



Our new-look, updated website is live!

In November 2019 we launched our updated, new-look website, www.dravet.org.uk.

The new website includes an expanded '[About Dravet Syndrome](#)' section with comprehensive information about seizures, co-morbidities, latest treatment options and transitioning to adulthood.

We have of course retained all the good stuff you are used to seeing on our previous website. For example, the 'For Families' section has information about our events, such as the Center Parcs weekend and our Parent/Carer Conference. Under '[Apply for Grants](#)', you can find detailed information about financial assistance with seizure monitors, transitioning to adulthood, bereavement and meet ups with other families.

There's a '[Dravet Stories](#)' section, with real life insights into living with Dravet Syndrome shared by our amazing community of families. If you would be happy to share your story in this section of our website, please do get in touch (see our contact details on page 2).

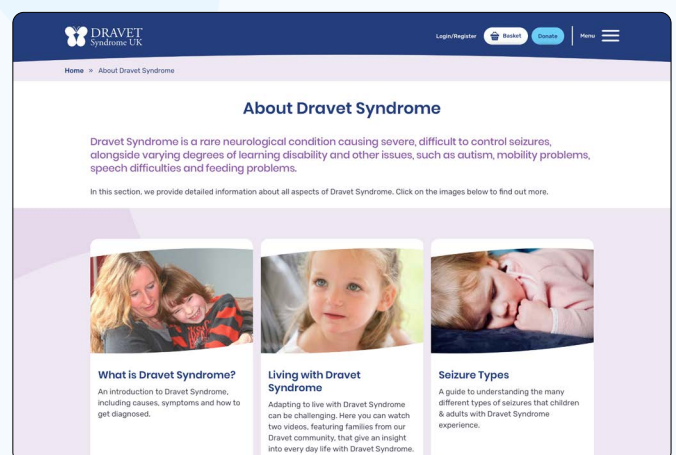
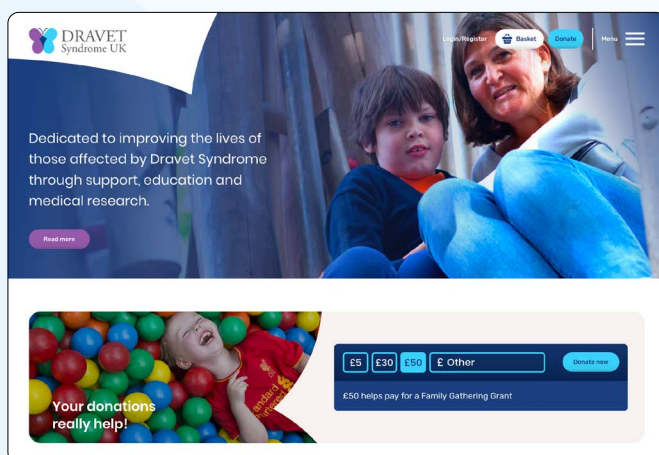
Under '[Helpful Resources](#)' you can find our leaflets and guides.

Under '[Fundraise](#)', we've gathered together ideas, tips for success and detailed resources to help support your fundraising events. We also have our expanded and updated 'Shop' and information about all the different ways you can '[Make a Donation](#)' to DSUK.

As before, there's also a section of the website dedicated to '[Healthcare Professionals](#)', with information and useful resources to help further knowledge and understanding about Dravet Syndrome.

We'll continue to add updates and new information to our website throughout the year, so do look out for these. Your feedback is important to us, so if you haven't already, please check out the new www.dravet.org.uk and let us know what you think!

Note: If you previously registered with us, you will need to reset your password on your first visit to the website (just click on the 'forgotten password' button).



Thank you card competition

We are running a competition to find a new design for the thank you cards that we send to our wonderful supporters.

See **Page 10** for details on how to enter



What is the Center Parcs weekend about and who is it for?

The Family Weekend away to Center Parcs is our annual event, bringing together families living with Dravet Syndrome for an amazing weekend of fun and community support.

It offers time out for parents to meet, unwind and talk with others who really understand what living with Dravet Syndrome means, sharing experiences and knowledge.

Siblings also have a chance to meet, chat and have fun with other youngsters who are in exactly the same position. And of course, each weekend includes lots of events and activities for our Dravet adults and children.

We know it can feel daunting to book Center Parcs for the first time. It's a very friendly and welcoming environment, with plenty of time to relax with your family as well as join in activities, and because everyone there is part of a family living with Dravet Syndrome, everyone is in the same situation.

Whether it's your first time to our Family Weekend or you've been with us since the beginning, we would really love you to join us!



Contact Us



We love hearing from you, whichever way you choose to contact us!

Please share your stories, photos and fundraising successes using any of the methods below.

Phone:
You can call us on **01246 912 421**

Post:
Some people still like to write to us. Our address is:
Dravet Syndrome UK
PO Box 756, Chesterfield, S43 9EB

Email:
Most people like to contact us by email because it's quicker. Send to: **info@dravet.org.uk**

Social Media:
Why not send us a message via Facebook or Twitter?
f Facebook: **Dravet Syndrome UK**
t Twitter: **@dravetUK**
You can find us on:
in LinkedIn: **linkedin.com/company/10990437**
yt YouTube: **DravetSyndromeUK**
ig Instagram: **dravetsyndromeuk**

Get Ready for Center Parcs 2020

Announcing a £300 grant for families joining our 10th weekend away

We're excited to confirm the dates for our annual Center Parcs weekend, which will take place from Friday 19th to Monday 22nd June 2020 at the gorgeous Sherwood Forest venue.

We are delighted to be able to offer a Center Parcs grant of £300 to every registered family who wants to join us for this very special weekend. Each year the size of our grant is determined by the amount fundraised. This year, we're really pleased to be able to offer £300 due to the continued support of our inspirational fundraising community and the generosity of our sponsors XTX Markets.

This year is also rather special as it is DSUK's 10th year at Center Parcs and we are very much looking forward to celebrating this anniversary with you all.

The weekend kicks off on Friday afternoon with a 'Meet and Greet for Families'. We will host a fun-filled siblings activity on Saturday and we are thrilled to announce that we will be able to once again hold a party for everyone attending on Sunday afternoon.

Thank you to GW Pharma for their generosity in providing an unrestricted grant, which funding the party and costs for a photographer and paramedic support.

We'll share more information about these events soon, but can reveal that **the theme for this year's party is 'Dravet Superheroes'**. We hope this gives everyone plenty of time to think about their superhero costumes!

How to book

Center Parcs has kindly agreed to waive or refund the extra (£50) fee that is usually added for booking accommodation in a centrally-located lodge. This is a special refund agreed only for guests attending our family weekend to provide easier access to central areas, including the medical support lodge.

There are two ways to ensure your booking includes this waiver or refund.

The easiest way is to book your accommodation through the Center Parcs contact centre (call **03448 267 723**). Let the agent know you are attending the Dravet Weekend at Sherwood Forest & they should offer the central accommodation as part of the booking process, without the extra charge.

If you book online, you will need to pay the upfront fee for a central lodge, and then subsequently obtain a refund by sending a separate email to **pre-arrivals.services@centerparcs.co.uk**. You will need to explain that you have a booking as part of the Dravet Weekend at Sherwood and provide your booking reference number. The refund adjustment will be made manually by Center Parcs.

Once you have booked your accommodation, you can apply for a Center Parcs Grant via our website by clicking on this link: **<https://www.dravet.org.uk/apply-for-grants/center-parcs-grant/>**. You will need to upload a copy of your Center Parcs booking confirmation as part of the application process.



Conference report - DSUK London 2019

In mid-November, we held our fourth DSUK conference, at the Tower Hotel in London. Hosted once every two years, it is the only scientific meeting in the UK that is dedicated to furthering knowledge about Dravet Syndrome.

The DSUK Conference comprises a Professional Day and a Parent/Carer Day, bringing a packed agenda of leading voices in Dravet Syndrome to enable discussion of the latest updates, news and medical research.

This year we were delighted to bring together more than 80 professionals

and 170 parents and carers from across the UK.

Speakers included our Professional Advisory board, including Professor Helen Cross, Professor Sameer Zuberi, Dr Elaine Hughes, Professor Sanjay Sisodiya and Epilepsy Nurse Specialist, Neil Williamson, and guest speakers, including Dr Andreas Brunklaus, Professor Paul Gringras, Professor Rima Nababout, SUDEP Action CEO Jane Hanna, and Stephanie Smith, who gave a powerful presentation to healthcare professionals on life as a Dravet parent.

We'd like to thank all our conference speakers, everyone who attended and helped on the day for making the London 2019 conference one of our best yet. We look forward to welcoming even more of you to DSUK 2021.

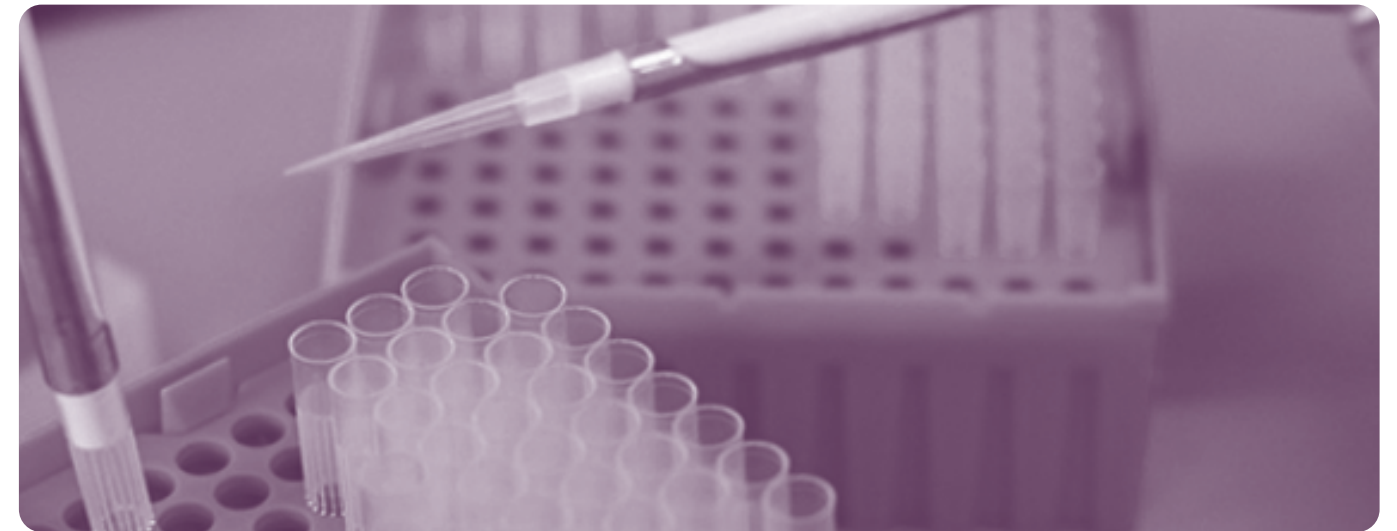
We really appreciate the time attendees made to complete our

feedback forms. We'll be taking all this feedback into account in the planning of our next Conference, in particular, we'll be looking to incorporate more sessions on Dravet Syndrome in adulthood.

Whilst it was wonderful to bring so many of our Dravet community together, we know there were also lots of people who weren't able to attend. With this in mind, we are sharing as much as possible from the conference on our website. Visit the 'Parent/Carer Conference' pages to find more information, including speaker slides and video interviews that we filmed with our conference speakers, specifically for sharing on the website.



Encouraging times for the treatment of Dravet Syndrome



In 2019, we saw real progress in the development and availability of new treatments for Dravet Syndrome.

Epidyolex (cannabidiol)

In December, Epidyolex was approved by the NHS for people with Dravet Syndrome (aged 2 years or older, in conjunction with clobazam). Whilst Epidyolex may not be suitable for all Dravet individuals, and responses to the treatment vary, it's a wonderful step forward to have a new treatment option available that offers hope to Dravet families searching for better seizure control, and we were pleased to see this recognised by NICE (the body that decides which treatments should be available free of charge via NHS).

Fenfluramine

The next new treatment likely to be approved for Dravet Syndrome is fenfluramine. Results from two clinical studies are now published in major scientific journals, The Lancet and JAMA. Both studies show that fenfluramine significantly decreased the number of seizures experienced by Dravet individuals, who previously had poor seizure control. Although it's likely to be some months before fenfluramine is approved and available in the UK, it's very exciting to have another potential treatment on the horizon that may improve seizure control in Dravet Syndrome.

Other treatment developments

In 2019, we also saw several important advances in genetic or gene therapy as a future approach to treating Dravet Syndrome. Dravet Syndrome is a genetic condition, caused by a particular gene change in a part of the brain known as the sodium ion channel. Scientists are discovering that by intervening to 'fix' that specific gene change, they may be able to treat the underlying causes of Dravet Syndrome.

Several studies are currently underway, trialling different genetic or gene therapy treatments. While these new studies will take around 2-3 years to complete, and they might not all be successful, this research could lead to significant treatment breakthroughs, opening up the future possibility of a cure for Dravet Syndrome.



There is more information about the latest treatments in Dravet Syndrome, on our website, including a series of video interviews that we filmed in November with Professor Helen Cross. Visit the '[New and Emerging Treatments](#)' page to hear Professor Cross discuss Epidyolex, the differences between cannabidiol and CBD oil, what we might expect from fenfluramine, and how new therapies may affect the future treatment of Dravet Syndrome.





DSUK Seizure Monitor Fund

Using a seizure monitoring device (e.g. night-time monitoring) may help reduce the risks of SUDEP. Providing free night-time monitors is one of the ways in which we support families living with Dravet Syndrome. Visit the '[Seizure Monitor Fund](#)' section of our website for more information.



DSUK Research Fund

The DSUK research fund receives at least 10% of our yearly income, in addition to specific donations and fundraising from our supporters. In 2019, two grants were awarded to support further research in gene therapy and genetics.

UCL Institute of Neurology

Our first research grant was awarded to the UCL Institute of Neurology for a project to advance gene therapy for Dravet Syndrome. Their aim is to try find out if it is possible to fix the mutation in the SCN1A gene in mice, by injecting them with a gene therapy aimed at increasing the healthy expression of the SCN1A gene. Findings could help pave the way for future gene therapies that target the underlying causes of Dravet in humans.

The Genetic Epilepsy Service

Our second research grant was awarded to the The Genetic Epilepsy service based at the Royal Hospital for Children in Glasgow, to fund a database manager to oversee a research database for SCN1A and childhood developmental and epileptic encephalopathy. Since 2013, DSUK has funded the hire of a database manager, who has been working with colleagues to build and develop a research database on childhood onset epilepsies, containing both genetic data and phenotype information. So far, the database has found more than 700 variants of SCN1A variants has found that Dravet Syndrome is much more common than previously thought.



Talking about SUDEP

In October, we ran a social media campaign to raise awareness of the risks of SUDEP (Sudden Unexpected Death in Epilepsy) in Dravet Syndrome, in support of SUDEP Action's annual awareness day on 23rd October.

The risk of SUDEP in Dravet Syndrome is up to 15 times higher than other childhood-onset epilepsies. It's the biggest cause of death in Dravet Syndrome, responsible for nearly half of all DS deaths. Sadly, SUDEP tends to occur at a younger age (73% before the age of 11) than in other epilepsies.

The good news is that there are things we can do to help reduce the risks of SUDEP. Talking about SUDEP with your medical team is an important step in working towards finding the best treatment and seizure control plan for your Dravet child or adult.

Medical teams can find it hard to talk about the risks of SUDEP. As several families have told us, sometimes SUDEP isn't discussed at all. Yet most families say they do want an informed discussion about SUDEP. If you have SUDEP concerns, but have never raised these with your medical team, now could be the time to ask. Before your next appointment, make a list of questions. For example, you might want to ask - What are the risks of SUDEP for my child? What are the options for working together to reduce these risks? What can we do through medication? What could we do through diet or other treatment strategies? What can we do at home?

For more information about SUDEP, please visit the [SUDEP Action website](#), which has a range of helpful resources for both families and healthcare professionals.

If you've been impacted in anyway by SUDEP, please know specialist and experienced support is available from [SUDEP Action](#) or [Child Bereavement UK](#).

We send our thoughts and love to all who have lost a loved one through SUDEP.



Super Siblings – Our 2019 Awards

Recognising inspirational bravery and selflessness

Many parents often speak about the many, amazing little things that these brothers and sisters do for everyone in the family and how they could not manage without their super siblings. Unfortunately, the demands of everyday life means that siblings don't always get the recognition they deserve. Our annual Super Sibling award is for these young, unsung heroes of the Dravet family.

We're delighted to announce the names of our 2019 Super Siblings, who all received a teddy bear, gift, and of course an official Super Siblings certificate. Huge congratulations go (in no particular order) to:

Teddy & Ruby Podmore
Zac Freeston
Kodi, Olly & Aston Daly
Lilly Susan Thorogood
Ella Smith
Betsy-Rose Simmons
Lacey Anderson
Ryan Dickinson
Elle Campbell
Ilieah & Kynen Davies
Oli Penswick
Nyla Clark
Poppy Liddle
Beatrice & Arthur Williams

We're so impressed by the wonderful stories shared by your proud parents & families - you are all SUPER!!



Don't forget there are specialist sibling support groups, such as the organisation [Sibs](#), which provides useful information and support for siblings of disabled children, and for parents too. Visit the 'Super Siblings' section of our website for more information.

Making Christmas Special for Dravet Adults

How your fundraising makes a difference

The DSUK 16+ Assistance Fund is made possible through the support and generosity of our fundraisers and donors. During 2019, we were able to provide 16+ grants for 13 adults with Dravet Syndrome.

Thanks to the fund, Christmas was made extra-special this year for two young Dravet adults, Becky and Harvey.

Harvey's mum, Alison applied for a new iPad and keyboard. She told us: *"He's delighted with it! We gave it to him as a Christmas present from DSUK. We thank you so much and he says 'thank you' too".*

Becky's mum, Allie applied for the grant for a new bed and wardrobe - part of a big bedroom makeover surprise for her daughter.

Allie told us: *"Wow, what can I say apart from a huge thank you for helping me make Becky's Christmas surprise perfect. It was reveals on Christmas Eve, her smile says it all! The Dravet Monster unfortunately paid a visit on Christmas Eve and being able to lay next to her while she recovered because of your grant enabling her to have a 'grown up' bed made such a difference. No more sitting on the floor next to a single bed. She loves her wardrobe too!"*



The fund is available for families living with one or more adults with Dravet Syndrome, who are aged 16 and over. Any items of equipment or assistance that will improve the life of the adult with Dravet syndrome will be considered. Families can apply for one item or one project (which may require several items). The limit on each application is usually up to £1000 per year per Dravet adult. Visit the 'Apply for Grants' section of our website for more details.

Thank you to our all our fundraisers and supporters for helping us make these positive differences to young Dravet adults like Harvey and Becky and their families.



Singing our socks off in Trafalgar Square



Back by popular demand, our Christmas Carols fundraiser returned in December 2019. Despite the chilly weather, we had a great turn out in London's Trafalgar Square, with fantastic support from the Barnet Volunteer Police Cadets.

Many thanks to Galia Wilson for organising the return of our favourite Christmastime event' and to Victoria Mirauer for both arranging the festivities and conducting the wonderful Crib Notes Choir, who were in their finest carol-singing form.

We raised over £1,000 on the night and we would like to thank everyone who came to sing and help us collect on the night.

Fundraising in 2020



Each year we need to raise over £250,000 to keep providing our much needed services. We could not survive without the fundraising efforts of our amazing supporters.

There are so many ways to raise awareness and donations for DSUK. If you're looking for inspiration, check the 'Fundraise' section of our website. There's plenty of ideas and information to set you on your way.

Regular donations also make a huge difference to our fundraising. An easy way to do this is to set up a monthly standing order. Or you may want to consider leaving a legacy gift to our charity in a will. Visit the 'Make a Donation' page for details how the different ways to donate directly to DSUK.

Every one of your donations truly does make a difference. For example, £1,000 pays for a Pulse Oximeter Package for one family, £250 pays for an epilepsy mattress monitor (MedPage Monitor) for one family and £200 pays for a video monitor for one family. These monitors help save lives and we are committed to providing them without a waiting list for any Dravet family that applies.



Thank you card competition

We are running a competition to find a new design for the thank you cards that we send to our wonderful supporters.

We feel what better way to say 'thank you' than with a card designed by our very own Dravet children, adults and siblings?

Once we have received all your artwork, we will select three designs for our new cards - one from a Dravet child under 16, one from a Dravet adult (aged 16 or older) and one from our wonderful siblings.

We will leave the format and topic of these masterpieces up to the brilliant artists. They could be butterflies like our logo, hand prints, self portraits, or more - wherever the imagination takes them!

How to submit your pictures.

We will need pictures to be submitted in square format as large as possible above 150mm, this way we can edit and crop as necessary without losing any definition. Please do not fold the artwork when you post them, as the pictures won't be suitable to print if creased. Pictures can be posted to **Dravet Syndrome UK, PO Box 756, Chesterfield, S43 9EB**. If you would like the picture to be returned please do include a stamped addressed envelope for us to return it.

The deadline for picture to be sent is 1st March 2020

Thank you and we can't wait to see the resulting artwork!



Join Team Dravet

If you're looking for a way to keep fit in 2020 and fundraise for a good cause, we have the ideal solution - **join Team Dravet** for either the **Great North Run** (on 13th Sept) or **London's Royal Parks Half Marathon** (on 11th Oct).

You can secure a place for £55 today, when you pledge to fundraise £400 for Dravet Syndrome UK. We would be thrilled to welcome you to the team!

There's limited places available so don't delay. Visit the 'Shop' section of our website to purchase your race token. Once you have purchased your token a member of our team will be in touch to arrange your fundraising pack and running vest.





Perspectives from a family newly-diagnosed with Dravet Syndrome



In 2019, the number of families living with Dravet Syndrome that DSUK supports grew to over 500. The Podmore family joined us in August 2019, shortly after 20-month year old Penelope was diagnosed with Dravet Syndrome. Carrie Podmore, Penelope's mum, tells us about the family's Dravet journey so far and how support from DSUK has helped to make a difference.

Penelope Podmore was born on the 22nd December 2017. It was a very normal delivery and Penny was a happy healthy baby. Adam and I couldn't wait to take her home to meet her two older siblings, Ruby and Teddy, and enjoy our new addition to the family.

The Dravet journey begins

Exactly six months later, on the 22nd June 2018, I witnessed Penny's first seizure. At first sight, it wasn't obvious. I had never seen a seizure before and my first thoughts, with her being so young, was that she was having some sort of heart problem. We called an ambulance and the seizure stopped just as the paramedics arrived. It was 13 minutes long. She had a slight fever (37.8). Having two older children, I wouldn't have batted an eyelid at that figure. She gave no signs of viral illness and ate well all day.

We went to Sheffield Children's Hospital where she was checked over and we were discharged. It was thought Penny had a febrile seizure and that she had tonsillitis. However, it was a warm day and so, knowing what we know now about Dravet, we think this was probably most likely to be the trigger. On that day, our Dravet journey began.

Diagnosing Dravet Syndrome

A few days later we were back up at the hospital. She was having focal seizures in clusters. I started to flit around the internet to see what I could find. I found Dravet Syndrome and was devastated. I knew this was what Penny had. She ticked all the boxes.

In November 2018, Penny suffered a particularly tough seizure. She was intubated and placed in intensive care for the first time (unfortunately not the last). At this point the consultant agreed to a genetic test for the SCN1A gene. In August 2019, the results came back positive - Penny has a SCN1A mutation.

Joining DSUK

Although this confirmation of what we already suspected was difficult, it also made things a lot easier. With the letter of diagnosis, we were able to join DSUK (I had looked at their website time and time again before the diagnosis) and gain access to the wealth of knowledge available via the Facebook Parents and Carers Forum.

DSUK provided us with a grant from their Seizure Monitor Fund for a Pulse Oximeter, which monitors Penny's heart rate and oxygen levels and alerts us to potential seizures.

In November 2019, we attended the DSUK Conference in London. We left the day feeling very positive, as it became apparent that there are professionals fighting to get a better understanding of our children's condition and to find a way to better manage it. There is activity happening behind the scenes all the time, and I would highly recommend attending a future conference, if you can get there.

We have recently booked the Center Parcs weekend and cannot wait to meet other Dravet children, parents and siblings. Sometimes, it can be quite an isolating condition and no matter how hard people try, they never fully understand what a Dravet family goes through on a daily, hourly and sometimes minute by minute basis. This is what makes the Center Parcs weekend so special, there are lots of people there who are in the same situation as you and your family.

Our other two children, Ruby and Teddy, were nominated by family members for the DSUK Super Sibling award and recently were awarded with a certificate, a lovely Dravet bear and an amazon gift voucher. The excitement for them was immense when they received something through the post with their names on. They are both such valuable members of 'Team Pod', so this really gave them some great encouragement to keep up the good work.

Penny today - an amazing little girl

Penny is doing well at the moment. She is on the Ketogenic diet and three other medicines. She goes to nursery three afternoons per week and we are putting things in place ready for when she starts school. She's walking and saying the odd word. She isn't as developed as her peers, but we have come to terms with that and we are pushing her forward as best we can.

For all that Penny goes through, a lot of the time you would never know she has Dravet Syndrome. She's a very happy little girl and very much loved by us all.

Our advice to any recently diagnosed family would be that it's not all doom and gloom, once you get your head around it. It's not what we would choose for our children, and you will have your good days and your bad, but they will amaze you every single day.





A warm welcome to John Lloyd

John joined last year, having followed and supported the charity for several years. Once upon a time John made television documentaries but that was too much fun so he left to do something more useful. He has spent most of the last decade helping former viewers to see better, by working with ophthalmologists in the NHS.

Since then he has worked as a consultant with a variety of different charities, including ones working with children and in social care, helping them develop their strategies and approaches to governance. He now helps to lead a small data protection consultancy which shows companies how to do the right thing with people's personal data. John lives in South London, where he is also a governor of a local primary school.



A change in role for Teresa Finch

A heartfelt thank you goes to Teresa Finch who is stepping back as a Trustee after seven years in post. Since Teresa joined the Board she has been a passionate advocate for families, drawing on her own experiences as mum to Amy who has Dravet Syndrome and is now 24 years old.

In Teresa's time as a Trustee the charity has grown considerably in size, reaching over 500 families and expanding the support offered. Teresa has worked incredibly hard to support the charity through-out all of this. Whilst Teresa will be missed as a Trustee, we're really pleased to say she will remain closely involved in the charity's running, as our Family Support Manager. Many thanks Teresa for all you've done for DSUK as a Trustee!

Galia Wilson, Chair, and Kelvin Hughes, Treasurer, continue in their roles as Trustees.



Welcoming Dr Andreas Brunklaus, our new Advisory Board member

We're delighted to announce that Dr Andreas Brunklaus, Paediatric Neurologist at the Royal Hospital for Children, Glasgow, has agreed to become the latest member of the DSUK Professional Advisory Board.

Originally from Germany, Dr Brunklaus trained at the Charité Medical School, Humboldt University Berlin and completed his child neurology training at the Royal Hospital for Children in Glasgow and Great Ormond Street Hospital in London.

Today, Dr Brunklaus is one of the UK's leading experts in Dravet Syndrome. In addition to treating Dravet patients on a daily basis in Glasgow (where he works alongside Professor Sameer Zuberi, another DSUK Advisory Board member), he has made important contributions to furthering scientific understanding of Dravet Syndrome and is the author of several key publications that have helped to improve medical knowledge about this complex condition.

Most recently, Dr Brunklaus and colleagues completed a 10-year study on the impact of Dravet Syndrome on quality of life (visit the '[Comorbidities](#)' section of our website for some early insights from this study).

Dr Brunklaus has previously provided valuable support and advice to DSUK, including speaking at our DSUK Conference, providing guidance on our website content and even contributing an article to a previous issue of this newsletter.

It is therefore fantastic news that he has agreed to become a formal member of the DSUK family. We are excited about the opportunity to continue to working closely with Dr Brunklaus, especially during this time of some much change and progress in the understanding of Dravet Syndrome.

You can read more about our board of [Professional Advisors](#) on our website.

Professor Helen Cross takes up Chair role



As we have seen, the medical and scientific environment is changing quickly for Dravet Syndrome, with promising times ahead. During 2019, we very much appreciated the lead that Professor Helen Cross took for Professional Advisory Board as we look to navigate this changing environment and set priorities for where DSUK can make the most difference.

We're delighted that Professor Cross has formally accepted the role of Chair and we are looking forward to working with her and our fantastic panel of UK experts during 2020. Professor Helen Cross was awarded an OBE in 2015 for her services to Children with Epilepsy. She is the Prince of Wales's Chair of Childhood Epilepsy at UCL-Institute of Child Health, Great Ormond Street Hospital for Children, London and the National Centre for Young People with Epilepsy, Lingfield, UK.

Introducing our new Director, Helen Evans



In September 2019, we were delighted to welcome Helen Evans as the first ever Director for our charity.

The new Director role builds upon the achievements of our team to date, and will enable us to navigate the opportunities and challenges that we are currently seeing in the changing medical and scientific environment.

When DSUK first started, we supported around 30 families, now - thanks to the hard work of our team, led by Teresa Finch and Linzi Cowley - we support more than 500. It's an incredibly exciting and hopeful time for the future of Dravet Syndrome, with new and emerging treatments on the horizon.

Helen brings the ideal experience to the new Director role. She has a wealth of experience, having worked as a charity director since 2008. She understands rare diseases and will help us continue to meet our objectives during these momentous times for the Dravet community.

"I'm thrilled to be joining DSUK at such an exciting time. I'm inspired by all the great work achieved to date. I look forward to building on these successes as the charity aspires to reach even more families and help drive forward improved treatment options."

For the past 10 years I've had the privilege of being a charity Director, something I'm thrilled to continue with my appointment as Director of Dravet Syndrome UK in 2019.

I began my career in the private sector in Human Resources. In 2008 I moved into the aid sector heading up Oxfam GB's Human Resources function in the Middle East. In 2012 I went on to lead Oxfam GB's global Safeguarding function, and later campaigned successfully for changes in UK law to better safeguard beneficiaries from abuse.

In recent years, I've been Chief Executive of rare disease charity Cavernoma Alliance UK and Oxfordshire advocacy service Getting Heard. In this time, I've worked with families across the UK to provide much needed care and support, as well as driving forward important research.

In my home-life, I'm a mum to my wonderful son Sammy and his therapy dog Lizzie. My son has autism and whilst life can have its twists and turns, it's endlessly rewarding."



Coming up in 2020 - Events to look out for!

We've got lots of activity planned for 2020. Here's a summary of just some of our upcoming events.

February

Adult Rights Webinar with Fiona Scolding QC

Fiona's presentation on Family Rights was one of the most popular sessions at last year's DSUK Parent/Carer conference. We're delighted that Fiona has agreed to taking part in a live webinar with DSUK, focusing on the transition to adulthood and helping families know and use the rights available to them to support the best care and quality of life for their young Dravet adults.

The webinar will take place on Friday 6th March from 12.30-2pm. To receive information on how to register or if you have any questions that you would like to submit in advance to ask Fiona, please email info@dravet.org.uk.

We will also make the webinar available as a podcast, so if you are not able to listen live you will be able to catch up at a time convenient to you.



June

Center Parcs Family Weekend Away - 10th Anniversary.

This year's Center Parcs weekend is taking place at Sherwood Forest, Friday 19th to Monday 22nd June.

Reserve your place by first booking your accommodation via the Center Parcs website or by telephone on **03448 267 723**. Once you have booked your accommodation you can apply for a [Center Parcs Grant](#) via our website. You will need to upload a copy of your Center Parcs booking confirmation as part of the application process. **If you have any questions, please contact Teresa Finch (teresa.f@dravet.org.uk).** See page 1 for more details.

September

Family Meet Ups in London, Oxfordshire, Sheffield

We know that the families we support really enjoy and appreciate the opportunity to meet with other families, so we are thrilled to announce we are planning to hold for 'Meet Ups' across the UK in London, Oxfordshire, Sheffield and Newcastle.

These will be casual, friendly meetings, offering an opportunity to meet with others who are living with Dravet Syndrome and members of the DSUK team.

Currently, the Family Meet Ups are being scheduled for September 2020, with exact dates still to be confirmed. Please lookout for further news later in the year.

