Welcome to the IDEA League UK Autumn newsletter.

As always it has been a busy few months and we are excited to fill you in on our latest developments.

Once again in November we will be celebrating The IDEA League UK’s Dravet Syndrome Awareness month and we invite our members (or members families and friends) to host a coffee morning anytime in November to help us raise much needed funds for research. You can read more about our coffee morning ideas and how to get involved on page 3.

In this edition we share two very different stories on schooling and how different methods have worked for different children. And of course we have two presentations at our upcoming conference on education, covering both mainstream and further education.

We were absolutely thrilled to attend The Global Symposium on Dietary Treatments for Epilepsy, IDEA League UK Cycling Team & Dravet Syndrome awareness Month in October and more information on this can be found on page 3.

Don’t forget our UK One-day conference on Saturday 6th November. There are a small number of spaces available so please check out our website for more information or contact us at marie.b@idea-league.org.

We have information on 2 very exciting challenges coming up in 2011. Firstly the Bupa 10K run in London in May. We are thrilled to have a number of charity spaces and information on how to run for the IDEA League UK can be found on page 4. Our second event is the Northern Rock Cyclone. We are looking to recruit more members to our ‘Team Dravet’ cycling team so have a look at page 3 for more information.

And of course we have our ‘In Appreciation’ pages. This charity simply would not run without the support of our wonderful families and friends. In this issue you can read how people have run marathons, walked for miles at midnight, bungee jumped and cycled across countries - all to raise money for children affected by Dravet Syndrome and other related genetic sodium channel epilepsies.

So a big thank you for your continued support and may you have a happy and healthy run up to Christmas.

Marie, Amy, Dawn and Frances
IDEA League UK Trustees
We are delighted to be able to share with our readers two different accounts on schooling. Many thanks to Sue Perry and Annabel Hughes for sharing these stories with us.

**TOM PERRY**

By Sue Perry

Tom is 16, he has had severe epilepsy since he was 5 months old and just last year was diagnosed with Dravet syndrome. This is about Tom’s transition into residential schooling.

Tom started going to The National Centre for Young People with Epilepsy (NCYPE) a year ago this September. With the benefit of hindsight he should have gone when he went into senior school, but it is very hard to let your child (especially when they have disabilities) go to school residentially, and if it wasn’t for the educational psychologist at his previous school, telling us that it would be the best thing for Tom, because he needed the consistency of residential care, and staff that understood the intricacies of severe epilepsy, I really don’t think that we would have entertained the idea at all.

Toms’ behaviour had deteriorated badly and it had become increasingly difficult for his previous school (Bower Grove, also an excellent special needs school), to know how to best help him. This in turn meant that Tom was increasingly unhappy at school, to the point where he could only access school part time.

The only suitable school for Tom was NCYPE because they specialise in severe epilepsy, and it has worked brilliantly for Tom. He now has friends that he can be with both in and after school, carers and teaching staff that understand and encourage him, after school clubs, medical care on site and because the school, medical centre, physiology, physiotherapist and care in the house all work together, he has the consistency that he needs. This has allowed him to mature and discover a degree of independence, which he wouldn’t have at home, and I can now say that Tom is the happiest that I think he has ever been.

It wasn’t an easy decision for either my husband or I to let Tom go to a residential school, and it has been really hard getting used to him not being with us at home, but now we know that to give Tom the best chance for his future, it was definitely the right decision.

**REBECCA HUGHES**

By Annabel Hughes

Rebekah is at a delightful rural primary school. She attends school with her twin brother Henry, which is also the same school where previous generations of Rebekah’s family have attended.

The school is just 2 minutes from Rebekah’s house, which enables her to leave just before 9am giving ample time for getting ready in the morning, and when necessary she can come home easily if she needs to sleep, feels unwell or has O.T, Speech therapy appointments etc.

Being so close to the school also enables Rebekah to invite friends from school to play at her house, and in turn she can go to friends to play - as well at attending the frequent birthday party invites from her school friends. She also encounters her friends when we walk into town at the weekend, at the farmers market or just on a visit to the local park. Rebekah loves to see familiar faces around the town and calls them all ‘my friends’.

For me, as Rebekah’s mother, the close proximity of the school gives me peace of mind that I could be at the school within minutes if there was any need.

Rebekah has full time individual support while at school from Nicole (who Rebekah calls ‘Col’) and from Tracy. We are lucky that these individuals (as well as many of the other staff including the Head) have a genuine interest in furthering their knowledge of Dravet syndrome, and getting to know Rebekah.

Expectations for Rebekah are high, from both her peers and the staff. I believe that this encourages Rebekah to do her absolute best to keep up with her peers, physically & mentally and she rarely gives up – even when trying to run & chase her friends.

The school is a very old building which does not naturally lend itself to a physically safe place for Rebekah i.e. stone steps in addition to many children running fast past her etc. But the school along with our fantastic new OT Emma have helped enormously; I just wish that we had this in place from the start 2 years ago.

Being able to attend this school does entail a lot of willingness and time from the staff in order to accommodate Rebekah’s needs, from Midazolam training from the Epilepsy Nurse, to being involved in Rebekah’s O.T, Physiotherapy, diet, Speech Therapy sessions etc – I have never felt that any of this was too much for anyone at school to accommodate. It has been a battle finding support for Rebekah to compliment the schools work. We hear & read a lot about a holistic approach but have so far failed to see this – This however is very much down to the support services rather than the school.

We’ve seen some (thankfully very few) reactions from other children and parents / carers e.g. laughing and pointing at Rebekah walking difficulty, not understanding her speech, etc. This is always heartbreaking and could, and does, happen anywhere outside the school also – So to look at this positively, this is a true reflection of the larger community which she is open to. If she does notice this behaviour she chooses to ignore it, which goes beyond her 5 years of age. There is the other side to this and that is that the majority of the children at school are interested in Rebekah in a positive way, they understand that she different to them, they are ‘her friends’ and they accept and support her greatly in school.

Rebekah has learnt very quickly that people make allowances for her and she has used this to her advantage. I’ve seen her pretending that she couldn’t comply with a request or perhaps pretending she hasn’t heard/doesn’t understand, just so she can play with some toys of her choice in the classroom. The teachers and staff have got to know Rebekah well over the last two years and can now make a better judgement of when Rebekah is choosing to ‘opt out’.

Rebekah has been on a field trip today and went on coach only 2 miles away to a national trust park. She played hide-and-seek, made a den for fairies all with her friends – This all relied on the additional support for her of a separate car following in case she needed to leave earlier, medication bags etc, but how wonderful to seeing her playing with ‘her friends’ and hopefully sharing theses experiences with them for the next few years at the this school, and beyond this, as she maintains these relationships in her locally community.

Alison Cornell and Karen Grist from the NCYPE will be presenting at our one-day conference in November on both special needs further education and integration within mainstream schooling.
THE GLOBAL SYMPOSIUM ON DIETARY TREATMENTS FOR EPILEPSY

By Marie Baker

On the 5th October I headed to Edinburgh, Scotland with fellow charity trustee Frances Baker to exhibit the IDEA League UK stand at The Global Symposium on Dietary Treatments for Epilepsy. The professionals Symposium took place over 3 1/2 days and attracted professionals involved in epilepsy from all over the world.

We were delighted to be able to meet with Professor Helen Cross and Sameer Zuberi, 2 of our professional advisors from the UK. We also had the pleasure of meeting up with Dr Rima Nabbout from Paris, Dr Ingrid Scheffer from Australia and Dr Douglas Nordli from the US, all experts in the field of Dravet Syndrome.

We had the opportunity to network with a number of UK dieticians and epilepsy nurses who currently have Dravet patients on their caseload and it was very encouraging to keep hearing that the Ketogenic Diet was found to have positive results in many patients with Dravet Syndrome.

One big thing that I took away from this symposium was that Dravet Syndrome needs to be diagnosed far earlier than it has been in the past and that the Ketogenic Diet is something that should be offered as one of the first resorts - not just as the last resort!

The Saturday saw the Matthew’s Friends family conference and we were delighted to be able to meet up with one of our newer members who had come up for the meeting.

As always with these conferences it was an emotional event for many but the feeling of family was felt and we were delighted to be a part of the day.

Many thanks goes to Emma Williams, Julie Edwards and all the other supremely hard working people at Matthew’s Friends for putting on such an educational and successful symposium and family conference.

DRAVET SYNDROME AWARENESS MONTH

Coffee Mornings

For the third year running The IDEA League UK are celebrating November as Dravet Syndrome Awareness month. We are challenging all our families to help us raise a target of £2,500, which will go directly into our medical research fund. You can rest assured that every penny raised will go directly towards researching Dravet Syndrome and other related genetic sodium channel epilepsies.

We appreciate how difficult it can be to find the time (or energy) to fundraise so why not ask family, friends and colleagues to help out. And it doesn’t have to be a coffee morning - why not host a cheese and wine evening, a book club evening, an Avon party, a toddler party. Really the list is endless.

We can provide you with leaflets and posters and if you want to sell our Christmas cards at your event we can post some out to you too.

If you would like any advice or ideas on what you could do to help us achieve our target please contact Marie Baker at marie.b@idea-league.org. And don’t forget to take photos as we always love to see your events.

IDEA LEAGUE UK CYCLING TEAM

If there are any cyclists out there in the IDEA League UK “family” we would like to hear from you if you would be interested in taking part in the 2011 Northern Rock Cyclone.

The event is a 3 day festival of cycling designed for all ages and abilities set in the beautiful countryside of Northumberland.

On Saturday 25 June riders of all kinds – from amateurs and children to dedicated cyclists – take on the 33, 63 and 104 mile routes of the Northern Rock Cyclone Challenge ride (The longer two routes will take in parts of the National Elite Road Race Championships route).

The Northern Rock Cyclone Challenge is the biggest ride of its type in England. It makes the most of Northumberland’s beautiful countryside and quiet roads and features well-stocked feed stations, electronic timing, free bike checks at Newcastle’s Cyclological bike shop and a personalised certificate for every rider. To make sure everyone completes the course safely technical backup is provided by Madison, National Escort Group (NEG). Motorcycle outriders accompany participants and the route is marked out by Northumberland County Council. Photos of every rider are also available within 48 hours of the end of the ride.

As part of the weekend and taking place on Sunday, 26 June are the National Elite Road Race Championships. With national championships taking place across Europe on the same day the race attracts the very best of British riders from the international peloton with last year’s field including Emma Pooley, Nicole Cooke, Geraint Thomas and Mark Cavendish.

The 2010 entry fee was £20 for adults and we would expect it to be a similar level for 2011. Entries for 2011 open on 1 November, so if you fancy getting on your bike either to fundraise for us or perhaps just to enjoy the social aspect of the ride contact Martin Baker at martin_baker1@sky.com for further details or visit the website at www.northernrockcyclone.co.uk
CONTINUED SUCCESS FOR THE 3RD ANNUAL CHESTER CHALLENGE

by Dawn Paterson (Trustee and organiser of Chester Challenge 2010)

The Chester Challenge cycle took place on Sunday 29th August 2010 from Old Hall Country Club and Spa in Chester. What can I say - the weather was blooming awful. We were hoping for a sunny bright day and instead it was cold, wet and very windy. Not ideal riding conditions.

However that wasn’t enough to dampen the spirits and 99 riders showed up on the day and did their bit for DRAVET Syndrome and what a fantastic effort all round. So far we have managed to raise nearly £3,000 and there is still more to come in!

Special thanks to:-

-Sue Bloomberg and Donna Paterson of Old Hall Country Club who provided cookies and refreshments to all riders before and after the event.

-To all our wonderful marshalls: Diana Paterson, David and Val Paterson, Paula Norris, Jen Bramwall, Karen McKeivitt, Rita and Billy Taylor, Kelly Ludgate, and Karen Taylor /Barb Barton for helping with all the registration. We just couldn’t manage the event without their valuable support.

- Phil Spencer and Ian Kipps from Spencer Cameron Photography who followed the riders in the awful weather taking lots of photos showing varying levels of pain, anxiety, joy and relief on rider faces along the 12, 25, 60 and 80 mile routes Check them out on their website http://www.spencercameron.co.uk. 50% of all photo sales will be donated to our charity.

-S A insburys ran a promotion in store supporting the Charity over the same weekend putting buckets out at the end of tills to bump up the money raised.

It was a huge TEAM DRAVET effort all round. Thank you all so much.

BUPA 10K

LONDON

2011

The IDEA League UK are thrilled to be able to offer 9 places to people wishing to run this event, which takes place on May 30th next year (the May bank holiday weekend).

This event, which is a Virgin London Marathon Partnered Event, has only 10,000 places and takes place on the Olympic course, which of course with the Olympics being held here in 2012 makes the event even more exciting.

The event attracts many celebrities and is a great day out for the entire family.

Runners must raise a minimum of £300 for The IDEA League UK and we will supply you with a tee-shirt, sponsorship forms, a Justgiving Page and help and advice with training schedules if required.

Anyone interested in joining our ‘Team Dravet’ running team should contact Dawn Paterson at dawn.p@idea-league.org for more information.

CHRISTMAS CARDS

We’ve reached that time of year again when we need to start thinking about Christmas! We are once again selling Christmas cards and all the profit raised from the sale of these cards comes straight to the charity.

We will be selling these at the November conference but for those of you who are unable to come we can post them out to you.

Prices including p&p

1 pk - £4.50
2 pks - £8.50
3 pks - 13.50
4 pks - 17.25
5 pks - 21.00
6 pks - 25.20

Greeting inside reads “Merry Christmas and Happy New Year”

To order please post a cheque made payable to “The IDEA League UK”, with your name, address and the amount of packs you would like to:

Frances Baker
Kamona
8 Birch Way
Hailsham
East Sussex
BN27 3TS
Many thanks to Annette Wallington and Jane Fitchew who participated in the Moonlight Colourthon 10 mile walk raising £955 for us. Annette and Jane’s niece Alexis Carey, who lives in the US, suffers from Dravet Syndrome and the whole family have been a huge support to us since we set up. A massive thank you to Annette and Jane and everyone who sponsored them.

Walking for Dravet

On the 1st of October The Shamrock Bar in Bournemouth hosted a fundraising evening for The Dean Henshall Memorial Fund and McMillan Unit. The event, which was organised by Dean’s Aunt Vivienne Thompson, raised in excess of £400 - with money still coming in, half of which has been donated to Dean’s fund, which provides small grants to our families wishing to attend our annual weekend get together.

Money was raised through an auction of Everton and Manchester United memorabilia, bucket collections and a raffle.

Special thanks to Tony, who manages The Shamrock Bar and agreed to this event, Martin who is the chef at The Shamrock and agreed to having his chest wax (all in the name of charity of course) and Eddie, a customer who grew his beard and hair for 3 months and had it shaved off on the night.

Extra thanks to everyone who donated prizes, including Asda, Tesco, Alice in Wonderland Theme Park, Monkey World, Farmer Palmers, The Littledown Centre, Tower Park, The Balti House, West Point Restaurant, The Beauty Shop and all the individuals who donated wine and spirits.

Viv ensured the night was also a night for ‘Dravet awareness’ by giving out our leaflet to everyone who purchased raffle tickets.

Dean Henshall Fundraising Evening

Our thanks goes to Colin Greengrass and his running team who together raised £370 for us by running in the British 10k.

The team run every year and choose a different charity each time. We were absolutely thrilled to hear that The IDEA League UK was their chosen charity for this year.

Colin’s nephew has been diagnosed with Dravet Syndrome so this was a cause very close to the team’s heart.

British 10k

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Wedding Congratulations

Huge, huge congratulations to Jo Barfield and Daniel Beale who were married on Saturday 21st August this year.

Instead of asking for wedding gifts the generous couple asked for donations to 2 different charities, a local hospice and The IDEA League UK. And thanks to their generosity we received £160.

Jo and Daniel are good friends with one of Aimee Baker’s Auntsies so have seen first hand how much of a struggle it can be for a family affected by Dravet Syndrome.

Fabulous Fundraisers

As always we have too many people to thank so here’s just a small round up of how our supporters have been raising much needed funds for us.
TEAM DRAVET CYCLES FROM PARIS - GENEVA
By Martin Baker

September brought the IDEA League UK cycling team together for the Paris to Geneva cycle ride along with 25 others who were riding for various charities around the UK.

The team consisted of Adam Rigler (father to Harley), Alex Watts (brother to Laura), Willi Moore, Martin Baker (father to Aimee) and Keith Talbott (uncle to Aimee). We were also joined by Kyle Spiers who was raising funds for his daughter Libbie who has Dravet.

Day one was the first of four early starts as we set off to the Eiffel Tower for the official start and the first few of approximately 94 miles to Sens. Keith and Martin did three or four miles further than most, Martin missed one of the orange arrows they were supposed to be following and they got lost!

Day two, Sens to Semur en Auxois was about 84 miles and it pretty much rained all day... The evening in the hotel was spent hairdrying shoes so they would be dry for day 3!

The third day, the longest at 104 ish miles was pretty tough. The day finished with Adam, Willi and Kyle missing the hotel and going up a hill that was about two miles long and about 20% gradient, very steep at the end of 100 miles, especially when you should have been resting in the hotel!

The final day, which began with some of us tackling the huge climb for the second time, took us up into the Jura Mountains and the scenery was stunning. We climbed to about 1300 feet and a place called Saint Claude. We then climbed for about 10 miles before a couple of miles decent to Mijoux. From there the final 7 miles of climbing took us to the top of the Col de la Faucille at 4200 feet. Part of this climb has been used in the Tour De France and the sense of achievement in getting to the top was fantastic.

From the top of the Col we completed an exhilarating 10 mile decent into Geneva for champagne by Lake Geneva right in the heart of the city.

The trip was amazing, all the guys had a great time and thanks to the amazing efforts of Adam, Alex, Willi, Martin and Keith and the kind people who sponsored them, the team have raised approximately £6,000 between them. A fantastic achievement, well done and a huge thank you to you all from The IDEA League UK.

BUNGEE FOR DRAVET

On the 9th October Martin and Andrew Bleach took part in a bungee jump in Bristol to raise funds and awareness of Dravet Syndrome. Martin and Andrew’s cousin, Harley Rigler, suffers from Dravet Syndrome and so far the brave lads have raised over £150, with more still coming in.

Many thanks goes to the thrill seeking pair!

SWINGING SIXTIES FUNDRAISER

On the 30th July, a 60’s night was held at Saltburn Golf Club in North Yorkshire in aid of The IDEA League UK. The evening was organised by Jim Teasdale, a friend of Teddy Thompson’s nana, and entertainment was provided by local band The Delmounts. Guests enjoyed dancing and a pie and peas supper. The evening raised over £1,200, and in addition, Jim raised over £600 from his ‘sponsored slim’.

Many thanks goes to the thrill seeking pair!
DATES FOR YOUR DIARY

November
Dravet Syndrome Awareness Month.
Fundraising events nationwide raising money for research into Dravet Syndrome.

6th November
IDEA League UK Dravet Syndrome Professional & Family Conference, Copthorne, West Sussex.

26th March 2011
Purple Day - Nationwide fundraising events to be announced.

30th May 2011
Bupa 10K, Olympic Course, London. Contact Dawn Paterson at dawn.p@idea-league.org to find out more and book a place.

25th June 2011
Northern Rock Cyclone Event - Team Dravet participating. Contact marie.b@idea-league.org to find out more.

Summer 2011

TO BE ANNOUNCED

Bootcamp Challenge - not for the fainthearted!!!!

Summer Chillout Evening, Chester Golfclub - 2011

NO HANDS massage pamper evening, Chester - Venue to be confirmed

Patty Day - Raising money for research into Dravet Syndrome