



## NEWSLETTER APRIL 2013

### CHARITY UPDATES

#### CONTENTS

2 - SUPER SIBLINGS

3 - PURPLE DAY

4 - UPDATES

#### BOARD OF TRUSTEES

Marie Baker - Chairperson

Amy Thompson Treasurer

Dawn Paterson - Trustee

Emma Williams - Trustee

Galia Wilson - Trustee

Rachel Moran - Trustee

#### CONTACT DETAILS

PO Box 3180

Eastbourne BN21 9PP

07775 347234

[www.dravet.org.uk](http://www.dravet.org.uk)

[marie.b@dravet.org.uk](mailto:marie.b@dravet.org.uk)

Members of The Joint Epilepsy  
Council



Proudly supported by Roald Dahl's  
Marvellous Children's Charity



It's been a really busy few months for everyone involved with Dravet Syndrome UK and the next few months are going to be even busier.

We are delighted that the Joint Epilepsy Council accepted our proposal for the theme for this year's National Epilepsy Week. The theme for the week, which runs from the 19th - 26th May will be 'The Many Faces of Epilepsy'. Having this theme gives our children and adults, with a more complex epilepsy syndrome, the voice they deserve and so very often miss out on. We are also delighted to announce that we have joined Genetic Alliance UK. Genetic Alliance UK is a national charity of over 150 patient organisations, supporting all those affected by genetic conditions. As with the Joint Epilepsy Council, working with these umbrella bodies gives us a much louder voice and greater opportunities to work towards a common goal, of improving lives for patients and their families.

Back in February we welcomed a new trustee onto the Board. You can read more about Rachel on page 4 and what she brings to the charity.

Final approval has now been given for the joint research project that is to be funded by ourselves and Epilepsy Action. The project, which will be looking into cardiac rhythm in Dravet Syndrome and any possible links to SUDEP, will be managed by our Professional Advisor Professor Sanjay Sisodiya and we will be announcing full details in our summer newsletter. Huge thanks must go to Committee Member Annabel Hughes and her family as they raised the vast majority of the £20,000 needed for our contribution to this project.

We have been very busy working on a brand new resource for our families and will be launching our 'Family Guide to Dravet Syndrome' to coincide with National Epilepsy Week (hopefully). We have been extremely lucky to have Edelman, an International PR Company, working with us on this project. Edelman offered their services to us, free of charge, and we have been incredibly fortunate to have a fantastic team helping us with the family guide, as well as helping to generate some media interest surrounding National Epilepsy Week.

We will also be launching our new, improved website during National Epilepsy Week. Huge thanks to Anytime After 9 for all their hard work on this. It will be a great resource for families and once it's launched please do keep checking back for updates and information.

With lots of exciting things coming up over the next few months it just leaves me to say thank you to all the Dravet Trustees and Committee Members for all their continued hard work. Also thanks to all our families, fundraisers and supporters. The charity continues going from strength to strength and we are all extremely excited about what the future holds.

Marie Baker  
Chairperson/Trustee

## SUPER SIBLINGS

By Martin Baker

Once again 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 who are the latest “Dravet Syndrome UK Super Siblings”

### THOMAS SPRAY

Thomas is 11 years old and the best big brother ever to Jessie. He was 5 years old when she had her first seizure and from that moment on he has been a star calling 999, standing at the front door to direct ambulance crews and now he's older helping with care and medications.

Even when she's battering him over the head with the tv remotes or biting him he never gets angry or upset he remains caring towards her and tries to calm her down.

Tom loves music particularly rock and heavy metal and he is a very keen drummer. He has lessons every week and has just recently passed his grade 5 exam with distinction. He also, like most boys his age, loves his playstation.



*Thomas & Jessie Spray*

We are so proud of Tom for winning this award as he has been struggling with Dravet life in general lately, but we know he will always be there for his sister with a lot of patience and love.

Thank you DSUK for this wonderful recognition of our superstar Thomas



*Louie & sister Amy*

### LOUIE FINCH

“Louie is only 7 years old yet every time his big sister Amy has a seizure he takes it upon himself to fetch a pillow and a blanket for Amy and stays with her, strokes her head and tells her how brave she is.

Louie does all of these little things for Amy despite sometimes being scared of her seizures. Despite all the parties, days out and treats Louie has missed and all the days he has had no attention due to Amy's seizures he never complains. Louie spends so much time with Amy, playing together, watching tv, he is not only her little brother but also her friend” – Teresa Finch Mum to Louie, Ellie and Amy.

Wow, what amazing brothers, I'm sure you will all agree that Thomas and Louie really are “Super Siblings” and their 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.

Please keep the nominations coming in, it is amazing to hear of the wonderful brothers and sisters and reading all of the nominations has been truly inspirational. 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 on the enclosed form to Martin Baker at Dravet Syndrome UK, PO Box 3180, Eastbourne, BN21 9PP

Many thanks

Martin

### PURPLE POWER

The 26th March saw people all over the world coming together to raise awareness of epilepsy either by wearing purple or by holding events raising money for local epilepsy groups. Over the years Purple Day, which was the brainchild of Cassidy Megan from Canada, has become bigger and bigger and now it has become THE day for acknowledging epilepsy and those who suffer from it.



At Dravet Syndrome UK we were extremely lucky to have some of our members holding events for us. Fiona Fewings got together with some friends and Newton Abbot Leisure Centre to ‘Push the limit for Purple Day’. Fiona and friends took part in 9 back to back fitness sessions including body combat, Zumba, swimming and cardio circuits. As well as raising a lot of awareness through local publicity Fiona and her team raised an outstanding £887.20, which is amazing considering that Fiona’s initial target was £250!!!! Huge thanks to Fiona and everyone who took part or supported the event.

The Perry family also got involved with Purple Day and through 2 separate events raised a wonderful £700. Sue and Adrian’s local church, The Staplehurst Free Church, held a coffee morning on Purple Day raising £350 and then the following Friday a pizza day was held at local farm shop Frankies, raising another £350. Massive thanks to Sue, Adrian and Tom for all their hard work organising these events and to everyone who came along to support, join in and donate.



*Tom Perry*



Fitness was the subject of another Purple Day event for Dravet UK thanks to family member Lynne Reid. Lynne, who regularly attends a local fitness class, was delighted when her friend suggested that on Purple Day everyone came along wearing purple and donating to Dravet Syndrome UK. Thanks to everyone’s generosity £105.50 was raised.

All money raised through Purple Day goes directly into the Dravet Syndrome UK Research Fund. To date Dravet Syndrome UK has committed over £130,000 to research and is currently involved in 3 active research projects, alongside providing funding for a research administrator,

Nest year we plan to make Purple Day a big event for Dravet Syndrome UK so watch out early next year for ways to get involved and thanks to everyone who was involved in this year’s day, either through fundraising or wearing purple to raise awareness of epilepsy and Dravet Syndrome.



*Daisy & Jake Reay-Vernon*

## DRAVET SYNDROME UK ANNOUNCE NEW TRUSTEE

Since the charity began all the trustees agreed how beneficial it would be to have a trustee on the Board who, although has a sound knowledge of the condition, is not an actual parent of a Dravet child/adult. This would bring a new dimension and perspective to the decisions being made at the heart of the charity and therefore, it gives us great pleasure to announce our new trustee Rachel.

'My name is Rachel Moran, I'm married to Dave and have three children aged 18, 13 and 4, one of which has Aspergers Syndrome. I met Marie Baker at a local special needs group and we became friends and through this friendship I have learnt a lot about Dravet Syndrome and the effect it has on the families. I spend a lot of time with Marie and Aimee and I'm learning more everyday.

Before giving up work to look after my daughter I was a teacher in a Further Education College. I now teach companies and personal assistants both online and face to face in the areas required to meet the needs of special needs children and adults. After we received the diagnosis of Autism I quickly realised the lack of support in the community for parents and set up a charity called 'Special Parents' to support families of children with special needs. I grew the charity for four years before resigning in 2013.

I am proud to be a trustee for Dravet Syndrome UK and look forward to working with the other trustees and committee to raise awareness of the condition and to help support families'



*Trustee - Rachel Moran*

## STL - CHARITY OF THE YEAR

Last April we were contacted by Simon Tucker who owns STL, an East Sussex based firm of surveyors. Simon and his wife Caroline knew of Dravet Syndrome UK as they have been family friends of Chairperson Marie Baker for many years. STL adopted Dravet Syndrome UK as their charity of the year and we are delighted to announce that the grand total donated over the past year is a fantastic £2,359. They kicked off their year by purchasing a Pulse Oximeter Machine for one of our families and then, as well as monthly donations, held raffles and donated winnings from sweep stakes and their lottery syndicate. As well as raising an amazing amount for the charity they have also helped to raise awareness of Dravet Syndrome by including our logo and web address on all correspondence and by regular Twitter mentions.

Thank you to everyone at STL, in particular Rory Dunstall who coordinated the events.

## THE PIRATES

### Sponsor Dravet Syndrome UK

Massive thanks to Horwich St Mary's Football Club, also known as The Pirates, for sponsoring Dravet Syndrome UK last season. The Pirates sported the Dravet UK logo on their kit and on the back of their jackets and raised a phenomenal £373.75.

Katherine Patel, who works with the team, is Auntie to Luke Philbin who lives in Australia and is diagnosed with Dravet Syndrome.



*The Pirates*