

NEWSLETTER July 2014

Charity update

We've had a busy few months at Dravet Syndrome UK. Below is a taste of what has been going on, and what is planned for the future.

We ran pre-trial Epidiolex events at London, Glasgow and Chester which were a great success and incredibly informative. We held our quarterly Trustee meeting to discuss what's coming up for the charity over the next year.

We held the annual Centre Parcs weekend, 38 families attended, with children ranging in age from 6 months to 32 years. A big thank you to Rachel Spray for her hard work organising this, and previous year's, weekends, and also to Jeans for Genes for providing a grant which enabled us to subsidise costs.

Rachel has written a lovely account of the weekend which can be read on our website:

<http://www.dravet.org.uk/family-support/annual-centre-parcs/centre-parcs-2014/>

Teresa Finch, DSUK Trustee, has taken over organising Centre Parcs. Next year's weekend is already booked and the full details are below.

Trustee Annabel Hughes attended the Dravet Syndrome Foundation's 1st Biennial Family and Professional Conference in Chicago last month. She met Dravet specialists and families from around the world.

DSUK Chair, Emma Williams, has been in Sweden at the European Congress on Epileptology (ECE) and met with other European Dravet organisations.

Planning has started for the 2015 Dravet Syndrome UK conference, it is a mammoth task co-ordinating Dravet specialists from around the world to be in one place on the same day. Confirmation of the date will be announced in due course.

Stella and Derek have come on board as volunteers and are now moderating the facebook forum and adding new members.

We are very sorry to say goodbye to Frances Baker who has taken the difficult decision to step down as a Committee Member. Frances is one of the founding members and has been with the charity since its inception. We would like to say a huge thank you to Frances for all her hard work and dedication over the last six years.

Adult Education Workshop for Neurologists

We are excited to announce that in collaboration with Prof. Sanjay Sisodiya we are running a CPD approved Adult Education Workshop specifically for neurologists to discuss Dravet Syndrome; spread awareness; and share what is being done in the adult neurologist world.

Adults with Dravet Syndrome are often misdiagnosed and there are many adults without the correct diagnosis.

The event is taking place in November at the Epilepsy Society campus in Chalfont and we will feedback on the outcomes after the event.

International Dravet Syndrome Awareness Day 23rd June

On the 23rd June we joined forces with Dravet Syndrome groups and charities around the world to celebrate our first International Dravet Syndrome Awareness Day and it was a great success. We really enjoyed seeing all the different activities people were running across the world.

We had a very busy day keeping up with all the stories coming in and sharing them on facebook and twitter. Thank you so much for everyone who took part and helped make the day such a success.

Pre-trial meetings summary

We had a fantastic response to our recent events in London, Glasgow and Chester with the top UK specialists in Dravet Syndrome speaking.

In London Prof. Sanjay Sisodyia spoke about the latest research into SUDEP and Dravet Syndrome while Prof. Helen Cross spoke about the trials on the horizon, discussing both Epidiolex and Fenfluramine. There was a lot of interest from the families present about both treatments and how exactly the trials would be run; where the trial sites would be; and what the pre-requisites were for children to be accepted onto a trial.

In Glasgow Dr Sameer Zuberi talked about the upcoming trials and recent research into Dravet Syndrome. He presented data looking at the prevalence of the syndrome which indicated incidence is higher than first thought and possibly 1 in 30,000 births.

In Chester Dr Appleton discussed the history of Epidiolex and how the trials would be run in the UK, looking at the inclusion criteria and considerations such as the time lines, potential interactions with existing treatments and potential risks.

Ollie Johnson Memorial Fund

Tragically Ollie Johnson, who suffered from Dravet Syndrome, passed away on 27th December 2013, aged just 2 years and 8 months old.

To honour Ollie's life, his parents, Sarah and Stephen, set up the Ollie Johnson Memorial Fund to fund essential epilepsy alarms, camera monitors and pulse oximeters for Dravet families. To date they have raised in excess of £7,000 which has funded over ten monitors.

We would like to say a huge thank you to Sarah and Stephen for all their hard work and continued support of Dravet Syndrome UK.

www.justgiving.com/OLLIE210411





Centre Parcs 2015 – booking guide

Next years Centre Parcs weekend will take place on the **12th-15th June 2015** at Sherwood Forest Center Parcs, Nottinghamshire. You need to book your own accommodation by calling the booking line 08448 266266 or online at www.centerparcs.co.uk.

Once you have booked please email Teresa teresa.f@dravet.org.uk with:

- A copy of your booking confirmation from Center Parcs
- Your booking reference number
- Your villa area and number
- Name of all adults attending, and relationship to Dravet patient
- Name and age of Dravet patient
- Name and age of other children
- A mobile contact number for when we are there.

The villas in the central or middle location usually cost extra, however we have managed to negotiate getting this fee dropped. To do this send an e-mail to – guestservices.uk@centerparcs.co.uk stating the following:

- Your name and booking reference
- That you are coming to the Dravet Syndrome UK weekend on 12th-15th June 2015.
- That you are coming with a child with Dravet Syndrome, a life limiting condition and is disabled
- That you have been in touch with the organiser Teresa Finch who has arranged with Linda Pike to have the location fee refunded

If anyone is coming to Centre Parcs next year and is not already on our Centre Parcs events page, please let Teresa know and she will then add you on.

4th Global Symposium for Dietary Therapies for Epilepsy and other Neurological Disorders

Matthew's Friends, the Ketogenic Dietary Therapies charity are holding an event in Liverpool in October which includes a family day. If you are interested in attending or would like to find out more information please go to www.matthewsfriends.org

Research

We are currently taking applications from professionals and hope to be announcing our research for 2014 shortly.



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Thank you

We'd like to say a huge **thank you** to everyone fundraising for us, we really appreciate it and every penny raised really does make a difference.

Finally,

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 to keep up to date with all our latest news and events.

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