

DRAVET
Syndrome UK

Hope for families with life-limiting epilepsy



Dravet Syndrome UK

ANNUAL REVIEW

2023-24

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Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2024

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		
	G Wilson-John		
	J D R Lloyd		
	N Williamson		
	A Williams		
	S Smith	(Appointed 26 July 2023)	(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 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

WELCOME

The last financial year (February 2023 to January 2024) has been an eventful and exciting year for Dravet Syndrome UK (DSUK), with several key projects coming to fruition as we continue to deliver against our strategy.

Working with our expert Medical Advisory Board and other stakeholders, we have helped to lead the conversation about Dravet Syndrome in the UK, participating in a range of meetings and events to improve understanding of Dravet Syndrome. In November 2023, we hosted our sixth biennial conference, bringing together over 90 professionals and nearly 200 parents/carers, making this our largest educational event since the pandemic.

We have also delivered research that prioritises the needs of families. One of the highlights of the year was the launch of the SCN1A Horizons Natural History Study, by lead investigator Professor Andreas Brunklaus at the DSUK Conference. DSUK is a co-funder of this study, which has the potential to transform our understanding for SCN1A epilepsies, including Dravet Syndrome.

Families are at the heart of everything we do at DSUK and we were delighted to grow our community further last year, welcoming 30 new families. As set out in our strategy, our goals are to reach as many families as possible with our practical, emotional, and financial support, and empower them with the information and advice they need to meet the everyday challenges of living with Dravet Syndrome.

Another key highlight of the year therefore was the launch of our revised and updated Family Guide, a comprehensive resource with information, advice, practical tips and insights to empower families through every step of their life-time journey with Dravet Syndrome.

In January 2024, as part of our planned strategic growth to bolster organisational capacity, we were delighted to appoint Katherine Raven as Head of Marketing and Communications. Katherine brings almost 20 years of experience in leading multi-disciplinary communications and marketing in the health sector including for national charities and the NHS.

We want to say a huge thank you to all our staff, volunteers, advisors, researchers, health professionals, fundraisers, families and every member of the Dravet Syndrome community. Together we work towards our mission to improve the lives of all those affected by Dravet Syndrome.



Galia Wilson, Chair of Trustees



HIGHLIGHTS OF OUR YEAR

IN 2023-2024, DRAVET SYNDROME UK:

WELCOMED

30

new families, growing our registered number of beneficiaries to

532 children/adults living with Dravet Syndrome.



GATHERED TOGETHER

a record-breaking

70

families living with Dravet

Syndrome at our Annual Weekend Away, building lasting connections in a welcoming and supportive environment.



CELEBRATED

14

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

33

young adults living with Dravet Syndrome, with the award totalling more than

£22,500

from our 16+ Assistance Fund.



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

52

seizure monitors that provide an early alert to seizures occurring.



DISTRIBUTED

nearly

600

printed copies of our new Family Guide to registered parents/carers, and health and care professionals.



INCREASED our online support forum (our private Facebook group) from 410 members to

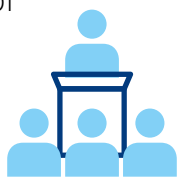
425

members.



HOSTED our 6th biennial conference the only scientific meeting dedicated to Dravet Syndrome, across two days in London, attended by a total of

92 professionals and
199 parents/carers.



SUPPORTED



4 ongoing research projects to improve treatment, care and family life with Dravet Syndrome, including two gene therapy projects, a scientific collaboration with Dravet Syndrome Europe organisations and a music therapy PhD.

PRESENTED

2 scientific posters at 2 medical conferences, including the world's biggest epilepsy meeting, American Epilepsy Society (AES), attended by more than

6,000 professionals.



REACHED more than

45,000 people with our video asking families to describe Dravet Syndrome in one word, raising awareness of the impact of the condition.



ANNOUNCED the launch of

SCN1A HORIZONS,

the first nationwide study to prospectively investigate the natural history of Dravet Syndrome in the UK.

SHARED information about Dravet Syndrome with over

36,000

website visitors (an increase of over

2,000

compared to the previous year.



BROUGHT TO LIFE all aspects of living with Dravet Syndrome via regular posts to our social media channels, which achieved a combined reach of over

250,000

across Facebook, Instagram, X and LinkedIn, while our videos gained over



63,000 views on YouTube.



SUPPORT

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

KEY ACHIEVEMENTS

Family support services

In 2023-24, 30 new families joined our Dravet Syndrome UK community. We now have 532 children/adults living with Dravet Syndrome, plus more than 700 parents/carers and 520 siblings registered with us.

When they register with Dravet Syndrome UK, families:

- ✓ receive a welcome pack of information – including the new Family Guide
- ✓ become eligible for our grants
- ✓ gain access to our private Facebook group and
- ✓ access to one-to-one advice from our Family Support Manager

Family Guide: Everything you need to know about living with Dravet Syndrome

In February 2023, we launched an updated and revised version of our Family Guide, the culmination of knowledge, lived experience and insights that we have gathered over the years, informed by the real-life experience of families, the expertise of our world-class Medical Advisory Board, and research about Dravet Syndrome. Whether newly diagnosed or caring for a child or an adult living with Dravet Syndrome for many years, parents and carers will find information, advice, practical tips and insights to help them on every step of their journey.

The Family Guide is a printed booklet covering every aspect of Dravet Syndrome in detail – from the characteristics of the condition and advice on managing these, to dealing with the challenges faced in everyday life.

We mailed out a print version of the Guide to every family registered with us and we provide a free copy in the Welcome Pack for every new family that registers. A downloadable PDF is also available on our website, and the print version is available to purchase on our Shop for £5. We have also given our copies of the guide to nearly 100 health and care professionals through attendance at medical meetings and conferences.

We have received overwhelming positive feedback on the Family Guide, here are just a few examples.

“

The Family Guide is an absolutely fantastic resource – comprehensive but understandable easy reading. Wish we'd had this at the beginning but as our daughter wasn't diagnosed (like many) until she was 18. I'll still be giving this to all her caregivers to read though as it still has information we didn't know. Thank you, Dravet Syndrome UK.

“

Just received the Dravet Syndrome UK Family Guide. Hats off to everyone involved in creating this absolute masterpiece! I've taken an extra copy to our daughter's new placement for staff to read - raising awareness and informing. I'm sure it will help so many families, well done! Brilliant guide!

Practical and emotional advice

Our Family Support Manager (who is also a parent to a young adult living with Dravet Syndrome) provides practical assistance (such as writing letters to support access to care) and emotional support to caregivers. She is available to provide one-to-one advice to families, or simply be there to listen to caregivers who need to talk to someone, who understands what they are going through.

The feedback from caregivers who have received 1:1 emotional and practical support provided has been consistently positive. In multiple cases, outcomes demonstrate specific and tangible benefits, such as the approval of applications for social care or schooling. In other cases, contact has helped to relieve the isolation and anxiety associated with living with a rare and devastating condition such as Dravet Syndrome.

We know that our families gain a huge amount of support from each other. In 2023-24, our private Facebook group grew from 410 to 425 members. There are usually around four or five new posts every day. Topics range from seizure medication to residential care options, as well as the ups and downs of everyday life with Dravet Syndrome. The forum is rooted in lived-experience and plays an essential part in reducing people's isolation and helping parents/carers and siblings feel less alone.

Bringing families together

In June 2023, 70 families living with Dravet Syndrome joined us at Center Parcs in Sherwood forest for our Annual Family Weekend Away. We fund two emergency paramedic crews and ambulances to be onsite with us throughout the weekend. Knowing that emergency medical support is there if needed is a key factor in enabling families to attend this weekend. We also provide a financial grant of £350 per family to help with costs.

The Annual Family Weekend is a rare opportunity for alleviating isolation and meeting other families going through similar challenges. The itinerary includes lots of opportunities for families to get together. It is a safe, inclusive and supportive environment for parents/carers and siblings to relax, knowing medical support is there if they need it, as they spend time with others who really understand what living with Dravet Syndrome is like.

“

After 25 years of our daughter being on this earth and receiving her Dravet Syndrome diagnosis 7 years ago, we feel that we have finally found “our tribe”.

Thank you to everyone who made us feel so welcome and at home. It's been such a special and emotional weekend. For every one of the Dravet Syndrome UK staff who organise the weekend, just know that your hard work matters and is appreciated more than we could put into words. Looking forward to next year already! **Mum to an adult daughter living with Dravet Syndrome**

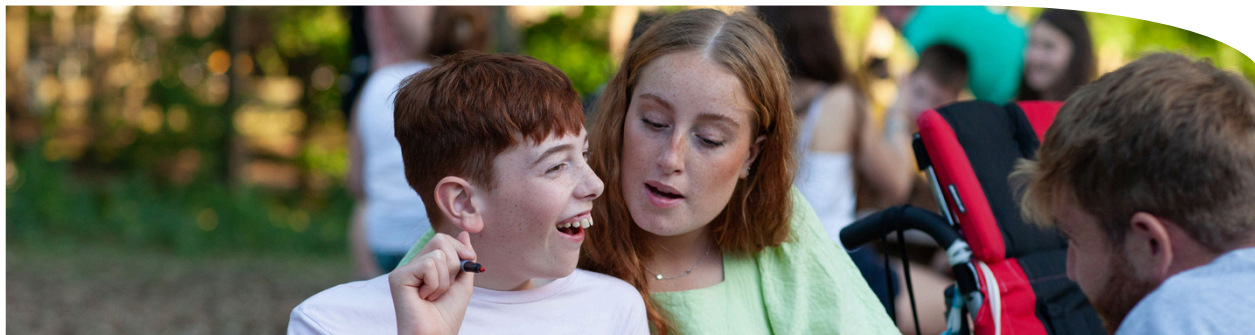
“

“Just wanted to message you and thank you so much for an amazing weekend. It was our first time coming to Center Parcs and at first I was really nervous and didn't know what to expect but I'm so glad me and the family came. It has really opened my eyes and speaking to other families made me understand a bit more on how to cope myself, deal with our son in different ways, and what to do” **Dad to a 2 year old boy living with Dravet Syndrome**



Sibling awards

Children who have a sibling with Dravet Syndrome have to adapt to day-to-day challenges – plans are cancelled, parents are stressed and exhausted, and they might see their sibling undergo upsetting emergency medical care. Our Sibling Awards recognise these unsung heroes of the Dravet Syndrome community. Last year, 11 children aged 5 to 15 received our Super Sibling Awards and 3 adults (16 years and older) gained our Sibling Recognition Awards. All were given 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 2023-24, our **Seizure Monitor Fund** awarded 52 seizure monitors, helping alert parents/carers early when their child or adult has a seizure. Responding early to a seizure can potentially reduce the risks of serious harm.

Our **16+ Assistance Fund** aims to help address the gap in grants available to families with disabled adults. We offer an annual grant of up to £1,000. The grant can be used to fund any items of equipment or assistance that will improve the life of a young adult with Dravet Syndrome, aged 16 or older. In 2023-2024, we awarded 33 grants totalling over £22,500. We funded a range of items including special educational apps, sensory equipment, therapy sessions and funding towards buggies and motability equipment.

“

Our daughter has now finished formal education and is doing some online courses and basic computer courses. She feels very important! Thank you so much for the opportunity to access a super-duper laptop through the Dravet Syndrome UK 16+ Assistance Grant!

Mum to a young adult living with Dravet Syndrome



Sadly, we also provided three **bereavement grants** to families who lost a child with Dravet Syndrome. The grants of £1,000 each help families manage funeral costs and can be a financial lifeline at the toughest time in their lives. The bereavement grants we offer are supported by funding we received from the St James's Place Charitable Foundation.

Harry's Story

Harry was diagnosed with Dravet Syndrome at 16 months old. He lives with his mum Beth, Dad Craig and sister Tilly. We are thankful to mum, Beth, for sharing the family's story.

“

Since joining Dravet Syndrome UK, I cannot put into words how much the support has benefitted us as a family.



“Harry had his first seizure when he was just 4 months old, on the evening of his 16 week vaccinations. He was checked over in hospital and they believed he had had a febrile seizure. A few weeks later he had another, again triggered by a temperature. The third time he had one he was 6 months old. He was diagnosed with epilepsy and he began medication.

Just after his first birthday, he had 48 hours of seizures. He was admitted to hospital and recommended for genetic testing. A month later, the consultant told us that Harry has an SCN1A related seizure disorder – Dravet Syndrome.

Being told that Harry had Dravet Syndrome changed our lives forever. While the rest of the week was a blur, where I spent hours upon hours researching, trying to find out what Harry's life was going to be like and what we as a family were likely to expect, having that diagnosis meant that I found Dravet Syndrome UK. We registered straight away.

Since joining Dravet Syndrome UK I cannot put into words how much the support has benefited us as a family. The wonderful team being there for us, makes us feel extremely supported. The Family Guide has been the most helpful resource - I hand it over to healthcare professionals so they can read it, instead of me having to explain it all.

To have contact with families on the private Facebook forum, who are going through what we're going through has been amazing - it makes us feel less isolated, gives us hope, and it's so beneficial to have access to a wealth of advice and information from lived-experiences!

The Annual Family Weekend Away is a brilliant experience. We feel 'part of something' and know we are somewhere where we aren't in the minority. We can truly relax and enjoy quality family time, with peace of mind that if anything were to happen, medical support is on hand. The DSUK Conference is also such a useful day, where I felt informed and hopeful after hearing about all the research that is happening. After having so many encounters with professionals who don't understand Dravet Syndrome, it was amazing to hear from engaging and passionate speakers who are making a big difference!

We are very lucky to be supported by a great family and have a brilliant support network. We also feel so very lucky to have Harry and although there are some really hard days, he always has that little glint in his eye that even when he isn't his normal happy self, he gives us all that little bit of happiness we need.”



EDUCATION

We raise awareness and understanding of Dravet Syndrome

KEY ACHIEVEMENTS

Raising public awareness

June is Dravet Syndrome Awareness Month. In 2023, we reached over 110,000 people through our month-long social media campaign, sharing key facts about Dravet Syndrome and real-life stories about its impact on the daily lives of those living with the condition and their families.

On Dravet Syndrome Awareness Day, 23rd June, we shared an impactful new video 'Dravet in One Word', featuring families who live with Dravet Syndrome describing what it means to them in one word. Responses included "life-changing", "a rollercoaster", "devastating" and "overwhelming", but also touched on the positive sides of family life, including the incredible love and "amazing rewards" that being a parent/carers can bring.

We published the video via our social media channels with a call to action to share to help raise awareness, encourage more diagnosis and improved support for families. It was viewed more than 45,000 times in June alone. You can watch the video in full here: <https://www.youtube.com/watch?v=6VICedy66QY>

Biennial conference

In November 2023, welcomed professionals and parents/carers to London for our two-day biennial conference, the only UK meeting dedicated to furthering knowledge about Dravet Syndrome. In total we educated 92 professionals and empowered nearly 200 parents/carers with valuable information and practical advice.



As in previous years, the conference took place across two days - one day for Professionals and one for Parents/Carers, with a packed agenda of leading voices in Dravet Syndrome to enable discussion of the latest updates, news and medical research. Both days featured presentations led by members of DSUK's world-class Medical Advisory Board, including Professor Helen Cross (chair), Professor Sanjay Sisodiya, Professor Sameer Zuberi, Professor Andreas Brunklaus and Dr Elaine Hughes, as well as guest speakers Professor Ingrid Scheffer and Dr Lisa Clayton.

The Parent/Carer day also included interactive workshops addressing some important topics that can be particularly challenging for parents/carers. Our expert speakers offered practical guidance and advice on issues including managing challenging behaviours, future financial planning, accessing Education, Health and Care plans (EHCP) and puberty and sexual behaviours in young people with Dravet Syndrome.

We're grateful to all our speakers including our Medical Advisory Board, Professor Scheffer, Dr Clayton, Professor Michael Absoud, Dr Jennifer Baulcomb and Laura Donaldson from Evelina Children's Hospital, the Wills and Trusts team from Mencap, Fiona Scolding KC and Neil Williamson, our Trustee and Epilepsy Nurse Specialist.

The Professional Day was accredited by the RCP and RCPCH and as in previous years, the DSUK Conference overall received very positive feedback on the educational quality of the presentations, the expert guidance provided, and the opportunity to network with specialists in Dravet Syndrome.

“

I'll be able to use new knowledge gained from a very informative and interesting day, when caring for my patient, and will have further understanding if I have a newly diagnosed child living with Dravet Syndrome join my caseload.

Healthcare Professional Attendee

“

“You learn so much from all the Professionals who are there at the Conference. You get to meet other families who are in the same circumstances as you and it makes such a difference. You go away from the Conference just feeling more empowered - more empowered because of information that you've been given and more empowered because you know you're not alone”.

Parent/Carer Attendee

Educating professionals at medical meetings and events

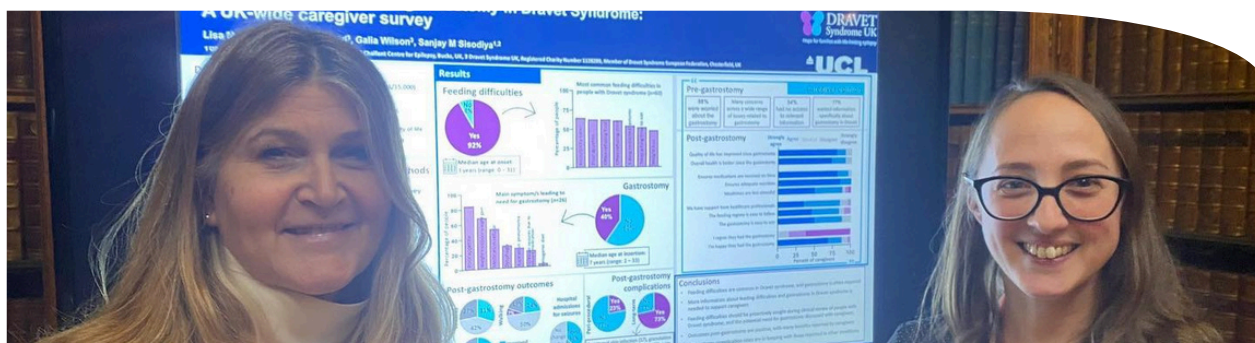
In 2023-24, we attended:

- **International League Against Epilepsy/International Epilepsy Conference (EEC/ICE)**, a leading scientific meeting attended by neurologists from across Europe. Our Chair and Director hosted an exhibition stand about Dravet Syndrome to raise awareness with delegates, met with researchers, experts and industry representatives and attended a collaborative meeting with our fellow patient organisations across Europe, hosted by the Dravet Syndrome European Federation.

- **American Epilepsy Society (AES) Annual Meeting**, the world's largest epilepsy meeting attended by more than 6,000 professionals. Our Chair and Director joined Professor Andreas Brunklaus and researcher Erin Freeman Jones to present a scientific poster analysing the results of our DSUK Family Survey, which described the profound impact that living with Dravet Syndrome has on individuals, caregivers and other family members, including siblings.

The study, based on responses from 165 caregivers of children and adults diagnosed with Dravet Syndrome, highlighted the huge impact of caregiving and concluded that families will benefit from improved communication with healthcare professionals, psychosocial interventions (such as family counselling) and better access to social care. We also learnt about the latest research developments in Dravet Syndrome and met with other patient organisations and leading experts.

- **British Paediatric Neurology Association (BPNA) Annual Conference**, where our Chair and Director shared another scientific poster which shared the top line results from DSUK's focus groups in collaboration with Glasgow University, looking at the emotional and psychological impact of caring for someone living with Dravet Syndrome. We also had an exhibition stand where we distributed our Could it be Dravet? leaflet and engaged one-to-one with professionals to help raise awareness.



Making sure parent/carer voices are heard

In 2023-24, we spoke at a range of meetings with other organisations involved in developing and providing current and future treatments for Dravet Syndrome. This included those from the rare diseases sectors, other charities with an interest in epilepsy/neurological conditions, the pharmaceutical industry, the NHS and the Scottish Medicines Consortium (SMC).

We are grateful to all stakeholders for listening to the patient and carer community, particularly when it comes to the impact on quality of life.



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

Our strategy sets out our aim to deliver research that puts the needs of the families living with Dravet Syndrome front and centre. Our research priorities are:

- ✓ Understanding, treating and improving care for the non-seizure related aspects of Dravet Syndrome (known as 'comorbidities')
- ✓ Improving treatment and care for adults living with Dravet Syndrome, from transition through to later adulthood
- ✓ Understanding the impact of the changing climate on people living with Dravet Syndrome
- ✓ Exploring how social care can help to improve the quality of life of people affected by Dravet Syndrome

We also support medical research into Dravet Syndrome by collaborating with researchers and companies developing treatments. Our aim is to bridge the gap between families affected by Dravet Syndrome and researchers. We make sure research meets the needs of families and that their voices and priorities are heard as studies are developed.

Ongoing research

SCN1A Horizons Natural History Study

The SCN1A Horizons Natural History study was launched at the DSUK Conference in November.

SCN1A-related epilepsy occurs in around 1 in 12,500 live births in the UK, with Dravet Syndrome occurring in 1 in every 15,000.



Despite advances in research about Dravet Syndrome, there remain many important unanswered questions, such as the impact of anti-seizure medications, neuro-developmental and behavioural comorbidities, and mortality rates (Dravet Syndrome has a higher risk of SUDEP compared to other epilepsies). Using a prospective data collection design, the SCN1A Horizons study will inform a better understanding of the condition and potential treatment options.

The nationwide study aims to define the seizure, neuro-developmental, and behavioural characteristics of SCN1A-related epilepsies in 400 children and adults over a period of three years, with the goal of improving and standardising care across the UK.

Chief Investigator, Professor Andreas Brunklaus, a Consultant Paediatric Neurologist based at the Royal Hospital for Children, University of Glasgow and member of DSUK's Medical Advisory Board, explains:

“

Natural history studies have a successful track record, for example in improving care and understanding of neuromuscular conditions. By systematically collecting data in detail and over an extended period, we can address many of the current unknowns in Dravet Syndrome and other SCN1A epilepsies. In addition, collecting data in a standardised way creates an opportunity to raise standards of care, not just in one centre but across the UK and beyond.

Neurodevelopmental assessments are a key part of this study, informing knowledge beyond the clinical perspective and profiling the neurocognitive development of those with Dravet Syndrome and other SCN1A-related epilepsies over time. During these assessment visits, the research assistants will also collect self-reported data from caregivers, to give a deeper insight into the impact SCN1A-related epilepsies has not only on the individual but also on the families.

SCN1A Horizons is a non-commercial study, sponsored by the NHS Greater Glasgow and Clyde and funded by a combination of commercial and charity funding, including from Dravet Syndrome UK.

For more information about the SCN1A Horizons Natural History Study, including information about participating centres, please contact the study team on SCN1AHorizons@glasgow.ac.uk.

Other current research projects

Other research projects supported by DSUK and ongoing in 2023-2024 include two gene therapy projects, a scientific collaboration with Dravet Syndrome European organisations, and a music therapy PhD. For more information on our current research projects, please visit our website: <https://www.dravet.org.uk/Research-Current/>

Future research projects

It is an exciting time for advancing research in Dravet Syndrome and at DSUK we actively seek partners to fund novel projects that address our research priorities.

In 2023-2024, we agreed a new collaboration with the Epilepsy Research Institute to fund a Joint Fellowship for research into Dravet Syndrome. We look forward to sharing more information about the outcome of the Fellowship and more in next year's Annual Report.





FUNDRAISING FOCUS

Community fundraising

We would like to pay tribute to our amazing community fundraisers, who raised a collective total of £347,330 in 2023-2024.

We are so grateful for the passion and dedication of our community fundraisers. Across every part of the UK, our supporters have been running, cycling, climbing, crafting, baking, wearing purple and much much more, to raise money for Dravet Syndrome UK.

Our first ever Awesome Abseil took place in Liverpool and London in the autumn, with 68 brave participants reaching new heights, raising a huge amount of awareness and a sky-high £33,500!

Thank you to Tamara Ward and her husband Mike for raising more than £85,000 in May 2023, for the third year of their epic 5K #EveryDayinMay4Dravet challenge. A phenomenal team of 280 runners, walkers, cyclists and swimmers joined from across the globe.

A special mention to Surrey Cricket Club and employee, cricketer Matt Dunn, who got behind this challenge, in memory of Matt's daughter, Florence. Matt and family gathered colleagues and friends to join them to run Every Day in May 4 Dravet, raised the profile of Dravet Syndrome in national and sports news, and worked with the club to arrange a Charity Match Day, which included a group run from Lourdes to the Oval, Dravet Syndrome UK advertising on screens within the stadium, a caps auction and press coverage.



We are so very grateful to Matt and family for their dedication to raising awareness and funds in tribute to Florence at such a devastating time.

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 2023-2024. The company contributed towards our family support, education and empowerment and research projects. The XTX Markets staff running club also took on both the Hackney Half Marathon and the Royal Parks Half Marathon for DSUK, and their efforts were kindly match-funded by XTX.



In 2023-2024, our partnership continued with construction industry company **Roofdec**, who kindly sponsored our Awesome Abseil fundraising event, and had a team of 8 employees take part in this sky-high challenge.

Our partnership with finance providers, **Cubefunder**, involved a company-organised Golf Day, sponsorship of our parent/carers conference, and a raffle for staff and clients, helping to increase awareness of Dravet Syndrome across their business networks.

Our ongoing partnership with **Kid-A** continued and we're looking forward to working with them more closely following their successful growth period.

Industry grants

We are grateful for continued support from the pharmaceutical industry and medical devices sector. We were particularly grateful to those companies sponsoring our biennial professional conference including, Biocodex, Encoded Therapeutics, Jazz Pharmaceuticals, Liva Nova, Stoke Therapeutics, Takeda, UCB. We were also grateful to Jazz Pharmaceuticals and UCB for providing restricted grants to enable family support and educational projects.

Trusts and foundations

We were delighted to be awarded a grant from the Wilmington Trust in January 2024. The grant contributed towards the costs of our Annual Weekend Away at Center Parcs, including family attendance grants (taking place in 2024).

The Boshier-Hinton Foundation supported us with a grant to help fund medical teams for our Annual Family Weekend Away. The medical teams are a primary enabler for families attending.

We'd like to thank St James's Place Charitable Foundation for funding our bereavement grants for the second year running.



LOOKING FORWARD

Next year, we will continue to be driven by our strategy which underpins and guides our work through to 2026. It provides a roadmap to help us reach our overall mission, as it has done in 2023-24.

We want to:

- reach more families
- deliver research that puts family needs first
- improve awareness and understanding amongst professionals, particularly in adult neurology and social services
- give families the tools and support needed to assert their rights.

The strategy includes the following four 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.



FINANCIAL REVIEW

Incoming Resources

Dravet Syndrome UK received income from the following sources:

	2024 £	2023 £
Community fundraising	347,330	325,697
Industry grants	75,625	55,564
Corporate sponsorship	44,830	47,000
Grants from Trusts/Foundations	4,500	22,500
Income generation	15,607	5,313
Total	487,892	456,074

Community fundraising has been an important source of income for DSUK and it continues to be so, supported by generous sponsorship and match funding initiatives from companies such as our corporate partner, XTX Markets. We are also grateful for restricted funding from the pharmaceutical industry to support our biennial conference and other educational activities.

Outgoing Resources

In 2023/2024 DSUK spent £436,435 (2022/2023: £371,118) 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
- The biennial Dravet Syndrome UK conference
- Dravet Syndrome UK merchandise for fundraising events & shop sales
- Staff costs, with 5 employees (4.0 FTE) paid for 152 hours of work per week on average for the year ended 31 January 2024.

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 2024, 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 2024-2025, six months of normal operating expenditure would be approximately £330,000. As of 31 January 2024, the unrestricted reserves of the charity amounted to:


	2024 £	2023 £
Unrestricted funds (note 23)	506,269	432,533
Less: Designated funds (note 23)	(199,000)	(73,000)
Less: Net book value of tangible fixed assets	(1,026)	(1,820)
Free reserves	306,243	357,713

While the charity was not fully meeting its reserves target at the year-end, it is important to note that the projected expenditure for the 2024-25 financial year is higher than in previous years, in anticipation of an increase in income for that financial year.

As set out in our 5-Year Strategy for 2021-2026, DSUK is currently implementing planned strategic and organisational growth. To enable this growth, our estimated expenditure in 2024-2025 is anticipated to exceed estimated income. Therefore, the current free reserves are deemed appropriate by the Board of Trustees to support planned growth while also ensuring continuity of charitable operations and provision of services to families affected by Dravet Syndrome.

The Trustee's Annual Report was approved on

And signed on behalf of the Board of Trustees by

Signed by:

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A Williams
Trustee and Treasurer

Date of signature 19 November 2024

Dravet Syndrome UK

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

Year Ended 31 January 2024

I report to the trustees on my examination of the financial statements of Dravet Syndrome UK ('the charity') for the year ended 31 January 2024.

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.

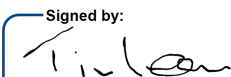
Independent examiner's statement

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:

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: 21 November 2024

Dravet Syndrome UK

Statement of Financial Activities (Incorporating Income and Expenditure Account)

Year Ended 31 January 2024

				2024	2023
	Note	Unrestricted funds £	Restricted funds £	Total funds £	Total funds £
Income					
Donations and grants	4	390,260	82,025	472,285	450,760
Charitable activities	5	6,961	–	6,961	–
Other trading activities	6	2,447	–	2,447	3,786
Investment income	7	1,975	–	1,975	603
Other income	8	4,224	–	4,224	925
Total income		<u>405,867</u>	<u>82,025</u>	<u>487,892</u>	<u>456,074</u>
Expenditure					
Expenditure on raising funds:					
Costs of raising donations and grants	9	46,727	2,642	49,369	41,058
Costs of other trading activities	10	2,548	–	2,548	1,896
Expenditure on charitable activities	11	270,104	114,414	384,518	328,164
Total expenditure		<u>319,379</u>	<u>117,056</u>	<u>436,435</u>	<u>371,118</u>
Net income		<u>86,488</u>	<u>(35,031)</u>	<u>51,457</u>	<u>84,956</u>
Transfers between funds		(12,752)	12,752	–	–
Net movement in funds		<u>73,736</u>	<u>(22,279)</u>	<u>51,457</u>	<u>84,956</u>
Reconciliation of funds					
Total funds brought forward		432,533	57,451	489,984	405,028
Total funds carried forward		<u>506,269</u>	<u>35,172</u>	<u>541,441</u>	<u>489,984</u>

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 27 to 37 form part of these financial statements.

Dravet Syndrome UK

Statement of Financial Position

31 January 2024

	Note	2024 £	2023 £
Fixed Assets			
Tangible fixed assets	17	1,026	1,820
Current Assets			
Stocks	18	12,389	10,965
Debtors	19	47,597	82,236
Cash at bank and in hand		496,275	442,720
		<u>556,261</u>	<u>535,921</u>
Creditors: amounts falling due within one year	20	<u>15,846</u>	<u>47,757</u>
Net Current Assets		<u>540,415</u>	<u>488,164</u>
Total Assets Less Current Liabilities		<u>541,441</u>	<u>489,984</u>
Net Assets		<u>541,441</u>	<u>489,984</u>
Funds of the Charity			
Restricted funds	23	35,172	57,451
Unrestricted funds	23	506,269	432,533
Total charity funds		<u>541,441</u>	<u>489,984</u>

These financial statements were approved by the board of trustees and authorised for issue on
19 November 2024, and are signed on behalf of the board by:

Signed by:

A Williams

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A Williams

Trustee and Treasurer

The notes on pages 27 to 37 form part of these financial statements.

Dravet Syndrome UK

Notes to the Financial Statements

Year Ended 31 January 2024

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.

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2024

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 2024

4. Donations and grants

	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
Bereavement grants	—	—	—
Professional website development	—	5,000	5,000
Family support	—	1,000	1,000
Fundraising grant	—	2,500	2,500
	<u>390,260</u>	<u>82,025</u>	<u>472,285</u>
	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £
Donations			
Donations	348,233	24,464	372,697
Grants			
DSUK conference	—	—	—
Center Parcs event	—	26,563	26,563
Bereavement grants	—	2,500	2,500
Professional website development	—	25,000	25,000
Family support	—	20,000	20,000
Fundraising grant	—	4,000	4,000
	<u>348,233</u>	<u>102,527</u>	<u>450,760</u>

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 2024 £	Unrestricted Funds £	Total Funds 2023 £
DSUK conference ticket income	<u>6,961</u>	<u>6,961</u>	<u>—</u>	<u>—</u>

6. Other trading activities

	Unrestricted Funds £	Total Funds 2024 £	Unrestricted Funds £	Total Funds 2023 £
Merchandise sales	<u>2,447</u>	<u>2,447</u>	<u>3,786</u>	<u>3,786</u>

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2024

7. Investment income

	Unrestricted Funds	Total Funds 2024	Unrestricted Funds	Total Funds 2023
	£	£	£	£
Bank interest receivable	<u>1,975</u>	<u>1,975</u>	<u>603</u>	<u>603</u>

8. Other income

	Unrestricted Funds	Total Funds 2024	Unrestricted Funds	Total Funds 2023
	£	£	£	£
Consultancy services	<u>4,224</u>	<u>4,224</u>	<u>925</u>	<u>925</u>

9. Costs of raising donations and grants

	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	<u>5,352</u>	<u>—</u>	<u>5,352</u>
	<u>46,727</u>	<u>2,642</u>	<u>49,369</u>

	Unrestricted Funds	Restricted Funds	Total Funds 2023
	£	£	£
Event costs	6,637	4,000	10,637
Wages and salaries	16,988	—	16,988
Employer's NIC	1,565	—	1,565
Pension costs	294	—	294
Fundraising consultancy fees	—	—	—
Merchandise used for fundraising	5,599	—	5,599
Just Giving charges	<u>5,975</u>	<u>—</u>	<u>5,975</u>
	<u>37,058</u>	<u>4,000</u>	<u>41,058</u>

10. Costs of other trading activities

	Unrestricted Funds	Total Funds 2024	Unrestricted Funds	Total Funds 2023
	£	£	£	£
Opening stock	10,347	10,347	13,402	13,402
Merchandise purchases	5,652	5,652	4,440	4,440
Closing stock	(11,240)	(11,240)	(10,347)	(10,347)
Merchandise used for fundraising	<u>(2,211)</u>	<u>(2,211)</u>	<u>(5,599)</u>	<u>(5,599)</u>
	<u>2,548</u>	<u>2,548</u>	<u>1,896</u>	<u>1,896</u>

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2024

11. Expenditure on charitable activities by activity type

	Activities undertaken directly £	Support costs £	Total funds 2024 £	Total fund 2023 £
Research funding	10,033	983	11,016	16,943
Raising awareness	174,688	17,901	192,589	193,103
Supporting families	130,840	12,814	143,654	98,210
Governance costs	—	37,259	37,259	19,908
	<u>315,561</u>	<u>68,957</u>	<u>384,518</u>	<u>328,164</u>

12. Analysis of support costs

	Analysis of support costs - charitable activities £	Total 2024 £	Total 2023 £
Staff costs	8,913	8,913	49,307
Premises	1,649	1,649	1,173
Communications and IT	16,009	16,009	8,131
Human resources	4,703	4,703	591
Finance costs	424	424	252
Governance costs	37,259	37,259	20,353
	<u>68,957</u>	<u>68,957</u>	<u>79,807</u>

13. Net income

Net income is stated after charging/(crediting):

	2024 £	2023 £
Depreciation of tangible fixed assets	794	463

14. Independent examination fees

	2024 £	2023 £
Fees payable to the independent examiner for: Independent examination of the financial statements	3,240	2,850

15. Staff costs

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

	2024 £	2023 £
Wages and salaries	123,013	121,352
Social security costs	6,813	10,868
Employer contributions to pension plans	2,726	2,331
	<u>132,552</u>	<u>134,551</u>

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2024

15. Staff costs *(continued)*

The average head count of employees during the year was 4 (2023: 4).

No employee received employee benefits of more than £60,000 during the year (2023: 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 £57,558 (2023: £48,976).

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 (2023: 1) that claimed expenses or had their expenses met by the charity as follows:

	2024 £	2023 £
Travel	644	85
Hotel and Subsistence	60	239
	<u>704</u>	<u>324</u>

17. Tangible fixed assets

	Fixtures and fittings £	Equipment £	Total £
Cost			
At 1 February 2023 and 31 January 2024	<u>490</u>	<u>5,811</u>	<u>6,301</u>
Depreciation			
At 1 February 2023	489	3,992	4,481
Charge for the year	—	794	794
At 31 January 2024	<u>489</u>	<u>4,786</u>	<u>5,275</u>
Carrying amount			
At 31 January 2024	<u>1</u>	<u>1,025</u>	<u>1,026</u>
At 31 January 2023	<u>1</u>	<u>1,819</u>	<u>1,820</u>

18. Stocks

	2024 £	2023 £
Stock of merchandise and consumables	11,240	10,347
Finished goods and goods for resale	1,149	618
	<u>12,389</u>	<u>10,965</u>

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2024

19. Debtors

	2024	2023
	£	£
Prepayments and accrued income	41,184	65,686
Other debtors	6,413	16,550
	<u>47,597</u>	<u>82,236</u>

20. Creditors: amounts falling due within one year

	2024	2023
	£	£
Accruals and deferred income	4,095	28,141
Social security and other taxes	2,663	2,709
Other creditors	9,088	16,907
	<u>15,846</u>	<u>47,757</u>

21. Deferred income

	2024	2023
	£	£
At 1 February 2023	21,375	26,563
Amount released to income	(21,375)	(26,563)
Amount deferred in year	–	21,375
At 31 January 2024	<u>–</u>	<u>21,375</u>

Deferred income released to the Statement of Financial Activities during the year related to funding received in respect of the DSUK Conference which was held in November 2023.

22. 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 £2,726 (2023: £2,331).

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2024

23. Analysis of charitable funds

Unrestricted funds

	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 educational materials fund	—	—	—	—	—
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
	<u>432,533</u>	<u>405,867</u>	<u>(319,379)</u>	<u>(12,752)</u>	<u>506,269</u>
	At 1 February 2022 £	Income £	Expenditure £	Transfers £	At 31 January 2023 £
General funds	359,425	353,547	(249,661)	(30,778)	432,533
Customer Relationship Management system	—	—	—	—	—
Designated educational materials fund	30,973	—	(30,973)	—	—
Designated strategic growth fund	—	—	—	—	—
Designated Center Parcs 2024 fund	—	—	—	—	—
Website development fund	—	—	—	—	—
Research fund	—	—	—	—	—
	<u>390,398</u>	<u>353,547</u>	<u>(280,634)</u>	<u>(30,778)</u>	<u>432,533</u>

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2024

23. Analysis of charitable funds *(continued)*

Designated Funds

Customer Relationship Management ("CRM") fund

The Trustees have 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. It is envisaged that the project will be completed by the end of the 2024-2025 financial period.

Website development fund

The Trustees have designated £35,000 of unrestricted funds to 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. It is envisaged that the project will be completed by the end of the 2024-2025 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. It was expected that the new roles would be filled by the end of the 2023/24 financial period but delays were experienced in the recruitment process and the process was actually completed in the early months of the 2024-2025 financial period.

Center Parcs 2024 event fund

During the 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. Any residual funding would then be applied to meet other costs of the event.

Research fund

During the 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 have designated this amount from unrestricted reserves. The research is due to commence in the 2024-2025 financial period.

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2024

23. Analysis of charitable funds *(continued)*

Restricted funds

	At 1 February 2023 £	Income £	Expenditure £	Transfers £	At 31 January 2024 £
Research	24,464	1,000	–	–	25,464
Center Parcs 2022 event	–	–	–	–	–
Seizure monitors - Nottinghamshire	500	–	(500)	–	–
16+ grants to beneficiaries	–	–	–	–	–
Educational videos	–	–	–	–	–
Bereavement grants	1,500	–	(1,500)	–	–
Fundraising	–	–	–	–	–
Center Parcs 2023 event	(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)
Jessie's Fund	–	1,000	–	–	1,000
Happy Feet Line Dancers	–	900	–	–	900
	<u>57,451</u>	<u>82,025</u>	<u>(117,056)</u>	<u>12,752</u>	<u>35,172</u>
	At 1 February 2022 £	Income £	Expenditure £	Transfers £	At 31 January 2023 £
Research	–	24,464	–	–	24,464
Center Parcs 2022 event	(933)	26,563	(56,408)	30,778	–
Seizure monitors - Nottinghamshire	500	–	–	–	500
16+ grants to beneficiaries	2,531	–	(2,531)	–	–
Educational videos	10,532	–	(10,532)	–	–
Bereavement grants	2,000	2,500	(3,000)	–	1,500
Fundraising	–	4,000	(4,000)	–	–
Center Parcs 2023 event	–	–	(938)	–	(938)
Family support	–	20,000	(3,922)	–	16,078
Website development	–	25,000	(9,153)	–	15,847
DSUK Conference 2023	–	–	–	–	–
Abseil	–	–	–	–	–
Center Parcs 2024	–	–	–	–	–
Jessie's Fund	–	–	–	–	–
Happy Feet Line Dancers	–	–	–	–	–
	<u>14,630</u>	<u>102,527</u>	<u>(90,484)</u>	<u>30,778</u>	<u>57,451</u>

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2024

23. Analysis of charitable funds *(continued)*

Transfers of £12,752 (2023: £30,778) have been made during the year from unrestricted funds to specific restricted funds to finance deficits in respect of projects for which specific funding was received.

In the reporting year, the charity was able to utilise funding from a number of pharmaceutical companies, including grants from UCB to fund further development of the charity's website as well as for the annual Center Parcs event and the biennial DSUK conference. Additionally funding was received from GW/Jazz Pharmaceuticals, Takeda, Stoke Therapeutics, Encoded Therapeutics and Biocodex in respect of the DSUK conference, which takes place every two years and was held in November 2023.

The charity also continued to receive financial support from its corporate partner, XTX Markets, which also included funding towards the cost of fundraising activities.

24. Analysis of net assets between funds

	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	<u>506,269</u>	<u>35,172</u>	<u>541,441</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £
Tangible fixed assets	1,820	–	1,820
Current assets	494,546	41,375	535,921
Creditors less than 1 year	(21,375)	(26,382)	(47,757)
Net assets	<u>474,991</u>	<u>14,993</u>	<u>489,984</u>

25. Related parties

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



Hope for families with life-limiting epilepsy

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



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