thank each and everyone of you who have raised funds for DSUK as it will now allow my son to have a holiday of a life time.”

If you would like more information about this fund please get in contact with us.

Dravet Syndrome Epidiolex Trial update

Finally, we have some upcoming meetings planned to discuss the Epidiolex trials which are open for all families to attend.

We have already held one very successful pre-trial meeting in Chester at the beginning of this month at the request of Dr. Appleton, and will be holding further meetings in London on Thursday 19th June, in Glasgow on Thursday 25th June and in Chester on Monday 14th July. A separate email announcement will be sent out very shortly with more information regarding these meetings and how to register your attendance.

Dravet Family conference

We are very excited to confirm that the Dravet Syndrome Family conference and evening event will take place next year. We will send out further details as soon as we have finalised the date and venue.

Don't forget you can contact us by email info@dravet.org.uk and like us on facebook www.facebook.com/dravetsyndromeuk and follow us on twitter [@DravetUK](https://twitter.com/DravetUK) to keep up to date with all our latest news and events.