



DRAVET
Syndrome UK

NEWSLETTER JANUARY 2013

HAPPY NEW YEAR

Very warm happy new year wishes to all our members. We sincerely hope you all had a fun filled and seizure free Christmas and New Year.

Things have been incredibly busy since our last newsletter. Of course November saw our 2nd Professional & Family Conference, which was a huge success, along with our fundraising ball which raised an amazing £6,465.49. Huge thanks to all our sponsors, in particular the main conference sponsors Emfit and the National Lottery's Big Lottery Fund and our main evening sponsor Ford & Slater. A conference update will be on our website very soon so please keep checking back.



Dr Chung, Professor Rees, Dr Hughes, Dr Brunklaus, Helen Cockerill, Dr Appleton, Dr Dravet, Dr Thomas, Professor Sisodiya and Professor Zuberi

Our AGM was held at the end of January and amongst other things our 2013 research project was agreed upon, more information on this will feature in our April Newsletter. Already this year we have exhibited at the British Paediatric Neurology Association Annual Conference reaching out to a vast number of professionals working in the field of paediatric neurology. 2013 is going to be a very busy year for us, we have lots of projects planned, new publications coming out, conferences to attend and of course some fun social gatherings too.

This newsletter is a bumper edition featuring reminders and updates on the various assistance programmes we currently run. If you feel your family would benefit from any of our programmes please do apply to us, we are here to support you and your family and to try and make life that little bit easier and nicer.

We also thought it would be nice to introduce you all properly to the Dravet UK team. The team has grown from the 4 initial founding trustees to 5 trustees and 5 committee members. Everyone works so hard behind the scenes so this newsletter provides a nice opportunity to get to know us all a little better.

As always thanks to you all for your unwavering support.

Marie
Chairperson

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Amy Thompson Treasurer

Dawn Paterson - Trustee

Emma Williams - Trustee

Galia Wilson - Trustee

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Council



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MEET THE TEAM

Dravet Syndrome UK have been registered as a charity for 4 years and thanks to our fabulous team have been able to fund research, support families and reach out to professionals in a bid to raise awareness and understanding of the condition. None of this would be possible without all the hard work of the amazing team who work tirelessly behind the scenes. We have come a long way since first setting up with just 4 trustees to now having 5 trustees and a team of 5 committee members. Every single member of the team works hard for our Dravet children and adults in an effort to improve their lives.

So let's meet this amazing team of people who dedicate their free time to improving the lives of those affected by Dravet Syndrome.



MARIE BAKER - TRUSTEE/CHAIRPERSON

Hi, I'm Marie and live in Eastbourne with 9 year old Katie and 7 year old Aimee, who was diagnosed with Dravet Syndrome at 9 months of age. Before Aimee came along I worked for East Sussex County Council in the Children's Disability team. As with most Dravet children the first couple of years were pretty awful with regards to seizure control so I ended up giving up work to enable me to stay at home (or in hospital) with Aimee. I found it very difficult to go from working to being at home all day every day so become involved in what was then known as The IDEA League in the US. I started off as a committee member and eventually joined the Executive Board. I enjoyed my time volunteering for the IDEA League but was frustrated with the lack of practical support and research opportunities within the UK.

In 2008 I met Amy Thompson and Dawn Paterson at a Chicago conference and we got chatting about setting up a UK specific charity. Things moved very quickly from that point and with the help of Frances Baker (my mother in law) we were registered as a UK charity in January 2009 with myself, Amy, Dawn and Frances as the founding trustees.

I am so incredibly proud of what we have achieved over the past 4 years from the practical aspects of funding monitors, the way we support families and put them in touch with one another to enable them to support each other and the fact that over the past 3 years we have been able to fund Dravet specific research projects in the UK to the figure of £130,000.

The past 4 years have been a massive learning curve for us all, we've made some mistakes along the way but the one thing that we always endeavour to do is to react to the needs of our membership. We are an incredibly close knit team who work really well together. I am the one at the end of the telephone and doing all the day to day bits and pieces, along with attending various conferences and working with our Professional Advisory Board on research projects. I love what I do for Dravet Syndrome UK and am excited to see how we continue to grow over the coming years.

AMY THOMPSON - TRUSTEE/TREASURER

My name is Amy Thompson and I live in Middlesbrough. I am mum to Teddy, aged 9, and Gabriel who is 8 weeks old. I work as an accountancy lecturer and I have been the treasurer of Dravet Syndrome UK since the charity began. Amongst other things, I deal with the Charities Commission and HMRC requirements on behalf of the charity.

I got involved in the formation of the charity after discussions with Marie at an International Dravet Conference in Chicago.

We were both keen to see more specific support for UK parents, like ourselves, struggling with their child's complex seizures and all of the other issues accompanying them.



I am incredibly proud of how far the charity has come in such a short period of time, and thrilled to see how much support families receive from DSUK and from each other. The fact that we are now able to fund grants for adult patients as well as original research programmes is down to all of the hard work that trustees, committee members and families do on DSUK's behalf and I am very grateful to be a part of this.

DAWN PATERSON - TRUSTEE

Hi, I am Dawn Paterson and one of the Founder Trustees of Dravet Syndrome UK. I live in Cheshire with my partner Adam, my daughter Hannah aged 9 and my son Harley aged 7 who was diagnosed with a deletion in the pore forming area of the SCN1A gene in January 2007.

Since the diagnosis, I haven't been able to return to work and have instead taken on various voluntary roles to improve my understanding and to make sure Harley gets all the support he needs. As well as charity work involvement I am a Parent Governor of Harley's special needs school, a Parent Forum volunteer and also on the steering committee of Cheshire West and Chester Parent Partnerships Service. In my spare time (and to keep my sanity) I am the U10's Assistant netball coach for my daughter's team at Chester Netball club and still play odd games for the senior team. I also bounce around doing zumba when time allows!

When my Harley was first diagnosed there was no support in the UK. Desperate to find out more, I discovered the IDEA LEAGUE international forum and travelled to Chicago and Paris where I was able to meet other parents. This is where I first met Marie Baker and Amy Thompson and I was so pleased in 2008 when Marie approached me to become a founding Trustee and get involved in setting up the Charity. I am so very proud of the achievements of the charity so far and how it has managed to bring together families, providing them with vital information through our biennial conferences, Facebook forums, offering family meet ups at Center Parcs along with regional meet ups. I am also incredibly proud of the research programmes we have funded and the close working relationship we have with our Professional Advisors.



I have had the privilege of meeting and making friends with some quite amazing, strong and inspiring families on my journey with the charity and all of us are united with one common interest to improve the outcomes for our children.

I look forward to 2013 bringing new opportunities for our charity to work with other Dravet Syndrome charities in Europe and the United States to achieve our common goals, along with amazing fundraising efforts and support from all our membership here in the UK to help us to continue research and to support our families

EMMA WILLIAMS - TRUSTEE

I am Emma Williams and am mum to Matthew (18) and Alice (16). Matthew has Dravet, he was diagnosed at the age of 14. The early years with Matthew can only be described as horrendous and it wasn't until I eventually gained access to the Ketogenic Diet that life turned around for not only Matthew but also his sister and me. Due to our experiences and Matthew's Story I set up the charity Matthew's Friends in 2004, which specialises in Ketogenic Dietary Therapies, and for the past 10 years I have worked exclusively in the field of complex, drug resistant epilepsy and Ketogenic Dietary Therapy. In 2011 we opened the Matthew's Friends Clinics alongside the charity where we provide treatment for both children and adults, as well as providing research, training and information for all those that need it. As well as Matthew's Friends, I am on the Executive Committee of the Joint Epilepsy Council, I am the Parent Representative for the Ketogenic Professional Advisory Group, International Patron of Diets for Epilepsy in India and I attend the All Party Parliamentary Group for Epilepsy as well as being a very proud member of the Trustee Board of Dravet Syndrome UK.

There was no question of me not becoming involved with Dravet Syndrome UK, it is obviously a subject very close to my heart. Since Dravet Syndrome UK has been in existence I have worked closely with Marie on several projects and the two charities complement one another as the Ketogenic diet can be such a good treatment for those with Dravet and I am always on hand to support those who want to know more about this therapy. This close working relationship means that money is not wasted, resources can be shared where appropriate and on my travels I can take DSUK information with me and we can spread the word a lot further and to more people.



I am very excited about the research projects that DSUK are funding in the hope that more can be done treatment wise and we can eventually find a cure for this awful condition. I am also looking forward to us being able to do more for adults with Dravet, after all, our children grow up and I also believe that there are many adults suffering with Dravet that haven't been diagnosed as yet and who could have their quality of life significantly improved with appropriate medication and treatment once their condition is identified. Raising awareness of Dravet is a top priority and I am very proud to be able to spread the word about Dravet and DSUK. It may be an awful condition but at least with DSUK there is support available for the families who need it. I look forward to helping the other Trustees and Committee Members to take DSUK from strength to strength.

GALIA WILSON - TRUSTEE

When my son Arlo was only 10 weeks old, on Boxing Day 2007, he had his first twenty minute long tonic clonic seizure. Then the long and often very scary journey started. Arlo continued to have regular complex partial seizures until at 5 months he had another tonic clonic seizure which lasted more than 30 minutes. For the next year and a half, he would go on to have many, many status seizures often lasting well over an hour and half. He was finally screened for SCN1a mutations at about a year but it took nearly 18 months for the results to come back positive and a further six months before he got the diagnosis of Dravet in April 2011.



One of the first things my husband and I did was to get in touch with Dravet UK and joined the facebook forum. We were also invited to attend the annual Center Parcs trip. This small holiday changed our perceptions utterly. It was a shock to see what the future might hold, but we met the most wonderful group of people who, to put it simply, just understood.

Before I had Arlo, I had a very busy job working for a large Public Relations Agency and had spent the previous 15 years working in healthcare communication, helping pharmaceutical companies with their new drugs. I had even worked on a number of anti-epileptic drugs. I had planned to return to work after having my child, but maintaining a child with Dravet Syndrome is full-time employment in itself. Given the amount of time Arlo was spending in hospital, it would have been impossible for me to return to my old work. This is why I am so excited to have the opportunity to use some of the skills I've accumulated to help raise awareness of Dravet Syndrome and Dravet UK.

FRANCES BAKER - COMMITTEE MEMBER

I first became aware of Dravet Syndrome 7 years ago when Aimee our granddaughter was diagnosed with the condition, and I first became involved with the charity about the summer of 2008, when our daughter-in-law, Marie, first started talking about setting up a Charity for Dravet Syndrome, and I feel quite privileged to have been involved right from the beginning. I became a trustee when we obtained our charity status in February 2009. I enjoyed the hard work and challenge in learning the ropes and meeting new people.

I resigned as a Trustee in the summer of 2011, but took on the role of Committee member and apart from decision making I continue to do the same work. My roles in the charity are distributing the DSUK collection boxes, buying and sending out birthday cards to all Dravet Syndrome people & their siblings under 16, sending out new member packs, Mailing the quarterly newsletters, and managing the printing of leaflets, compliment slips, business cards, and letter heads, all of which I am happy to continue doing. I have been fortunate too to have the help and support for all I do from my husband Peter.



TERESA FINCH - COMMITTEE MEMBER



Hello, I am married to Stephen and we have three wonderful children. Amy is almost 18 years old (diagnosed with Dravet Syndrome at the age of 3) and we are currently going through the dreaded transition process. We also have Ellie 15 years. who is a god send to us and I don't know what we would do without her and last but by no means least is our little boy Louie age 6 yrs.

After coping with Dravet Syndrome pretty much on our own for 16 years finding Dravet Syndrome UK has made a huge difference to us as a family but more importantly to Amy so when I was asked to take on the role as a charity committee member I was thrilled and honoured as this meant I could give something back.

For the past year I have worked organising fundraising events, everything from climbing mountains to bag packing at Sainsburys and in doing this I hope I have also raised awareness of Dravet Syndrome and the charity. This year I shall continue to organise more fundraising events some of which will give charity members a chance to get involved. Myself and Rachel Spray have also been working hard to raise money for something very special, hopefully we will be announcing just what that is soon!

I am very passionate about Dravet Syndrome UK and I am very proud to be a part if it.

ANNABEL HUGHES - COMMITTEE MEMBER

I am mum to 7 year old twins Rebekah and Henry, and we live in Norfolk along with my husband Haydn.

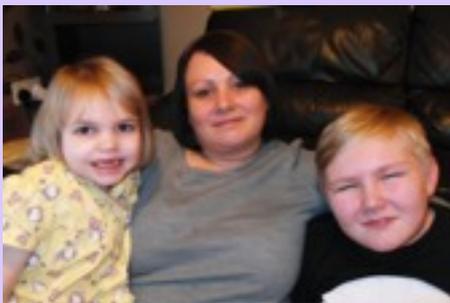
Rebekah has Dravet syndrome and has had a positive test for a mutation in her SCN1A gene. Rebekah & Henry both attend a mainstream school in Norfolk.

I attended the IDEA league (now Dravet.org) global conference in Chicago during 2007 to find out more about Dravet syndrome and to meet other Dravet families.

Since then with the UK charity being formed we have been fundraising (golf days and many other events) to raise funds for research into Dravet Syndrome, and as a family continue with this as our aim. Knowing how much research is currently going on into Dravet syndrome gives us a lot of hope.



**RACHEL SPRAY
COMMITTEE MEMBER**



My name is Rachel and I first came into contact with DSUK in 2010. I live in Derbyshire with my husband Dan, son Thomas (11) and Jessie who is 6 years old. Jessie had her first seizure at 10 months old and after many many more she was finally diagnosed with a positive SCN1A mutation in early 2010. Yes it took 4 years!! After nearly losing her several times I went on the hunt for help and advice as so little was known, and that's when I found Marie and DSUK. Marie and the charity immediately gave us a pulse oximeter which gave us such piece of mind due to her tendency to go into respiratory arrest. I knew these machines cost a lot of money so spent the next year doing little fund raising events so we could fund another monitor for another family to give them the same piece of mind and it's at this point Marie asked me if I would like to join the DSUK committee which I accepted with no hesitation.

I love being a part of DSUK and one of my main roles is sorting and organising our annual weekend away at Center Parcs, Sherwood Forest, which everyone that goes really enjoys. Spending time with other families is one of my highlights every year, I myself learnt so much and came away in 2010 with lots of info and advice, it has changed ours and Jessie's lives for the better. I am also still very active in fund raising for all aspects of the charities work but am most passionate about family support, gatherings and have a particular interest in the siblings of our members. Having Thomas is a great help to me and I know a lot of us rely on our other children a lot, they really are very special brothers and sisters.

I am so proud to be a part of this charity and will continue to work really hard for all our families. I hope I get to meet some of you at our annual break to Center Parcs this year.

SCOTT LIDDLE - COMMITTEE MEMBER

I am married to Sarah and have two children, Thomas aged four and Poppy aged two. We have recently moved back to Sheffield having lived in London for eight years. Thomas was diagnosed with the SCN1A mutation when he was two years old. Since then we have found the lifeline that is DSUK. We attended our first Professionals and Family Conference in 2010 and since then we have had a close connection with the charity. My wife and I have raised funds for DSUK from Sarah walking the West Highland Way (100 miles!!) and a running a 10k to myself running a half marathon and hosting a cake sale!

Apart from being involved with DSUK I am also chairman of Hope for Paediatric Epilepsy: London. This is a monthly activity session for families affected by Epilepsy to get together, share information and for children with Epilepsy and their siblings to have some fun.

I am also on the Advisory Board as a parent/ carer advisor for Roald Dahl's Marvellous Children's charity as well as working on occasion with Barnet and Chase Farm Hospital in London, speaking from the perspective as a parent to professionals working with children with epilepsy in education. When living in London I also campaigned to the local PCT to commission a paediatric epilepsy nurse.

I am really pleased to have the opportunity to be appointed to the DSUK committee and I hope to use my experiences and knowledge to enhance the services that DSUK offers for our families and to raise the profile of the charity and the awareness of Dravet Syndrome.



SUPER SIBLINGS

Thank you again for all of your “Super Sibling” nominations since the last newsletter. It is great to hear more stories of the amazing brothers and sisters out there in our community. As previously, all of the nominations will be carried forward and considered for the next award. Ok so let’s meet the latest “Dravet Syndrome UK Super Siblings”

Daniel Gregor Aged 9 is the Brother of Elizabeth

“Daniel was 2 ½ when Elizabeth came along and he adored her from day 1. We then moved to Holland and Elizabeth started having seizure after seizure. He spent days and nights in hospital with her, never complained, never any tantrums, just accepted everything. We then moved back to the UK and Daniel used to open the doors to the paramedics and come and hold Elizabeth’s hand. Daniel has been an absolute star, he adores Elizabeth and is so proud of her. He loves to be with her and puts up with all her tantrums!!! He misses out on a lot but he has always accepted everything. He has even at times declined friend’s sleepovers as he says Elizabeth won’t have anyone to play with if he doesn’t stay with her. We are so proud of Daniel, he’s our little superstar.” – Marie Gregor mum to Daniel and Elizabeth



Super Sibling Daniel with sister Elizabeth



Super Sibling Jade with Jimmy

Jade-Marie Barlow Aged 21 is the Sister to James (Jimmy) Ellis

“Since Jade was 7 years old when James had his first seizure her childhood changed. All through life support twice, emergency dashes to hospital at all times of the night she has never complained. At times when I hit severe depression she supported to me to help me care for James, even having to administer rectal medication to James as I was having an asthma attack. Unconditional love at all times.” – Tracy Groves mum to Jade and James

Jade loves the cinema and has a good circle of friends. She is also a budding poet, which has undoubtedly helped her to release the fears, pain and joy of living with Dravet.

I’m sure you will all agree that Daniel and Jade 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.

Please send any new “Super Sibling” nominations to:

Martin Baker at 32 Wilton Avenue, Eastbourne, East Sussex, BN22 9HZ.

Many thanks.

Martin

2013 FUNDRAISER

Following the success of the Dravet UK Ben Nevis Fundraiser last year, which raised a massive £23,500, committee member Teresa Finch is once more organising a large scale fundraiser. This year Team Dravet will be climbing the Yorkshire 3 Peaks on Saturday 14th September.

To take part in this years challenge a £60 deposit will be required, which covers the cost of the challenge & 2 nights accommodation in the Bunk House. A £30 deposit will be required for anyone wishing to organise their own accommodation. This year participants will be required to raise a minimum of £300. Anyone who would like to take part should email Teresa at teresa.f@dravet.org.uk. Sponsor packs & forms will be sent out and once we have received the deposit and signed form places will be secured. Please note there are only 20 places in the Bunk House so these will be given to the first 20 people who send their deposits with the signed form. After that participants will be required to make their own arrangements for accommodation.

This challenge is an opportunity to once more raise a large amount of money to go specifically to Dravet research. Social gatherings for Dravet families will continue to be organised as separate events.



2012 Team Dravet climb Ben Nevis

NIGHT TIME MONITORING PROGRAMME

Dravet Syndrome UK appreciate that different children/adults respond to different types of night time monitoring. We have therefore developed a scheme where our members can choose to apply for funding for 1 of 3 different types of monitor, depending on which one they feel will be most beneficial for their child and their family.

Families can choose between the following monitors:

Pulse Oximeter Machine

Pulse Oximeter Machines monitor a person's heart rate and oxygen levels. Typically when someone has a seizure their heart rate increases and their oxygen levels drop. If they are being monitored on a Pulse Oximeter Machine during a seizure and their vital signs alter the monitor will sound an alarm, informing the parents/carers who will then be able to administer emergency treatment if necessary. The pulse oximeter is attached to the patient by a sticky probe generally on the toe.

Unfortunately these machines are not routinely available on the NHS. Each machine, along with accessories, costs in the region of £800. We currently provide the 'Oxi-Pulse 30', along with all the accessories families will need.

The feedback we have received is that they can be tricky to use with very mobile patients or those with challenging behaviour.

Emfit Epilepsy Alarm

Emfit Epileptic Seizure Alarm is a state-of-the-art bed monitoring system, which monitors a sleeping person with epilepsy. It is the first alarm that detects both the person's convulsive seizures which occur in bed and the person's bed-exit with the same sensor.

New, patented sensor technology detects all of a person's movements while distinguishing normal movements from epileptic seizures. Emfit Epileptic Seizure Alarm also notices the presence and absence of a person. It alarms when the person is experiencing the convulsion phase of a seizure in progress and when the person leaves the bed and does not return within a preset time. Emfit Epileptic Seizure Alarm has an audible alarm with adjustable volume.

Once again these monitors are not available on the NHS and cost in the region of £500/600. If the Emfit monitor is requested our representative at Safety Systems UK will get in touch with the family to discuss the most suitable package for their needs.

The feedback we have received is that these monitors can take a while to set up for each individual patient and that they do not alert to the non-convulsive types of seizures that most Dravet patients experience

Summer Baby Touch Digital Video Monitor

The Baby Touch Colour Digital Video Monitor is the first ever touchscreen controlled baby monitor, making it the most innovative video monitor available on the market today. Features such as remote pan, scan and zoom are easily controlled through the large, intuitive and stunning 9cm colour LCD screen. The stylish magnetic recharging base for the handheld unit and battery pack for the camera make this monitor aesthetically pleasing and highly portable.

This monitor will not alert to seizures and is just a high quality video monitor. It costs in the region of £130 and the feedback we have received is that it has given families peace of mind, particularly for those who can not get along with other forms of monitoring.

As with all our assistance programmes the Night-Time Monitoring Programme is not means tested but families will have to provide a copy of a letter from a consultant or neurologist confirming their child's diagnosis. Families can only apply for one type of monitoring system only and applications will be considered at all times.

Application Details:

To apply for one of our monitors please download the application form from the 'Supporting Families' page on our website - www.dravet.org.uk or to further discuss the options please contact us by email to marie.b@dravet.org.uk or call us on 07775 347234.

CENTER PARCS 2013

Once more Dravet Syndrome UK are organising a family weekend away at the Sherwood Forest Center Parcs in Nottingham. Dates for this year are 3 nights from Friday 7th June and as always it will be a packed weekend with family activities, a siblings' activity, mum's night, dad's night and grandparents' get together. For details on how to book please contact committee member Rachel Spray at rachel.s@dravet.org.uk. We are delighted to be able to offer all our families a grant of £150 towards the cost of the break thanks to The Dean Henshall Memorial Fund.



Center Parcs 2012

ADULT ASSISTANCE FUND

Dravet Syndrome UK are delighted to be in a position to operate an adult assistance fund, which is open to any Dravet Syndrome UK member aged over 16. It is often very difficult for adults diagnosed with Dravet Syndrome to access grants as many charities have a cut off point of 16 years. Families are invited to apply to the fund for up to approximately £1,000 a year for anything they feel will enrich or improve the life of their young adult. This is a rolling programme so applications will be considered at any time and families can apply once every 12 months. All applications will be considered on an individual basis.

Examples of things already funded include I pads, a wheelchair swing, part-time placement at an independent living scheme, a week's holiday with a carer and laptops.

As with all the programmes run by Dravet Syndrome UK, the adult assistance fund is not means tested, all we require is a letter from a professional confirming diagnosis.

Application details:

To make an application to the adult assistance fund please download the application form from the 'Supporting Families' page on our website - www.dravet.org.uk or to further discuss an application please contact us by email to marie.b@dravet.org.uk or call us on 07775 347234.

THE XL CHALLENGE

2013 is the year of David McGarry's XL Challenge. In David's words "As I turn 40, I find myself wanting to mark the occasion by doing something special and out of the ordinary - and this fits the bill! In all honesty, I intended to raise some funds for Dravet Syndrome UK this year by completing my first marathon and I thought that would be that. My plans spiraled however and became the monster that is The XL Challenge and after mentioning it to a couple of people, I found that I couldn't really get out of the things my big mouth had promised".

David will be completing 40 challenges to mark his 40th year and the statistic that Dravet Syndrome affects approximately 1 in 40,000 people.

David has a great website where people can vote for the challenges they would like him to take part in so please get involved by following his website at www.thexlchallenge.com or follow him on Twitter @theXLchallenge or on Facebook at www.facebook.com/TheXLChallenge



DRAVET DAD'S LEAP OF FAITH

On the 4th of May Ian Kirwan, Dad to 5 year old George with Dravet Syndrome, will be taking part in a 10,000 foot parachute jump along with colleague Nikki Dennis to raise money for Dravet Syndrome UK.

In an effort to raise as much money as possible Ian and Nikki have already raised £140.00 through baking and selling cakes at Ford & Slater, who have been a great support to us in the past.

Ian and Nikki have a joint Justgiving page for donations www.justgiving.com/ian-kirwan

DRAVET FAMILY CHRISTMAS PARTY

Dravet Syndrome UK are absolutely delighted to announce that this year will see the first Dravet family Christmas Party. The party will be held on Sunday 22nd December at The Park Royal Hotel in Warrington, Cheshire. Further information will be sent out via email very shortly but please do save the date. The party is being organised by committee members Rachel Spray and Teresa Finch and they have some amazing plans and very exciting surprises up their sleeves.

DRAVET SYNDROME UK ONLINE

Don't forget to keep updated by regularly visiting our website

www.dravet.org.uk

You can also find us on Twitter and Facebook

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