DRAVET Syndrome UK

Hope for families with life-limiting epilepsy

Dravet Syndrome UK

Annual Review 2024-25

CONTENTS

Dravet Syndrome UK

Trustees' Annual Report

Year Ended 31 January 2025

Reference and administrative details

Registered charity name	Dravet Syndrome UK	
Charity registration number	1128289	
Principal office	PO Box 756 Chesterfield Derbyshire S43 9EB	
The trustees	K Hughes	(Resigned 28 February 2025)
	G Wilson-John	
	J D R Lloyd	
	N Williamson	
	A Williams	
	S Smith	(Appointed 26 June 2024)
Senior management	C Eldred	
Independent examiner	T G Leeman FCA MCABA Limited trading as Mitchells Chartered Accounts and Business Advisers 91 - 97 Saltergate Chesterfield Derbyshire S40 1LA	

Structure, governance and management

Governing Document

Dravet Syndrome UK is currently constituted under the original Declaration of Trust dated 31 January 2009 and supplemental deed dated 18th July 2018. Dravet Syndrome UK is registered as a charity with the Charity Commission.

Trustees Selection Methods

The appointment of trustees is governed by the Declaration of Trust. Trustees must act in the best interests of the charity at all times. Future trustees must be appointed for terms of office of four years by resolution of the trustees and may be re-appointed at the end of the term of office. All trustees must be over 18 and there must be a minimum of 2 and a maximum of 6 trustees. Under the trust deed a trustee may be appointed or removed by resolution of the trustees.

ABOUT DRAVET SYNDROME UK

Dravet Syndrome UK was established in 2009 by a group of parents who came together looking for support, resources and information relating to this rare condition. Today, much more is known about Dravet Syndrome and we are privileged to support many families affected by the condition in England, Wales, Scotland and Northern Ireland.

We are the only registered charity in the UK dedicated to improving the lives of families affected by Dravet Syndrome.

Our mission is to bring hope to families through support, education and medical research.

OBJECTIVES AND ACTIVITIES

The objective and main activities of the charity are expressed in the Trust Deed and are the "general purposes of such charitable bodies or for such other purpose as shall be exclusively charitable as the trustees may from time to time decide". The trustees must apply the income of the charity in furthering the following objects ("the objects"):

SUPPORT

To support families affected by Dravet Syndrome emotionally, practically and financially.

EDUCATION

To raise awareness and understanding of Dravet Syndrome.

RESEARCH

To fund medical research to increase understanding of Dravet Syndrome, improve its management, work towards better outcomes and hopefully one day find a cure.

All our activities are underpinned by guidance and support from a world-renowned Medical Advisory Board.

PUBLIC BENEFIT

The trustees confirm that they have complied with the requirements of Section 17 of the Charities Act 2011, having due regard to the public benefit guidance published by the Charity Commission for England and Wales.

To find out more about Dravet Syndrome UK, visit www.dravet.org.uk

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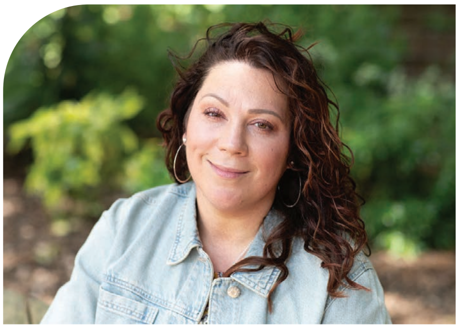
WELCOME

The financial year (February 2024 to January 2025) has been a transformative period for Dravet Syndrome UK, marked by significant strategic growth and expanded impact across all areas of our work. This year saw the successful implementation of several key elements of our 5-year strategy, including important investments in our team and infrastructure.



In the summer of 2024, we were pleased to strengthen our Trustee Board with the appointment of Stephanie Smith, whose 13-year-old son Jake is living with Dravet Syndrome. Stephanie, along with husband Wayne and Jake's twin sister Ella, has been an active part of the Dravet Syndrome UK community since Jake's diagnosis in March 2013 when he was just over 18 months old. Stephanie manages three businesses with her husband Wayne and is a qualified primary school teacher. We are delighted to welcome her to the Trustee Board.

We also grew our staff team significantly in 2024. We welcomed our new Head of Marketing and Communications in January, followed by our first-ever Head of Fundraising in April, and recruited our inaugural Head of Family Services in November. These appointments have already strengthened our capacity to reach and support more families, with a record 46 new families joining our community this year—the highest number in a single year to date—bringing our total to over 580 children and adults living with Dravet Syndrome across the UK.

Our commitment to empowering families remains at the heart of our work. We launched six new mini guides on critical topics and hosted targeted webinars, providing practical knowledge that helps navigate the complexities of living with Dravet Syndrome. We've also enhanced our emotional support offering, including the introduction of a dedicated bereavement service for families facing the most devastating aspects of this condition.

In research, we're particularly proud of several significant achievements. Our partnership with the Epilepsy Research Institute, with DSUK contributing £175,000 to co-fund two Joint Fellowship Research Grants, represents an important investment in developing future research leaders. The SCN1A Horizons Natural History Study continues to make excellent progress with more than 100 patients now recruited across 29 UK hospitals. Excitingly, we became one of the first international patient organisations to join the Chan Zuckerberg Initiative's Rare As One network, receiving a five-year that will significantly accelerate our research programme and enable us to appoint our first Chief Scientific Officer.

Throughout all these developments, our central focus has remained on representing the parent/carer voice in medical and scientific discussions. Our team has been active at key national and international meetings, ensuring that the real-world needs of families remain central to both current care practices and future research priorities.

None of these achievements would be possible without the dedication of our staff, trustees, volunteers, fundraisers, and the entire Dravet Syndrome community.

As we continue to build our organisational capacity and expand our reach, we are more confident than ever in our ability to make meaningful progress toward our mission of improving the lives of all those affected by Dravet Syndrome.

Galia Wilson, Chair of Trustees

HIGHLIGHTS OF OUR YEAR

IN 2024-2025, DRAVET SYNDROME UK:

WELCOMED

46 new families, growing our registered number of beneficiaries to **580** children/adults living with Dravet Syndrome.

GATHERED TOGETHER

66 families living with Dravet Syndrome at our Annual Weekend Away, building lasting connections in a welcoming and supportive environment.

AWARDED

2 Joint Fellowship Research Grants in partnership with the Epilepsy Research Institute to develop future leaders in Dravet Syndrome research.

CELEBRATED

9 winners of our Annual Siblings Awards, recognising the kindness and patience of super brothers and sisters of those living with Dravet Syndrome.

HELPED improve the lives of **34** young adults living with Dravet Syndrome, with the award totalling more than **£34,000** from our 16+ Assistance Fund.

EXTENDED SUPPORT to families at the saddest of times through our new bereavement service, providing comprehensive care when it's needed most.

PROVIDED

some reassurance and peace of mind to parents/carers, funding

52 SEIZURE MONITORS

that provide an early alert to seizures occurring.

INCREASED

our online support forum (our private Facebook group) from 425 members to over **450** members.

LAUNCHED

6 'MINI GUIDES'

on key topics from 'social services and your rights' to 'seizures: types and triggers and what to expect' to empower parents with essential knowledge.

SUPPORTED

the SCN1A Horizons Natural History Study with over **100** patients already recruited transforming our understanding of Dravet Syndrome.

JOINED

the Chan Zuckerberg Institute's Rare As One network, receiving a

5-YEAR GRANT

to accelerate research into unmet needs in Dravet Syndrome.

GAINED more than

37,000

visitors to our website, providing news, information and guidance on all aspects of living with Dravet Syndrome.

SHARED

Real life experience of living with Dravet Syndrome with short videos featuring family stories, which received over

160,000 views.

WELCOMED over

700 new followers to our social media platforms, Facebook, Instagram and LinkedIn, bringing our total number of followers to more than

10,000 resulting in over

50,000 engagements and interactions throughout the year.

HOSTED

2 WEBINARS

to empower families through access to expert guidance and advice on critical aspects of living with Dravet Syndrome.

RAISED AWARENESS

with more than

75 ITEMS

of media coverage throughout the UK in local/regional press, radio and TV.

SUPPORT

We support families affected by Dravet Syndrome emotionally, practically and financially

KEY ACHIEVEMENTS

Family support services

In 2024-25, 46 new families joined our Dravet Syndrome UK community, the highest number of families to join in a single year to date. We now have over 580 children/adults living with Dravet Syndrome, plus hundreds more parents/carers and siblings registered with us.

When they register with Dravet Syndrome UK, families:
- ✓ receive a welcome pack of information – including our Family Guide and transition guide
- ✓ become eligible for our grants
- ✓ gain access to our private Facebook group
- ✓ access to one-to-one advice from our Family Support team

Mini guides: Practical knowledge at your fingertips

This year, we launched six new 'mini guides' addressing key topics that families have told us are particularly challenging. These accessible resources cover:

- Social services and your rights
- Education and your rights
- Seizures: types, triggers and what to expect
- Living options for young people and adults living with Dravet Syndrome
- Growth nutrition and digestion
- Emergency medications and protocols

These mini guides complement our comprehensive Family Guide, offering quick, practical information on specific topics. Feedback from families has been overwhelmingly positive, with many expressing how these targeted resources have helped them navigate complex systems and better understand their rights.

Practical and emotional advice

Our Family Support team continues to provide both practical assistance and emotional support to parents and carers, including one to one advice and template letters to help access the support to which they are entitled as caregivers to children and adults living with Dravet Syndrome, a devastating and complex condition impacting every area of life.

BRINGING FAMILIES TOGETHER

DSUK private Facebook group

We continue to provide peer support via our private Facebook forum, which has now grown to over 450 parents and carers.

> *As soon as my son was diagnosed, I became a member of the private Facebook group and it was wonderful to meet so many people that knew exactly what you had been through and there is so much advice and a wonderful community to be part of. I am very close to one of the Mums as our children were diagnosed at similar times, and I would be lost without her now, we vent, we chat, we cry and we get each other through this journey.* **- Parent/Carer.**

DSUK annual weekend away

In June 2024, 66 families (more than 400 people) living with Dravet Syndrome joined us at Center Parcs in Sherwood Forest for our Annual Family Weekend Away. As in previous years, we funded emergency medical support throughout the weekend, providing families with the reassurance needed to relax and connect with others who understand their experiences. DSUK also offered a grant of £400 towards the cost of the weekend to help make it accessible for a wider range of families.

The weekend offers a rare opportunity for reducing isolation and building supportive relationships. Parents and carers consistently tell us how valuable these connections are, providing both practical advice and emotional support that extends well beyond the weekend itself. Here are just a couple of examples of feedback we received.

> *Be ready to laugh, cry and meet people that understand your journey. No questions are stupid and we are all constantly learning. It's a great weekend to spend time with other families that just get it!*

> *It is a wonderful weekend with the unique assurance of a medical team on hand at all times and surrounded by people who completely understand the challenges you face. And the setting is just perfect.*

Bereavement service

Sadly, the risk of early death due to SUDEP (Sudden Unexpected Death in Epilepsy) is higher with Dravet Syndrome is up to 15 times higher than in other epilepsies. Due to SUDEP and other seizure-related event, around 15-20% of children don’t survive into adulthood.

DSUK provides a final ‘gift’ of £1,000 to families registered with the charity who experience a bereavement. This year, in recognition of the support that families need at this saddest of times, we introduced a dedicated bereavement support service. This includes a resource pack, including information to help families navigate the aftermath of bereavement and support on managing grief.

Our volunteer, Debbie Dalligan, a bereaved parent who lost her own son, George, to Dravet Syndrome at age 19, leads a new support network, specifically for bereaved families.

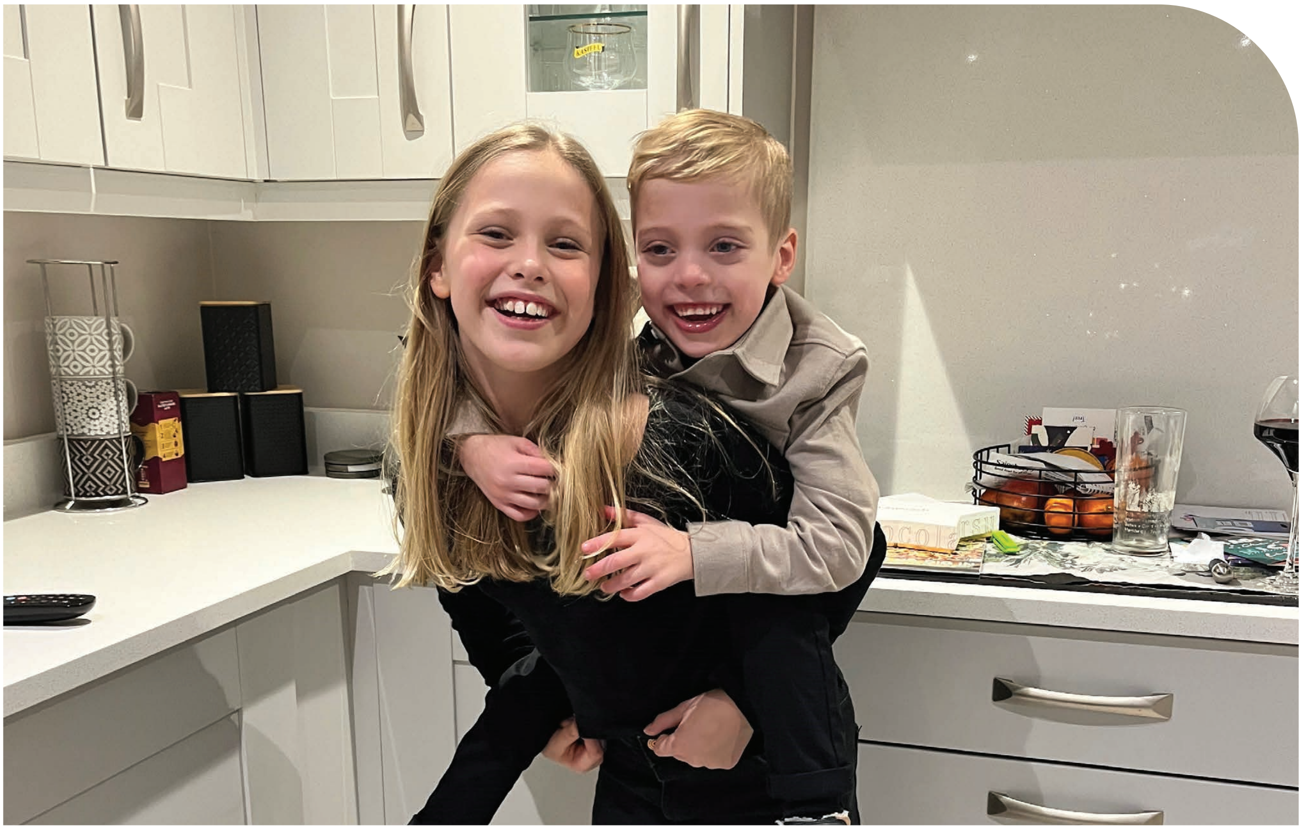
> *I lost my beautiful son George in January 2017. He was 19. When George passed away, I felt completely lost. A constant flow of people used to come to our house, I would be arranging appointments and juggling lots of things and suddenly it all stopped. It was very isolating, and I felt like I had to work out my purpose in life having cared for George for so many years. I had the worry of how I would afford George’s funeral, having to sort out all the paperwork and inform all the services we had relied on for so many years. Over time this led me to talk to the team at Dravet Syndrome UK about the need for a support network for bereaved families and a safe space for them to connect, share stories, and feel understood.*
>
> *This was when we set up the Dravet Syndrome Bereavement forum, a private Facebook group run jointly between Dravet Syndrome UK and US Dravet Syndrome Foundation, and I became actively involved in running it. This group includes around 40 families, who all share the experience of having lost a child. It is a safe space for them to talk, ask questions and gain support.* **- Debbie Dalligan, bereaved parent and volunteer.**

Sibling awards

Our Sibling Awards continue to be an important way of recognising the unique contributions made by brothers and sisters of those living with Dravet Syndrome. Siblings of those diagnosed with Dravet Syndrome have to experience many things that you would never wish your child to see: prolonged seizures, ambulance trips, hospital intervention and challenging behaviour, to name just a few. Despite all these difficulties, many families report how caring and loving siblings can be to their brothers and sisters.

> *Thank you so much for the siblings awards from our whole family, we are all super emotional and overwhelmed! Thank you so much for the generous vouchers, lovely gifts and certificates, we are very grateful!*

Our Annual Siblings Awards celebrate both children and young adults and the very special role they occupy in the lives of families living with Dravet Syndrome. Recipients received gift vouchers and certificates.



Financial support

We offer a range of financial grants to support families living with Dravet Syndrome, none of which are means-tested.

In 2024-25, our Seizure Monitor Fund awarded 52 seizure monitors, helping alert parents/carers early when their child or adult has a seizure and potentially reducing risks of serious harm.

Our 16+ Assistance Fund continues to address the gap in grants available to families with disabled adults. This year, we awarded 34 grants, funding essential items including communication technology, sensory equipment, therapy sessions and mobility equipment.

EDUCATION

We raise awareness and understanding of Dravet Syndrome

KEY ACHIEVEMENTS

Raising public awareness

In 2024-2025, we gained the highest amount of press coverage in a single year to date, achieving over 75 articles in local/regional, radio/TV and online media, helping to raise awareness across the UK.

Our social media also went from strength to strength. We gained over 700 new followers across our social media platforms, Facebook, Instagram and LinkedIn, representing 7% growth across all channels bringing our total followers to more than 10,000. Across the year, we achieved a reach of over 300,000, engaging more than 50,000 people in posts about Dravet Syndrome.

In addition, our website (www.dravet.org.uk) was visited more than 37,000 (a 23% increase vs the previous year). Our awareness raising videos also received more than 160,000 views.

TWO CAMPAIGNS SIGNIFICANTLY RAISED AWARENESS

Every Day in May for Dravet

Our amazing supporter Tamara (Tats) Ward, whose nephew Dominic is living with Dravet Syndrome, led the 'Every Day in May for Dravet' campaign for its fourth and most successful year to date to raise funds and awareness for Dravet Syndrome. As usual Tats went above and beyond promoting the campaign, as did other participating families across the UK – leading to coverage in regional press and radio across the country.

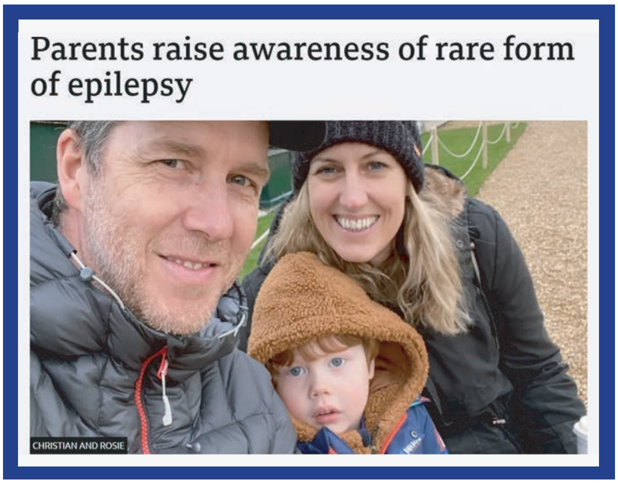
Dravet Syndrome Awareness Month/Day – Little Moments Matter

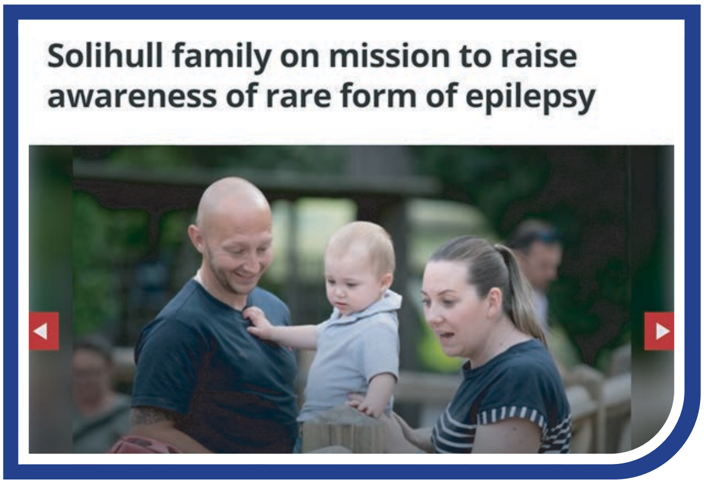
June is Dravet Syndrome Awareness Month, and in 2024 our 'Little Moments Matter' campaign highlighted how seemingly small achievements represent significant milestones for those living with Dravet Syndrome.

Partnering with a video agency called Faltrego, we produced a video featuring three families with children of different ages (aged 2, 9 and 34). You can watch the resulting film here which was boosted on social media to reach the widest audience possible: https://fb.watch/uFhn_nQCfd/

By harnessing this powerful storytelling, Little Moments Matter became our most successful awareness campaign to date:

- Media coverage for awareness month reached a wider audience than ever before, with more than 30 articles across national, regional and local TV, radio, newspapers and online coverage, with a potential 1.5 billion opportunities for people to watch, hear or read about Dravet Syndrome
- The awareness day video received 76,000 views across our social media channels
- (43,000 within a week of launch) and 58,000 of these on Facebook
- Added over 200 followers on our social media channels during June 2024
- 6,400 engaged with content (shared, reacted and commented) on Facebook (8% increase compared to June 2023), 57,800 reach on Facebook (8% increase compared to June 2023) and 6,600 visits to our Facebook profile (33% increase compared to June 2023)
- 4,100 reach on Instagram (37% increase compared to 2023) and 1,300 Instagram profile visits (14% increase compared to 2023)


Parents raise awareness of rare form of epilepsy


Solihull family on mission to raise awareness of rare form of epilepsy

Raising awareness of the impact of caregiving

During 2024-2025, we achieved 3 publications in scientific journals aimed at providing an evidence base of the impact of Dravet Syndrome on family life including:

- Clayton LM, et al. Feeding Difficulties and Gastrostomy in Dravet Syndrome: A UK-Wide Survey and 2-Center Experience. Neurol Clin Pract. 2024
- Freeman-Jones E, et al. Caregiver burden and therapeutic needs in Dravet syndrome - A national UK cross-sectional questionnaire study. Eur J Paediatr Neurol. 2024
- Mercier A, et al. Trauma, coping, and adjustment when parenting a child with Dravet syndrome. Eur J Paediatr Neurol. 2025

We want to say thank you to all authors involved in these publications.

Family webinars

In 2024, we held 2 family webinars reaching over 100 parent/carers, on important topics for families – 'Transition to adulthood and living options' with Anna Selby-Wells from Home from Home Care and 'The Emotional Impact of Caregiving' with Dr Anthony Mercier, Clinical Psychologist in the Paediatric Neuropsychology Department at the Royal Hospital for Children in Glasgow shared his findings from his research paper which explores how parents cope and adjust when parenting someone living with Dravet Syndrome.

'The Emotional Impact of Living with Dravet Syndrome' Webinar

Speaker: Dr Anthony Mercier
Clinical Psychologist, Paediatric Neuropsychology Department at the Royal Hospital for Children in Glasgow

We received overwhelmingly positive feedback from families for both webinars; here is just a selection of comments.

Transition

> *The webinar was very informative and helped understand the way things might move forward and what to look for and questions to ask when looking for a suitable home before it becomes too difficult and lack of resources at home.*

> *So good to know that there are residential homes of such high quality. It now makes me consider going down that track when my daughter is 18. I will be 60 then and I would love to have a life back. She is very complex and I am sure it would take a team to do what we do for her.*

Emotional Impact of Caregiving

> *[The webinar showed that] there is understanding and hopefully will be more from neurologists etc about the implications for families re trauma and stress of living with a child with Dravet Syndrome.*

> *[It was good to hear] that my experience is not that different from other Dravet Syndrome carers. That we are being seen and heard by DSUK, and that the conversation around DS is evolving in the right direction.*

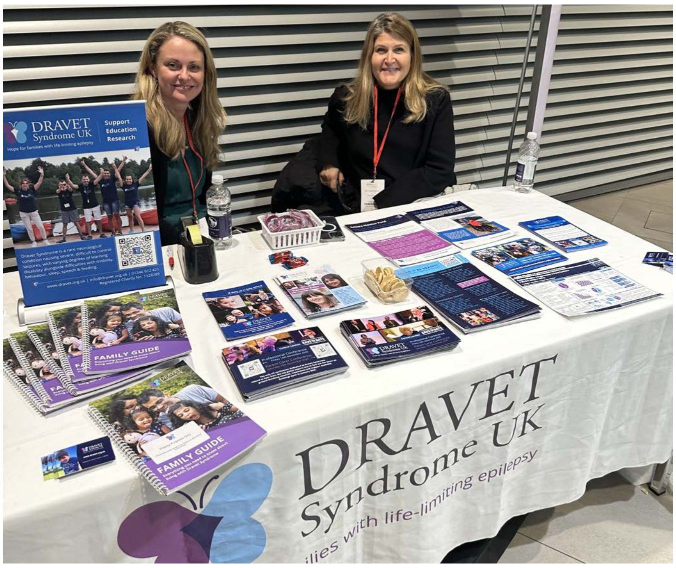
Representing the parent/carer voice

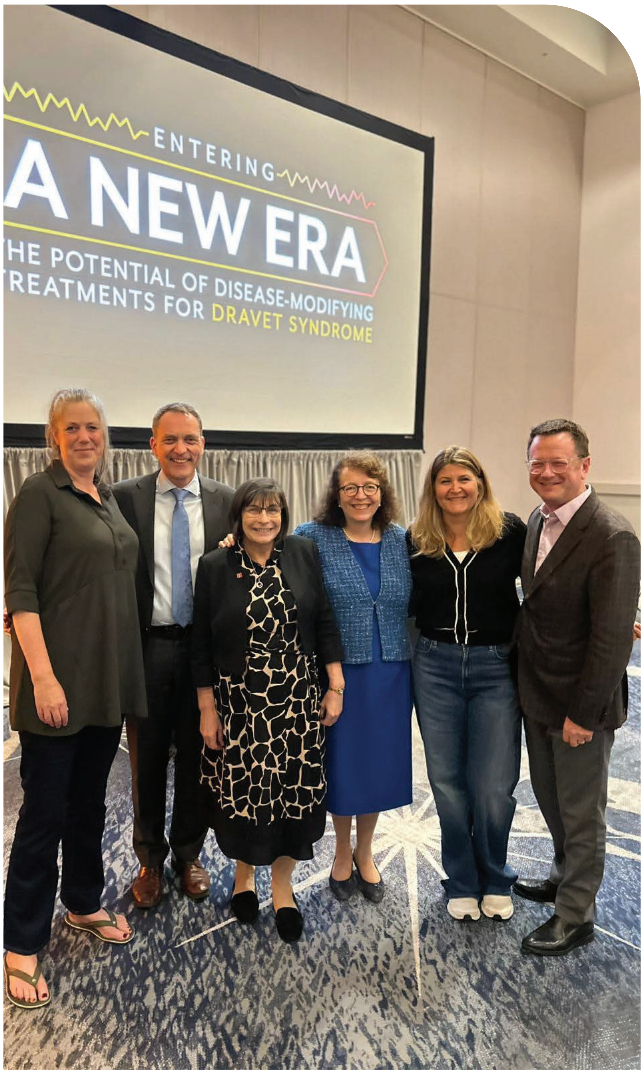
Throughout the year, we've continued to ensure that the experiences and perspectives of parents and carers remain central to discussions about Dravet Syndrome at both national and international levels. The DSUK leadership team attended key medical conferences and scientific meetings, including the British Paediatric Neurology Association, the British International League Against Epilepsy Meeting, the European Dravet Syndrome meeting, the European Epilepsy Congress and the American Epilepsy Society meeting, sharing insights from our community and building relationships with healthcare professionals and researchers.

We also spoke at two regional nurse meetings in the UK and held a stand at the North West CYP Epilepsy Transition Conference in March 2024.

We have been active members of umbrella associations in the UK and Europe including, Rare Epilepsies Together UK, the Neurological Alliance, the Genetic Alliance and the European Dravet Syndrome Association.

Last but not least, we have also engaged with companies and researchers who are driving new research and developing much needed new treatments in Dravet Syndrome, representing the patient/caregiver. This advocacy work is essential in shaping both current care practices and future research priorities, ensuring they address the real-world needs of families living with Dravet Syndrome.





EPILEPSY RESEARCH INSTITUTE PARTNERS WITH DRAVET SYNDROME UK TO INVEST IN FUTURE LEADERS IN DRAVET AND EPILEPSY RESEARCH

EPILEPSY RESEARCH INSTITUTE UK

DRAVET Syndrome UK

RESEARCH

Funding medical research to increase understanding of Dravet Syndrome, improve its management, work towards better outcomes and hopefully one day find a cure.

KEY ACHIEVEMENTS

Joint Fellowship Research Grants

DSUK was delighted to partner with the newly launched Epilepsy Research Institute to co-fund two Joint Fellowship Research Grants as part of the Institute's 2024 Research Awards programme. This partnership represents a shared commitment to developing future research leaders in the field of Dravet Syndrome, with DSUK contributing £175,000 towards the awards. The awards were announced during National Epilepsy Week to two exceptional researchers, both based at the Queen Square Institute of Neurology, University College London:

Dr Lisa Clayton's project focuses on understanding autonomic dysfunction (dysautonomia) in adults with Dravet Syndrome. This often-overlooked aspect affects bodily regulation of essential functions such as heart rate, body temperature, and digestion. Her research aims to develop effective methods for screening and predicting dysautonomia in people with Dravet Syndrome, and crucially, to find ways to prevent, limit, or alleviate related problems.

Dr Jenna Carpenter's project focuses on advancing precision medicine through genome engineering for on-demand gene therapy in Dravet Syndrome. Her research will enhance our understanding of how the SCN1A gene is read and provide more information about the genetic changes that cause Dravet Syndrome and related epilepsies. If successful, this project will establish a groundbreaking treatment strategy not only for Dravet Syndrome but potentially for other genetic epilepsies as well.

As our Chair Galia Wilson noted:

> *Both projects engage with important, unexplored areas of research and have the potential to contribute vital new insights into Dravet Syndrome and its future treatments, making a real difference to the lives of families affected by this rare and complex epilepsy.*

This collaboration aligns with our strategy to enable research that is vital to families and improves the lives of those affected by the condition. We are immensely grateful to all our fundraisers whose support has made this significant research investment possible.

SCN1A Horizons Natural History Study

DSUK continues to support the SCN1A Horizons Natural History Study, which is anticipated to be a milestone in the understanding of Dravet Syndrome and other SCN1A Epilepsies. In 2024-2025, DSUK helped promote the study to the Dravet Syndrome community with a series of videos and other communications activities, contributing to the recruitment of more than 100 patients across 29 UK hospitals.

This detailed longitudinal study is the first to capture comprehensive data about both the clinical and neuropsychological aspects of Dravet Syndrome, creating a valuable resource for both current care recommendations and future treatment development.

Other research

In addition to the studies mentioned above, two other projects are ongoing:

- A co-funded gene therapy project (with GOSH) led by Professor Wood at Oxford University utilising RNA editing
- A PhD project exploring the impact of music therapy on challenging behaviour in children with Dravet Syndrome

Chan Zuckerberg Initiative's Rare As One Network

In October 2024, DSUK was awarded a major boost to accelerate research from the Chan Zuckerberg Initiative (Cycle 3), which gives 30 patient-led rare disease organisations the opportunity to join the Rare As One Network. This programme provides both substantial funding and capacity-building support to patient-led organisations working to accelerate research in rare diseases.

We were delighted to be successful in our application, becoming one of the first international patient organisations to join the Rare As One network. Our first step has been to recruit a Chief Scientific Officer, who will help further develop our research network and drive collaboration between families affected by Dravet Syndrome, scientists and clinicians.

FUNDRAISING FOCUS

Community fundraising

We are so grateful for the passion and dedication of our community fundraisers who raised a collective total of £448,185 in 2024-2025. Across every part of the UK, our supporters have been running, cycling, climbing, crafting, baking, golfing, wearing purple and much more, to raise money for Dravet Syndrome UK.

In its fourth year, the epic Every Day in May challenge raised an astonishing £200,000 (including gift aid). Our huge thanks to Tamara Ward and her husband Mike for all their work in devising, promoting and supporting us in this event. A phenomenal team of 446 adults and children joined from across the globe to run, walk, cycle and swim in what has now become the highlight of the DSUK fundraising calendar.

Not satisfied with that, Tamara and Mike's daughter Mimi, then aged 10, became the youngest girl to complete the London to Paris cycle ride raising £20,000 in her wake.

In September our team of 31 brave participants were inspirational, conquering the fastest zipline in the world, reaching speeds of 100mph and raising £12,500 (including Gift aid). Additional thanks goes to Zipworld employee Matt Britton, Dad to Zac, for all his support

A special mention to Chloe Davies who hosted the beautiful Dravet Butterfly Ball in October raising an incredible £18,788 in honour of her daughter Winnie, and to Annabel and Haydn Hughes, parents to Rebekah, for their sensational 'hole-in-one' of a golf day, where they raised £14,800.

Thank you so much to everyone who has contributed. With your help we're able to continue our mission to improve the lives of families affected by Dravet Syndrome.

Corporate partners

We'd like to thank our corporate partners for their support, involvement and dedication this year. Long-standing partners, XTX Markets, helped us to make considerable progress in delivering against our charitable aims in 2024/2025. The company's generous three-year donation agreement (in its second year in this reporting period) and London Marathon match funding is essential in our work towards our family support, education and empowerment and research projects.

Industry grants

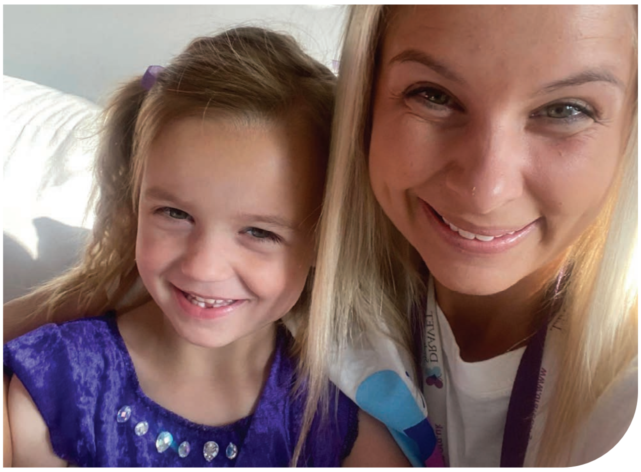
We are grateful for continued support from the pharmaceutical industry and medical devices sector. We were particularly grateful to Biocodex, Encoded Therapeutics, Jazz Pharmaceuticals, Liva Nova, Stoke Therapeutics, Takeda and UCB for providing restricted grants towards redeveloping our website and updating our Transition Guide. These organisations have had no involvement in the development of these activities, or any of their content.

Trusts and foundations

A highlight of the year was being awarded funding from the highly prestigious Chan Zuckerberg Initiative to accelerate research into Dravet Syndrome. We will receive $800,000 (approximately £600,000) over five years to accelerate our research programme. Starting with the appointment of our first Chief Scientific Officer (CSO), the grant will enable us to develop our research network and drive collaboration between families, scientists and clinicians. The funding grant cannot be used directly to fund research but allows us to build capacity and will put us in an even stronger position as a charity to drive forward further research.

We are also very grateful to the Xerox Charitable Trust and to the Bergqvist Charitable Trust who each donated £2,000 in much needed unrestricted income as well as Jeans for Genes, who kindly provided £750 towards our Transition Guide

Finally, we'd like to thank St James's Place Charitable Foundation for funding our bereavement grants for the third year running.



STRATEGIC GROWTH AND LOOKING FORWARD

During 2024-2025, DSUK has invested in planned strategic growth as part of our 5-year strategy.

In January 2024, we appointed our new Head of Marketing and Communications, Katherine Raven, and we have seen the impact of this increased resource and expertise throughout the year. A strong performance in raising awareness and engaging with a wide range of healthcare professionals has contributed to 46 new families joining DSUK, the highest number of new families in a single year to date.

Throughout the year we have continued to grow our headcount and internal resources, thanks to the funds that we have been able to build throughout this and past years. In April 2024, we appointed our first Head of Fundraising, Tania Lewis, to drive our long-term strategic goal of diversifying our income streams and driving sustainable growth.

In November 2024, we recruited for another important role, our first Head of Family Services. Sandra Awuah, a former senior social worker, joined the team in March 2025. In April 2025, we appointed Ceri Hughes as our first Chief Scientific Officer (enabled by our Rare As One grant). In addition to her background in neuroscience Ceri brings direct experience of caring for someone with Dravet Syndrome – her younger brother Iwan lives with the condition. These appointments will enable us to further drive forward our strategy, including long term goals to reach even more families and empower parents/carers with the tools and support needed to assert their rights, while at the same time accelerating our research and scientific engagement activities.

During 2024-2025, we also invested in our infrastructure, embedding a new database (CRM) and website, to enable us to better reach and support both families and professionals with the information and guidance. The appointment of a Team Administrator in June 2024 also supported our improvements to our infrastructure, improving our efficiency and enabling staff members to focus their time directly on charitable activities.

With this boost to our resource and capability, we are well-placed to make further strides against our strategic plan, which continues to be the core roadmap in progressing our overall mission of bringing hope to families through support, education and medical research.

The strategy includes our four established strategic objectives:

1) Every family counts

Every UK family living with Dravet Syndrome will be aware of Dravet Syndrome UK and the support we offer. We will help them to access this support and know that all of our activities and research are driven by the things that count the most to them.

2) Leaders in the field

We will lead the conversation about Dravet Syndrome in the UK, making the best possible use of research funds, collaborating internationally as opportunities arise, and developing an authoritative global voice.

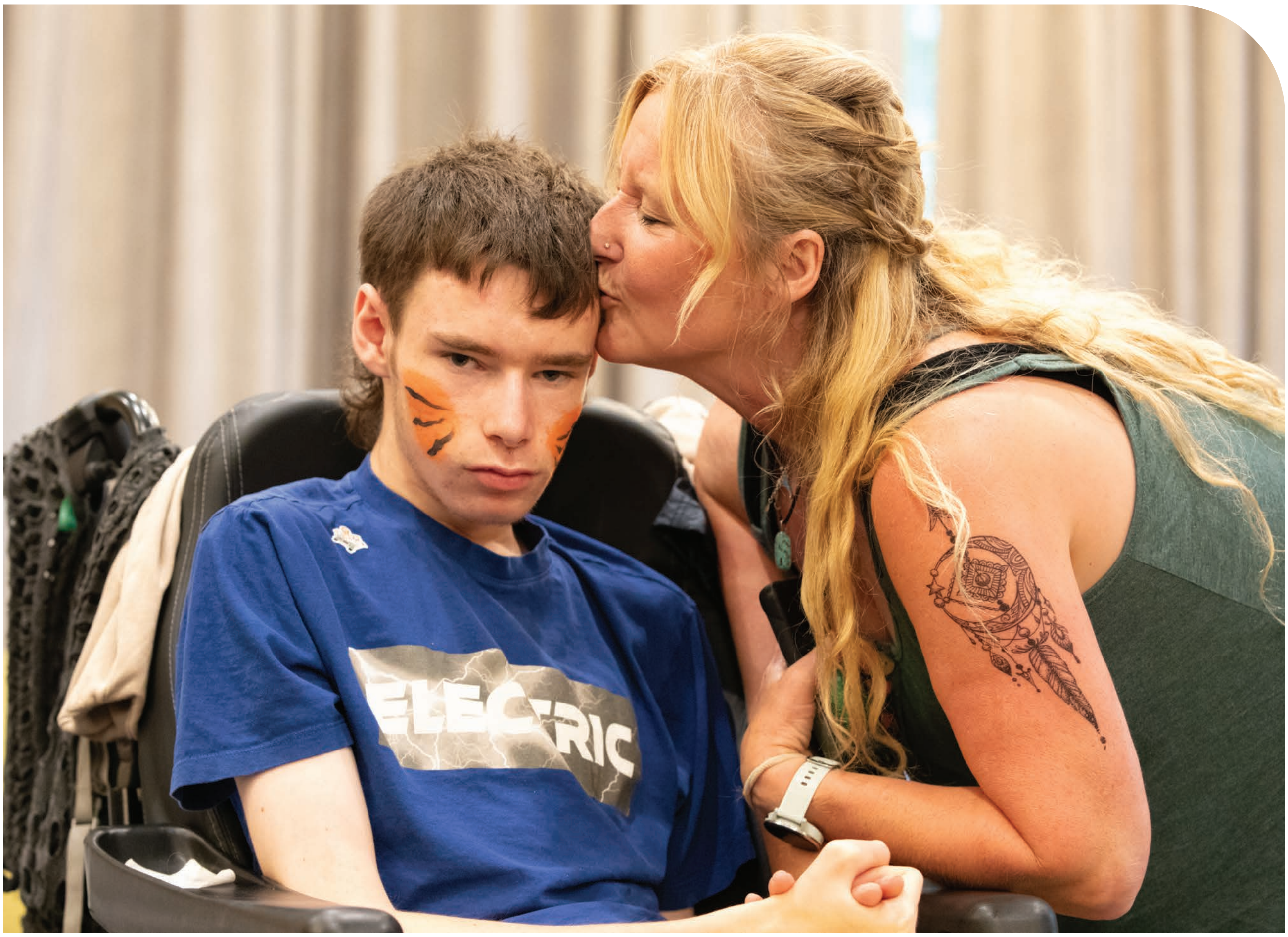
3) Support for professionals

We will seek to broaden the range of health and social care professionals with an improved understanding of Dravet Syndrome, enabling earlier diagnosis and providing accessible pathways to the best possible treatment and care for all ages.

4) Empowerment of families

Families living with Dravet Syndrome will know and understand their rights and feel empowered to assert these rights to get the support they need.

With the continued support of our community, partners and supporters, we look forward to another year of meaningful progress towards our vision of a better life for all those affected by Dravet Syndrome.



FINANCIAL REVIEW

Incoming Resources

Dravet Syndrome UK received income from the following sources:

	2025 **£**	2024 £
Community fundraising	**448,185**	347,330
Industry grants	**35,466**	75,625
Corporate sponsorship	**52,835**	44,830
Grants from Trusts/Foundations	**8,000**	4,500
Income generation	**17,496**	15,607
Total	**561,982**	487,892

Outgoing Resources

In 2023/2024 DSUK spent £796,545 (2023/2024: £436,435) delivering its charitable objectives.

During this reporting period costs have been incurred in respect of the following:

- Seizure monitors, 16+ Assistance Fund and Bereavement Grant
- Family support events (such as the Annual Family Weekend to Center Parcs)
- Educational and awareness raising materials (including website, social media, educational leaflets and videos)
- Meetings with expert clinicians, researchers and industry to develop research opportunities and represent the patient/caregiver voice
- Funding research via the Epilepsy Research Institute
- Development of the charity's new Customer Relationship Management system and new website
- Investing in the creation of new roles within the charity to facilitate the delivery of the long-term strategy
- Staff costs, with 7 employees (5.3 FTE) paid for 225 hours of work per week on average for the year ended 31 January 2024.
- Dravet Syndrome UK merchandise for fundraising events & shop sales

Reserves Policy

Dravet Syndrome UK is required to ensure that free reserves are available each financial year to meet any reasonably foreseeable contingency. For the financial year ending 31st January 2025, the Board of Trustees has agreed to a Reserves Policy of maintaining a minimum of six months' normal operating expenditure. Based on our current forecasts for 2025-2026, six months of normal operating expenditure (excluding one-off costs and fully funded projects) would be approximately £290,000. As of 31 January 2025, the unrestricted free reserves of the charity amounted to:

	2025 **£**	2024 £
Unrestricted funds	**305,878**	506,269
Less: Designated funds	**-**	(199,000)
Less: Net book value of tangible fixed assets	**(1,271)**	(1,026)
Free reserves	**304,607**	306,243

The Trustee's Annual Report was approved on 23 July 2025

And signed on behalf of the Board of Trustees by

Signed by:
Alex Williams
19B4F4C74941485...

A Williams
Trustee and Treasurer **Date of signature** 23 July 2025

Dravet Syndrome UK

Independent Examiner's Report to the Trustees of Dravet Syndrome UK

Year Ended 31 January 2025

I report to the trustees on my examination of the financial statements of Dravet Syndrome UK ('the charity') for the year ended 31 January 2025.

Responsibilities and basis of report

As the trustees of the charity you are responsible for the preparation of the financial statements in accordance with the requirements of the Charities Act 2011 (‘the Act’).

I report in respect of my examination of the charity's financial statements carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

Since the charity’s gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants in England and Wales (ICAEW), which is one of the listed bodies.

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the charity as required by section 130 of the Act; or
2. the financial statements do not accord with those records; or
3. the financial statements do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a ‘true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Signed by:
T Leeman
BE9BD1D6C2314D3...

T G Leeman FCA
Independent Examiner

MCABA Limited trading as
Mitchells Chartered Accounts and Business Advisers
91 - 97 Saltergate
Chesterfield
Derbyshire
S40 1LA

Date: 23 July 2025

Dravet Syndrome UK

Statement of Financial Activities (Incorporating Income and Expenditure Account)

Year Ended 31 January 2025

		2025			2024
	Note	Unrestricted funds **£**	Restricted funds **£**	**Total funds £**	Total funds £
Income					
Donations and grants	**4**	498,014	46,472	**544,486**	472,285
Charitable activities	**5**	–	–	**–**	6,961
Other trading activities	**6**	5,755	–	**5,755**	2,447
Investment income	**7**	2,303	–	**2,303**	1,975
Other income	**8**	9,438	–	**9,438**	4,224
Total income		515,510	46,472	**561,982**	487,892
Expenditure					
Expenditure on raising funds:					
Costs of raising donations and grants	**9**	63,354	–	**63,354**	49,369
Costs of other trading activities	**10**	4,339	–	**4,339**	2,548
Expenditure on charitable activities	**11**	643,757	85,095	**728,852**	384,518
Total expenditure		711,450	85,095	**796,545**	436,435
Net (expenditure)/income		(195,940)	(38,623)	**(234,563)**	51,457
Transfers between funds		(4,451)	4,451	**–**	–
Net movement in funds		(200,391)	(34,172)	**(234,563)**	51,457
Reconciliation of funds					
Total funds brought forward		506,269	35,172	**541,441**	489,984
Total funds carried forward		305,878	1,000	**306,878**	541,441

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The notes on pages 28 to 39 form part of these financial statements

Dravet Syndrome UK

Statement of Financial Position

31 January 2025

		2025		2024
	Note	**£**	**£**	£
Fixed Assets				
Tangible fixed assets	**18**		**1,271**	1,026
Current Assets				
Stocks	**19**	**7,741**		12,389
Debtors	**20**	**66,336**		47,597
Cash at bank and in hand		**446,425**		496,275
		520,502		556,261
Creditors: amounts falling due within one year	**21**	**214,895**		15,846
Net Current Assets			**305,607**	540,415
Total Assets Less Current Liabilities			**306,878**	541,441
Net Assets			**306,878**	541,441
Funds of the Charity				
Restricted funds	**24**		**1,000**	35,172
Unrestricted funds	**24**		**305,878**	506,269
Total charity funds			**306,878**	541,441

These financial statements were approved by the board of trustees and authorised for issue on 23 July 2025, and are signed on behalf of the board by:

Signed by:
Alex Williams
19B4F4C74941485...

A Williams
Trustee and Treasurer

The notes on pages 28 to 39 form part of these financial statements

Dravet Syndrome UK

Statement of Cash Flows

Year Ended 31 January 2025

	2025 **£**	2024 £
Cash Flows from Operating Activities		
Net (expenditure)/income	**(234,563)**	51,457
Adjustments for:		
Depreciation of tangible fixed assets	**1,120**	794
Other interest receivable and similar income	**(2,303)**	(1,975)
Interest payable and similar charges	**139**	424
Changes in:		
Stocks	**4,648**	(1,424)
Trade and other debtors	**(18,739)**	34,639
Trade and other creditors	**199,049**	(31,911)
Cash generated from operations	**(50,649)**	52,004
Interest paid	**(139)**	(424)
Interest received	**2,303**	1,975
Net cash (used in)/from operating activities	**(48,485)**	53,555
Cash Flows from Investing Activities		
Purchase of tangible assets	**(1,365)**	–
Net cash used in investing activities	**(1,365)**	–
Net (Decrease)/Increase in Cash and Cash Equivalents	**(49,850)**	53,555
Cash and Cash Equivalents at Beginning of Year	**496,275**	442,720
Cash and Cash Equivalents at End of Year	**446,425**	496,275

The notes on pages 28 to 39 form part of these financial statements

Dravet Syndrome UK

Notes to the Financial Statements

Year Ended 31 January 2025

1. General information

The charity is a registered charity in England and Wales and is unincorporated. The address of the principal office is PO Box 756, Chesterfield, Derbyshire, S43 9EB.

2. Statement of compliance

These financial statements have been prepared in compliance with FRS 102, 'The Financial Reporting Standard applicable in the UK and the Republic of Ireland', the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (Charities SORP (FRS 102)) and the Charities Act 2011.

3. Accounting policies

Basis of preparation

The financial statements have been prepared on the historical cost basis. The financial statements are prepared in sterling, which is the functional currency of the entity. The charity meets the definition of a public benefit entity under FRS102.

Going concern

The trustees have prepared and reviewed budgets and are confident that these show that the charity is able to operate within its available resources and meet its liabilities as they fall due for the foreseeable future. Accordingly, the trustees consider it appropriate to continue to adopt the going concern basis of accounting in preparing the financial statements.

Judgements and key sources of estimation uncertainty

In application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates. The estimates and underlying assumptions are reviewed on an ongoing basis. The trustees consider that there are no key sources of estimation uncertainty affecting these financial statements.

Fund accounting

Unrestricted funds are available for use at the discretion of the trustees to further any of the charity's purposes and general objectives. Designated funds are unrestricted funds set aside by the trustees for particular future projects or commitments. Restricted funds are subjected to restrictions on their expenditure imposed by the donor or which have been raised for particular purposes. Any costs of raising and administering such funds are charged against the specific fund.

3. Accounting policies *(continued)*

Incoming resources

All income is included in the statement of financial activities when entitlement has passed to the charity, it is probable that the economic benefits associated with the transaction will flow to the charity and the amount can be reliably measured. The following specific policies are applied to particular categories of income:

- income from donations or grants is recognised when there is evidence of entitlement to the gift or grant, receipt is considered probable and its amount can be measured reliably.

- income from the sale of merchandise is recognised at the point of sale.

- income from donated services and facilities are recognised as income when the charity has control over the item, any conditions associated with the donated item have been met, the receipt of economic benefit from the use by the charity of the item is probable and that economic benefit can be measured reliably.

Resources expended

Expenditure is recognised on an accruals basis as a liability is incurred.

Expenditure on raising funds includes the costs of all fundraising activities, events, non-charitable trading activities, and the sale of purchased and donated goods.

Expenditure on charitable activities includes all costs incurred by a charity in undertaking activities that further its charitable aims for the benefit of its beneficiaries, including those support costs and costs relating to the governance of the charity apportioned to charitable activities.

Tangible assets

Tangible assets are initially recorded at cost, and subsequently stated at cost less any accumulated depreciation and impairment losses.

Depreciation

Depreciation is calculated so as to write off the cost or valuation of an asset, less its residual value, over the useful economic life of that asset as follows:

Fixtures, fittings, equipment - 25% straight line
Computer equipment - 33% straight line

Stocks

Stocks of goods for resale are measured at the lower of cost and net realisable value.

Pensions

The charity operates a defined contribution pension scheme, the assets of which are held separately from those of the charity. Contributions payable for the year are shown within the statement of financial activities.

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2025

4. Donations and grants

	Unrestricted Funds £	Restricted Funds £	**Total Funds 2025 £**
Donations			
Donations	498,014	3,006	**501,020**
Grants			
DSUK conference	–	–	**–**
Center Parcs event	–	–	**–**
Seizure monitors	–	2,000	**2,000**
Bereavement grants	–	2,000	**2,000**
Professional website development	–	18,000	**18,000**
Family support	–	–	**–**
Fundraising grant	–	–	**–**
Transition Guide	–	15,500	**15,500**
CZ Rare As One funding	–	5,966	**5,966**
	498,014	46,472	**544,486**

	Unrestricted Funds £	Restricted Funds £	Total Funds 2024 £
Donations			
Donations	390,260	1,900	392,160
Grants			
DSUK conference	–	66,625	66,625
Center Parcs event	–	5,000	5,000
Seizure monitors	–	–	–
Bereavement grants	–	–	–
Professional website development	–	5,000	5,000
Family support	–	1,000	1,000
Fundraising grant	–	2,500	2,500
Transition Guide	–	–	–
CZ Rare As One funding	–	–	–
	390,260	82,025	472,285

The trustees confirm that the above restricted income recognised in respect of the DSUK Conference 2023 in the comparative period is compliant with The Association of the British Pharmaceutical Industry Code of Practice.

5. Charitable activities

	Unrestricted Funds £	**Total Funds 2025 £**	Unrestricted Funds £	Total Funds 2024 £
DSUK conference ticket income	–	**–**	6,961	6,961

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2025

6. Other trading activities

	Unrestricted Funds £	**Total Funds 2025 £**	Unrestricted Funds £	Total Funds 2024 £
Merchandise sales	5,755	**5,755**	2,447	2,447

7. Investment income

	Unrestricted Funds £	**Total Funds 2025 £**	Unrestricted Funds £	Total Funds 2024 £
Bank interest receivable	2,303	**2,303**	1,975	1,975

8. Other income

	Unrestricted Funds £	**Total Funds 2025 £**	Unrestricted Funds £	Total Funds 2024 £
Consultancy services	7,917	**7,917**	4,224	4,224
Sundry fundraising activities	1,521	**1,521**	–	–
	9,438	**9,438**	4,224	4,224

9. Costs of raising donations and grants

	Unrestricted Funds £	Restricted Funds £	**Total Funds 2025 £**
Event costs	12,905	–	**12,905**
Wages and salaries	32,040	–	**32,040**
Employer's NIC	2,253	–	**2,253**
Pension costs	651	–	**651**
Fundraising consultancy fees	–	–	**–**
Merchandise used for fundraising	5,833	–	**5,833**
Just Giving charges	9,672	–	**9,672**
	63,354	–	**63,354**

	Unrestricted Funds £	Restricted Funds £	Total Funds 2024 £
Event costs	16,739	2,642	19,381
Wages and salaries	17,500	–	17,500
Employer's NIC	932	–	932
Pension costs	393	–	393
Fundraising consultancy fees	3,600	–	3,600
Merchandise used for fundraising	2,211	–	2,211
Just Giving charges	5,352	–	5,352
	46,727	2,642	49,369

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2025

10. Costs of other trading activities

	Unrestricted Funds £	**Total Funds 2025 £**	Unrestricted Funds £	Total Funds 2024 £
Opening merchandise stock	11,240	**11,240**	10,347	10,347
Merchandise purchases	6,151	**6,151**	5,652	5,652
Merchandise used for fundraising	(5,833)	**(5,833)**	(2,211)	(2,211)
Closing merchandise stock	(7,219)	**(7,219)**	(11,240)	(11,240)
	4,339	**4,339**	2,548	2,548

11. Expenditure on charitable activities by activity type

	Activities undertaken directly £	Support costs £	**Total funds 2025 £**	Total fund 2024 £
Research funding	193,068	17,249	**210,317**	10,031
Raising awareness	181,763	70,921	**252,684**	187,716
Supporting families	143,800	56,108	**199,908**	140,599
Governance costs	–	65,943	**65,943**	46,172
	518,631	210,221	**728,852**	384,518

12. Analysis of support costs

	Analysis of support costs - charitable activities £	**Total 2025 £**	Total 2024 £
Staff costs	28,289	**28,289**	6,236
Communications and IT	105,018	**105,018**	16,009
General office	2,937	**2,937**	1,649
Human resources	7,895	**7,895**	4,703
Finance costs	139	**139**	424
Governance costs	65,943	**65,943**	46,172
	210,221	**210,221**	75,193

13. Net (expenditure)/income

Net (expenditure)/income is stated after charging/(crediting):

	2025 £	2024 £
Depreciation of tangible fixed assets	**1,120**	794

14. Independent examination fees

	2025 **£**	2024 £
Fees payable to the independent examiner for:		
Independent examination of the financial statements	**3,900**	3,240

15. Staff costs

The total staff costs and employee benefits for the reporting period are analysed as follows:

	2025 **£**	2024 £
Wages and salaries	**200,411**	123,013
Social security costs	**14,095**	6,813
Employer contributions to pension plans	**4,070**	2,726
	218,576	132,552

The average head count of employees during the year was 7 (2024: 4).

No employee received employee benefits of more than £60,000 during the year (2024: None).

Key Management Personnel

Key management personnel include all persons that have authority and responsibility for planning, directing and controlling the activities of the charity. The total compensation paid to key management personnel for services provided to the charity was £57,971 (2024: £57,558).

16. Trustee remuneration and expenses

No remuneration or other benefits from employment with the charity or a related entity were received by the trustees.

There are 4 trustees (2024: 4) that claimed expenses or had their expenses met by the charity as follows:

	2025 **£**	2024 £
Travel	**1,274**	644
Hotel and Subsistence	**91**	60
	1,365	704

Additionally allowances of £1,000 (2024: £1,000) were paid to 2 trustees (2024: 2) in respect of their attendance at the annual Center Parcs event.

17. Transfers between funds

A transfer of £4,451 (2024: £12,752) was made from unrestricted funds to restricted funds during the year. This transfer was to cover expenditure incurred in excess of amounts received for the stated purpose.

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2025

18. Tangible fixed assets

	Fixtures and fittings £	Equipment £	**Total** **£**
Cost			
At 1 February 2024	490	5,811	**6,301**
Additions	–	1,365	**1,365**
At 31 January 2025	490	7,176	**7,666**
Depreciation			
At 1 February 2024	489	4,786	**5,275**
Charge for the year	–	1,120	**1,120**
At 31 January 2025	489	5,906	**6,395**
Carrying amount			
At 31 January 2025	1	1,270	**1,271**
At 31 January 2024	1	1,025	1,026

19. Stocks

	2025 **£**	2024 £
Merchandise and consumables	**7,219**	11,240
Monitors	**522**	1,149
	7,741	12,389

20. Debtors

	2025 **£**	2024 £
Prepayments and accrued income	**66,336**	41,184
Other debtors	**–**	6,413
	66,336	47,597

21. Creditors: amounts falling due within one year

	2025 **£**	2024 £
Accruals and deferred income	**85,466**	4,095
Social security and other taxes	**2,932**	2,663
Other creditors	**126,497**	9,088
	214,895	15,846

22. Deferred income

	2025 **£**	2024 £
At 1 February 2024	**–**	21,375
Amount released to income	**–**	(21,375)
Amount deferred in year	**78,115**	–
At 31 January 2025	**78,115**	–

Deferred income at the year-end represents funding received where entitlement to the income has not yet passed to the charity at that date.

23. Pensions and other post-retirement benefits

Defined contribution plans

The amount recognised in income or expenditure as an expense in relation to defined contribution plans was £4,070 (2024: £2,726).

24. Analysis of charitable funds

Unrestricted funds

	At 1 February 2024 £	Income £	Expenditure £	Transfers £	**At 31 January 2025 £**
General funds	307,269	515,510	(538,968)	22,067	**305,878**
Customer Relationship Management system	61,650	–	(35,132)	(26,518)	**–**
Designated strategic growth fund	3,684	–	(3,684)	–	**–**
Designated Center Parcs 2024 fund	27,333	–	(27,333)	–	**–**
Website development fund	23,000	–	(23,000)	–	**–**
Research fund	83,333	–	(83,333)	–	**–**
	506,269	515,510	(711,450)	(4,451)	**305,878**

	At 1 February 2023 £	Income £	Expenditure £	Transfers £	At 31 January 2024 £
General funds	432,533	378,534	(310,063)	(193,735)	307,269
Customer Relationship Management system	–	–	–	61,650	61,650
Designated strategic growth fund	–	–	(9,316)	13,000	3,684
Designated Center Parcs 2024 fund	–	27,333	–	–	27,333
Website development fund	–	–	–	23,000	23,000
Research fund	–	–	–	83,333	83,333
	432,533	405,867	(319,379)	(12,752)	506,269

24. Analysis of charitable funds *(continued)*

Designated Funds

Customer Relationship Management ("CRM") fund

The Trustees designated £61,650 of unrestricted funds to the planned implementation of a CRM system to enable the charity to deliver against its strategic objectives, in line with the forecast costs of the project. The project was in the final stages of completion at the year-end and the system was in use early in the 2025-2026 financial period.

Website development fund

The Trustees designated £35,000 of unrestricted funds towards the planned implementation of development work to improve the charity's website for the benefit of all users, in line with the forecast costs of the project. The project was in the final stages of completion at the year-end and the enhanced website was completed in the 2025-2026 financial period.

Strategic Growth fund

The Trustees designated £13,000 of unrestricted funds to the Strategic Growth Fund, whose purpose was to fund the recruitment of two senior roles within the charity. The work was ongoing at the end of the comparative period and was completed in the 2024-2025 financial period.

Center Parcs 2024 event fund

During the comparative year the charity received an unrestricted donation from Wilmington Trust of £27,333, which the Trustees decided to designate to meet the cost of family grants paid to service users to help fund their costs of attending the Center Parcs event in June 2024. The funding was fully utilised during the year.

Research fund

During the comparative year the charity entered into a memorandum of understanding with Epilepsy Research Institute UK to provide funding for research into Dravet Syndrome. The commitment made by the charity was for £83,333 and the Trustees designated this amount from unrestricted reserves. In the 2024-2025 financial year the charity made an unconditional commitment to fund £176,998 of research to be carried by Epilepsy Research Institute UK.

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2025

24. Analysis of charitable funds *(continued)*

Restricted funds

	At 1 February 2024 £	Income £	Expenditure £	Transfers £	**At 31 January 2025 £**
Research	25,464	3,006	(28,470)	–	**–**
Bereavement grants	–	2,000	(1,000)	–	**1,000**
Website development	12,259	18,000	(30,259)	–	**–**
Center Parcs 2024	(4,451)	–	–	4,451	**–**
Music therapy research	1,000	–	(1,000)	–	**–**
Monitors	900	2,000	(2,900)	–	**–**
Transition Guide	–	15,500	(15,500)	–	**–**
Chan Zuckerberg Rare As One	–	5,966	(5,966)	–	**–**
	35,172	46,472	(85,095)	4,451	**1,000**

	At 1 February 2023 £	Income £	Expenditure £	Transfers £	At 31 January 2024 £
Research	24,464	1,000	–	–	25,464
Seizure monitors - Nottinghamshire	500	–	(500)	–	–
Bereavement grants	1,500	–	(1,500)	–	–
Center Parcs 2023	(938)	5,000	(4,062)	–	–
Family support	16,078	–	(16,078)	–	–
Website development	15,847	5,000	(8,588)	–	12,259
DSUK Conference 2023	–	66,625	(79,377)	12,752	–
Abseil	–	2,500	(2,500)	–	–
Center Parcs 2024	–	–	(4,451)	–	(4,451)
Music therapy research	–	1,000	–	–	1,000
Monitors	–	900	–	–	900
	57,451	82,025	(117,056)	12,752	35,172

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2025

24. Analysis of charitable funds *(continued)*

In the reporting year, the charity was able to utilise funding from a number of pharmaceutical companies for development work on the charity's website and the updating of the Transition Guide. This included grants from Encoded Therapeutics, Stoke Therapeutics, Takeda Pharmaceuticals, Jazz Pharmaceuticals and UCB.

The charity also continued to receive financial support from its corporate partner, XTX Markets.

25. Analysis of net assets between funds

	Unrestricted Funds £	Restricted Funds £	**Total Funds 2025 £**
Tangible fixed assets	1,271	–	**1,271**
Current assets	519,502	1,000	**520,502**
Creditors less than 1 year	(214,895)	–	**(214,895)**
Net assets	305,878	1,000	**306,878**

	Unrestricted Funds £	Restricted Funds £	Total Funds 2024 £
Tangible fixed assets	1,026	–	1,026
Current assets	521,089	35,172	556,261
Creditors less than 1 year	(15,846)	–	(15,846)
Net assets	506,269	35,172	541,441

26. Analysis of changes in net debt

	At 1 Feb 2024 £	Cash flows £	**At 31 Jan 2025 £**
Cash at bank and in hand	496,275	(49,850)	**446,425**

27. Related parties

No transactions with related parties occurred in either the current or comparative year which require disclosure within these financial statements.

DRAVET
Syndrome UK

Hope for families with life-limiting epilepsy

Dedicated to improving the lives of people affected by
Dravet Syndrome through support, education and research.

Registered charity number: 1128289

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