DRAVET SYNDROME UK

England & Wales · Charity number 1128289

Details

Other names	THE IDEA LEAGUE UK
Status	Registered
Legal form	Trust
Registered	2009-02-26
Register	View on the Charity Commission register

Contact

Address	PO Box 756 Chesterfield S43 9EB
Phone	01246 912 421
Email	info@dravet.org.uk
Website	www.dravet.org.uk

Activities

Objects: 1) TO FUND RESEARCH INTO DRAVET SYNDROME AND OTHER RELATED GENETIC SODIUM CHANNEL EPILEPSY'S TO BENEFIT SUFFERERS OF DRAVET SYNDROME AND THEIR FAMILIES.2) TO ADVANCE THE EDUCATION OF THE MEDICAL COMMUNITY IN THE SUBJECT OF DRAVET SYNDROME, THEREFORE PROMPTING ACCURATE AND EARLY DIAGNOSIS AND BENEFITING SUFFERERS OF DRAVET SYNDROME AND THEIR FAMILIES.3) TO PROMOTE THE PHYSICAL AND MENTAL HEALTH OF SUFFERERS OF DRAVET SYNDROME AND THEIR FAMILIES THROUGH THE PROVISION OF FINANCIAL ASSISTANCE, SUPPORT, EDUCATION AND PRACTICAL ADVICE.

Activities: Support for children and adults suffering from Dravet syndrome and their families

Classification

- **How:** Makes Grants To Individuals, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, People With Disabilities

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Geography

- **Area of benefit:** UNDEFINED. IN PRACTICE, NATIONAL
- Northern Ireland
- Scotland
- Throughout England

Finances

Period end	Income	Expenditure	Assets	Employees
2025-01-31	£561,982	£796,545	£306,878	7
2024-01-31	£487,892	£436,435	-	-
2023-01-31	£456,074	£371,118	-	-
2022-01-31	£342,790	£364,519	-	-
2021-01-31	£345,071	£305,812	-	-

Trustees

Name	Role	Appointed
Galia Wilson-John	Chair	2015-05-12
Alex Williams		2023-07-26
John David Rees Lloyd		2019-02-01
Neil Williamson		2020-09-01
Stephanie Smith		2024-06-26

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DRAVET SYNDROME UK

England & Wales - Charity number 1128289

Accounts

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Dravet Syndrome UK

Annual Review 2024-25

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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.

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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

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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.

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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.

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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

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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.**



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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.**

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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.

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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.

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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)





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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.



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.*

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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.







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EPILEPSY RESEARCH INSTITUTE UK

DRAVET Syndrome UK

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

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.

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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.

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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.

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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.







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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.

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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.



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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

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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
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A Williams
Trustee and Treasurer

Date of signature 23 July 2025

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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:
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

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Dravet Syndrome UK

Statement of Financial Activities (Incorporating Income and Expenditure Account)

Year Ended 31 January 2025

	Note	2025 Unrestricted funds £	2025 Restricted funds £	2025 **Total funds £**	2024 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

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Dravet Syndrome UK

Statement of Financial Position

31 January 2025

	Note	2025 £	£	2024 £
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
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A Williams
Trustee and Treasurer

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

Docusign Envelope ID: AA5776EA-76CF-482E-B40A-F81487FC7751

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

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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.

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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.

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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

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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

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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

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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.

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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

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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).

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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

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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.

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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

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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.

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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

@DravetSyndromeUK Dravet Syndrome UK

Dravet Syndrome UK, PO Box 756, Chesterfield S43 9EB

Tel: 01246 912 421 · **Email:** info@dravet.org.uk · **Web:** www.dravet.org.uk

DRAVET SYNDROME UK

England & Wales - Charity number 1128289

Accounts

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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 (Appointed 26 July 2023) 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 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.

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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 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

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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.

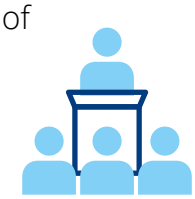
INCREASED our online support forum (our private Facebook group) from 410 members to **425** members.

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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.

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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

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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.

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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**



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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.

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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."

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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/carer 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=6VlCedy66QY

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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**

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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.

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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.

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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.

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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.



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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.

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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/carer 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.

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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.

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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.

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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:
A Williams
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A Williams
Trustee and Treasurer

Date of signature 19 November 2024

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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

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Dravet Syndrome UK

Statement of Financial Activities (Incorporating Income and Expenditure Account)

Year Ended 31 January 2024

	Note	Unrestricted funds £	Restricted funds £	2024 Total funds £	2023 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		405,867	82,025	**487,892**	456,074
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		319,379	117,056	**436,435**	371,118
Net income		86,488	(35,031)	**51,457**	84,956
Transfers between funds		(12,752)	12,752	**–**	–
Net movement in funds		73,736	(22,279)	**51,457**	84,956
Reconciliation of funds					
Total funds brought forward		432,533	57,451	**489,984**	405,028
Total funds carried forward		506,269	35,172	**541,441**	489,984

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.

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Dravet Syndrome UK

Statement of Financial Position

31 January 2024

	Note	2024 £	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
		556,261		535,921
Creditors: amounts falling due within one year	**20**	**15,846**		47,757
Net Current Assets			**540,415**	488,164
Total Assets Less Current Liabilities			**541,441**	489,984
Net Assets			**541,441**	489,984
Funds of the Charity				
Restricted funds	**23**		**35,172**	57,451
Unrestricted funds	**23**		**506,269**	432,533
Total charity funds			**541,441**	489,984

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.

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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.

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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.

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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**
	390,260	82,025	**472,285**

	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
	348,233	102,527	450,760

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	6,961	**6,961**	–	–

6. Other trading activities

	Unrestricted Funds £	**Total Funds 2024 £**	Unrestricted Funds £	Total Funds 2023 £
Merchandise sales	2,447	**2,447**	3,786	3,786

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7. Investment income

	Unrestricted Funds 2024 £	**Total Funds 2024 £**	Unrestricted Funds 2023 £	Total Funds 2023 £
Bank interest receivable	1,975	**1,975**	603	603

8. Other income

	Unrestricted Funds 2024 £	**Total Funds 2024 £**	Unrestricted Funds 2023 £	Total Funds 2023 £
Consultancy services	4,224	**4,224**	925	925

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	5,352	–	**5,352**
	46,727	2,642	**49,369**

	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	5,975	–	5,975
	37,058	4,000	41,058

10. Costs of other trading activities

	Unrestricted Funds 2024 £	**Total Funds 2024 £**	Unrestricted Funds 2023 £	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	(2,211)	**(2,211)**	(5,599)	(5,599)
	2,548	**2,548**	1,896	1,896

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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
	315,561	68,957	**384,518**	328,164

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
	68,957	**68,957**	79,807

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
	132,552	134,551

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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
	704	324

17. Tangible fixed assets

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

18. Stocks

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

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19. Debtors

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

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
	15,846	47,757

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	**–**	21,375

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).

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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**
	432,533	405,867	(319,379)	(12,752)	**506,269**

	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	–	–	–	–	–
	390,398	353,547	(280,634)	(30,778)	432,533

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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.

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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**
	57,451	82,025	(117,056)	12,752	**35,172**

	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	–	–	–	–	–
	14,630	102,527	(90,484)	30,778	57,451

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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 Theraputics, Encoded Theraputics 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	506,269	35,172	**541,441**

	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	474,991	14,993	489,984

25. Related parties

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

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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 with FUNDRAISING REGULATOR

www.dravet.org.uk

Dravet Syndrome UK
PO Box 756, Chesterfield, S43 9EB
Tel: 01246912421
Email: info@dravet.org.uk

@DravetSyndromeUK
@DravetUK
Dravet Syndrome UK

Registered Charity No: 1128289

DRAVET SYNDROME UK

England & Wales - Charity number 1128289

Accounts

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DRAVET Syndrome UK



Dravet Syndrome UK

ANNUAL REVIEW & UNAUDITED FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 JANUARY 2023

Registered charity number: 1128289

DocuSign Envelope ID: D0B4AD65-33D7-49CD-BC79-834564B7D3B3

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35 Detailed statement of financial activities (incorporating income and expenditure account)

Dravet Syndrome UK

Trustees' Annual Report

Year Ended 31 January 2023

The trustees present their report and the unaudited financial statements of the charity for the year ended 31 January 2023.

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
Independent examiner	T G Leeman FCA MCABA Limited trading as Mitchells Chartered Accountants 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.

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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

February 2022 to January 2023 was a tough year for our community of families affected by Dravet Syndrome, a rare and life-limiting neurological condition. While the immediate challenges of the Covid-19 pandemic subsided, the ever-changing political climate, cost-of-living rises, and the impact on health and social care provision meant that our families still faced a great deal of uncertainty and worry, making the vital services provided by Dravet Syndrome UK ever more important.

At Dravet Syndrome UK, we put the needs of families at the heart of everything we do. During the pandemic, we put emergency measures in place to inform and support families during unprecedented times. In 2022 to 2023, we have been able to refocus efforts on moving forward with the implementation of our five-year strategy – reaching and empowering more families, educating more professionals and supporting more research.

Through our support services, we reached more families than ever before, empowering caregivers through emotional, practical and financial help. This year, following the easing of COVID-19 restrictions, we were able to host our Annual Family Weekend Away once again, bringing over 60 families together to help overcome the isolation of living with a rare condition. We conducted research to gather more data and evidence to support the needs of families. We also spoke at key medical meetings, and met with experts to raise awareness and understanding among healthcare professionals.

> **"In 2022 to 2023, we have refocused efforts on moving forward with the implementation of our five-year strategy – reaching and empowering more families, educating more professionals and supporting more research."**

As we look ahead, there is much to feel positive about. There are new treatments on the horizon and a growing awareness of Dravet Syndrome and its devastating impact on families.

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

Galia Wilson
Chair of Trustees



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HIGHLIGHTS OF OUR YEAR

IN 2022-23, DRAVET SYNDROME UK:

WELCOMED

41 new families, growing our registered number of beneficiaries to

502 children/adults with Dravet Syndrome,

689 parents/carers and

498 siblings.

PROVIDED

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

29 seizure monitors that provide an early alert to seizures occurring.

HELPED

improve the lives of

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

£25,500

from our 16+ Assistance Fund.

LAUNCHED

the healthcare professional section of our website, initially focusing on diagnosing and managing Dravet Syndrome.

FACILITATED

5 research focus groups to highlight the needs of parents/carers and the challenges they face.

CELEBRATED

16 winners of our annual 'Sibling Awards', recognising the kindness and patience of super brothers and sisters of those living with Dravet Syndrome.

ATTENDED

4 scientific conferences to raise awareness among healthcare professionals.

INCREASED

our online support forum (our private Facebook group) from 384 to

410 MEMBERS

SHARED

information about Dravet Syndrome with over

34,000

website visitors – an increase of over

4,000 OR **12%**

compared to the previous year.

SUPPORTED

ongoing research projects to improve treatment, care and family life with Dravet Syndrome, including two gene therapy projects.

RAISED AWARENESS

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

650,000

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

72,000

views on YouTube.

GATHERED TOGETHER

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

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SUPPORT

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

Key achievements

Family support services

In 2022-23, 41 new families joined our **Dravet Syndrome UK community**. We now have 502 children/adults with Dravet Syndrome, 689 parents/carers and 498 siblings registered with us.

When they register with Dravet Syndrome UK, families:

- Receive a welcome pack of information.
- Become eligible for our grants.
- Gain access to our private Facebook group.
- Access to one-to-one advice from our Family Support Manager.

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.

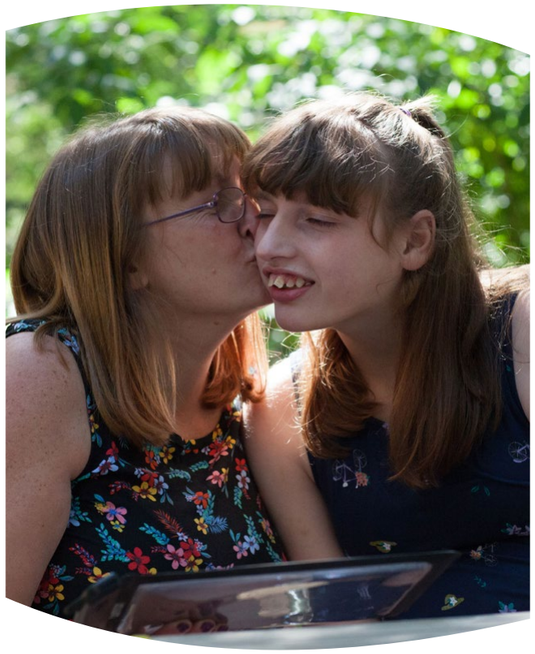
We know that our families gain a huge amount of support from each other. In 2022-23, our **private Facebook** group grew from 384 to 410 members. There are usually around four or five new posts every day. Topics range from seizure medication to residential care options, as well as the ups and downs of 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 2022, 66 families living with Dravet Syndrome joined us at Center Parcs in Sherwood forest for our **Annual Family Weekend Away**. Children and adults with Dravet Syndrome are prone to 'status epilepticus', prolonged seizures or clusters of seizures that are close together with no recovery time, necessitating emergency treatment. For many families this means they are unable to enjoy a holiday for fear of being unable to access medical care in time. That's why 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 £300 per family to help with costs.

> "As a parent, living with Dravet Syndrome is mentally and physically draining. And I always think it must be for the children too. At the Annual Family Weekend Away, they're surrounded by other brothers and sisters who know exactly what it's like to live that life. It's great just to watch them have fun, play and run around together. They come away with so many memories. It's a massive benefit mentally as well."
>
> Mum of a 12-year-old with Dravet Syndrome

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's 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.



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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, 12 children aged 5 to 15 were nominated for our Super Sibling Awards. We also introduced a new award for adult siblings, with 4 over-16s receiving our Sibling Recognition Awards. They each receive a gift voucher and certificate.



Financial support

We offer a range of **financial grants** to support families living with Dravet Syndrome, none of which are means-tested. In 2022-23, our **Seizure Monitor Fund** awarded 29 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 caring for 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 2022-2023, we awarded 29 grants totalling over £25,000. We funded a range of items including special educational apps, a beach wheelchair and sensory garden equipment.

> **"I just wanted to let you know that we are all loving our daughter's beach wheelchair, funded by a Dravet Syndrome UK 16+ Assistance Fund grant. We've just had a fabulous holiday in an accessible safari tent and we got to explore beaches that would have been impossible without it. Thank you so much to everyone who made this possible."**
>
> Mum to a young adult 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 St James's Place Charitable Foundation.

Looking to the future

Our plans for 2023-24 include:

- Empowering parents/carers with knowledge, with the launch of our updated 'Family Guide'. This comprehensive resource will provide information, advice, practical tips and insights to help families on every step of their journey – whether they're dealing with a recent diagnosis or have been caring for a child or adult living with Dravet Syndrome for many years.
- Organising informative plenary and interactive breakout sessions at our biennial conference for parent/carers which is being held in November 2023.
- Proactively supporting families by phoning them at key milestones. For example, newly diagnosed families, those going through the transition from child to adult services, and those living with Dravet Syndrome who are over 25. Our aim is to listen to families' needs to find out how we can adapt and improve the support we offer, being there for more families with the support they deserve.

CASE STUDY

We've been supported by Dravet Syndrome UK from the start and that has made such a huge difference to us

Meet Carrie, Mum to 5-year-old Penny who lives with Dravet Syndrome. Here, they share the impact that support from Dravet Syndrome UK has had on their lives.

"Although the diagnosis of Dravet Syndrome was difficult, it also made things a lot easier. Because Penny had an early diagnosis, it's meant that we've been supported by Dravet Syndrome UK from the start and that has made such a huge difference to us. The private Facebook forum for parents/carers, for example, has been so useful. It's so reassuring talking to other parents and sharing knowledge and understanding.

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

We've attended the Dravet Syndrome UK Conferences, which have left us feeling very positive – it became apparent that there are professionals fighting to get better understanding of our child's condition and to find ways to better manage it. There is activity happening behind the scenes all the time, and we would highly recommend attending a future conference, if you can get there.

We've had an amazing time at the Annual Family Weekend Away, meeting other families living with Dravet Syndrome. Sometimes, it can be quite an isolating condition and no matter how hard people try, they never fully understand what a Dravet family goes through on a daily, hourly and sometimes minute by minute basis. This is what makes the Family Weekend so special, there are lots of people there who are in the same situation as you and your family.

Our other children, Ruby and Teddy, were nominated by family members for a Dravet Syndrome UK Sibling Award. The excitement for them was immense when they received something through the post with their names on. They are both such valuable members of the family, so this really gave them some great encouragement to keep up the good work."



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EDUCATION

We raise awareness and understanding of Dravet Syndrome

Key achievements

Educating health professionals

We educate health professionals involved in the care of people with Dravet Syndrome, aiming to increase diagnosis and improve the way the condition is managed. Last year, we developed a **new section of our website for health professionals**, launched at the British Paediatric Neurology Association conference in January 2023. The online content includes essential information on diagnosing and managing Dravet Syndrome and supporting families. We plan to grow this resource throughout 2023.

Raising public awareness

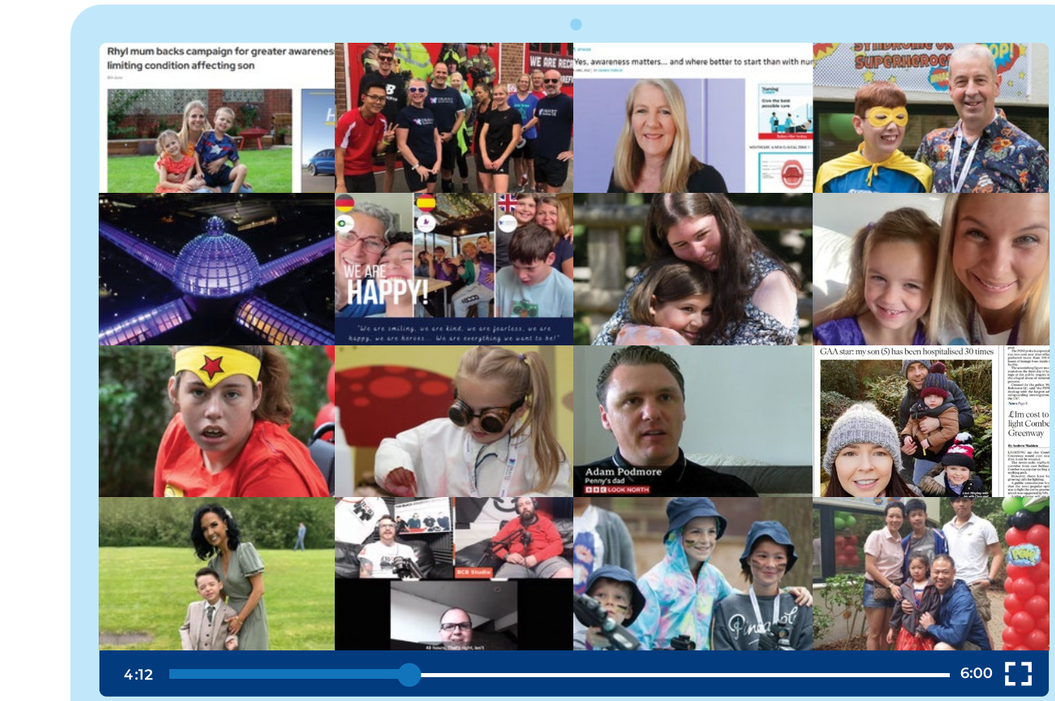
June is Dravet Syndrome Awareness Month. In 2022, we ran our biggest ever press campaign, supporting families to share their experiences with the media. We had coverage in local, national, print and online media, including BBC News Online where we were their eighth most read story on the day after publication.

Other press included *The Mirror, The Daily Record, Edinburgh Evening News, The Northern Echo* and a front-page mention on the *Belfast Telegraph*. Families and Dravet Syndrome UK spokespeople were interviewed on BBC Radio and on regional stations across the UK. They made TV appearances on *BBC Look North* and *ITV News West Country*.

Our Medical Advisory Board member, Amanda Tomalin, had an opinion piece published in the *Nursing Times*, raising vital awareness among nurses.

Other **awareness-raising activities** during June's awareness month included:

- Our world-class Medical Advisory Board shared facts and busted myths about Dravet Syndrome in a series of short videos, which were posted on our social media.
- We joined with the Dravet Syndrome European Federation to share an awareness-raising video featuring families from the European Dravet Syndrome community.
- We paid tribute to those we have sadly lost too soon, on Dravet Syndrome Remembrance Day on 15th June.
- We launched new family stories to the Dravet Journeys section of our website, sharing lived experience from our patient and family community. Collectively, these stories reached 12,000 people across our four social media channels.



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Educating professionals at medical meetings and events

Every year, our staff and trustees attend leading **medical conferences** so they can engage with health professionals and raise awareness of Dravet Syndrome. In 2022-23, we attended:

- **European Paediatric Neurology Society (EPNS) Congress** where we had an exhibition stand and distributed our *Could it be Dravet?* leaflet.
- **European Epilepsy Congress (EEC)**, a leading scientific meeting attended by neurologists from across Europe. Our Chair gave a presentation on 'Climate change and epilepsy: what to know and what to do', raising awareness of the impact of temperature change on people with Dravet Syndrome.
- **American Epilepsy Society (AES) Annual Meeting**, where our Chair and Director learnt about the latest developments in Dravet Syndrome and met with other patient organisations and leading experts.
- **British Paediatric Neurology Association (BPNA) Annual Conference** where we launched our new website for health professionals and gave a presentation on gastrostomy (tube feeding). 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 parents/carers' voices are heard

In 2022-23, 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 National Institute for Health and Care Excellence (NICE).

In particular, we were pleased to represent families affected by Dravet Syndrome, during a review of the drug fenfluramine (Fintepla), a new anti-seizure treatment specifically used for Dravet Syndrome. Initially, NICE had not recommended the treatment, but it was eventually approved to be used by the NHS in England and Wales in July 2022.

It was a long journey to get to this point and Dravet Syndrome UK was there every step of the way. We spoke up for the Dravet Syndrome community, reiterating how important it is to have the option to try new treatments, even if they don't work for everyone. We are grateful to NICE for listening to the patient and carer community, particularly when it comes to the impact on quality of life.

> **"Awareness and education are vital for all conditions, but particularly for rare ones like Dravet Syndrome. By sharing the kind of information Dravet Syndrome UK produces, we help dismantle damaging myths."**
>
> Amanda Tomalin, Epilepsy Nurse Specialist



Looking to the future

Our plans for 2023-24 include:

- Educating health and social care professionals about Dravet Syndrome at our biennial scientific conference in November 2023.
- Further developing the recently-launched section of our website for health professionals.
- Continuing to engage with healthcare professionals at scientific meetings, conferences and educational events.

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RESEARCH

We fund 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 2021-2026 strategy sets out our aim to deliver research that puts the needs of the families living with Dravet Syndrome front and centre. While current genetic research gives us hope that there will be effective gene-based treatments for Dravet Syndrome in the future, there are many other challenges faced by families today that need urgent attention. These are also important areas of focus for our charity.

Our research priorities are:

- **Improving treatment and care for adults** with Dravet Syndrome, from transition through to later adulthood.
- **Understanding, treating and improving care** for the non-seizure related aspects of Dravet Syndrome (known as 'comorbidities'), including intellectual disability, autism, attention deficit hyperactivity disorder (ADHD), behaviours that challenge, and difficulties with speech, mobility, eating and sleep.
- **Understanding the impact of the changing climate** on people with Dravet Syndrome.
- **Exploring how social care can help to improve the quality of life** of people affected by Dravet Syndrome.

We 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.

In 2022, we collaborated with the University of Glasgow to highlight the **emotional challenges faced by parents and carers.** We partnered with a team led by Professor Liam Dorris, the Lead Clinician for the neuropsychology service at the Royal Hospital for Children Glasgow, to organise a series of focus group meetings. In total, we held five focus groups with 24 parents/carers. The results of this research will be published later in 2023.

We also helped deliver new research investigating the **feeding difficulties** associated with Dravet Syndrome. We surveyed 65 families to explore feeding, swallowing and weight loss, and the impact of gastrostomy. We worked with Professor Sanjay Sisodiya and Dr Lisa Clayton from the Epilepsy Society's Chalfont Centre to analyse the results, which were presented at a British Paediatric Neurology Association meeting. A full publication is pending in 2023.



Professor Sanjay Sisodiya

We funded a PhD placement for arts therapist Leanne O'Keefe, who is exploring the **benefits of music therapy** for children with Dravet Syndrome, focusing on addressing challenging behaviours. We hope the research can help to change the way the music therapy profession views Dravet Syndrome and other neurological disorders.

Ongoing research

Two key pieces of **gene therapy** research, which we are co-funding with Great Ormond Street Children's Charity (GOSH), are underway. These are exciting and complementary additions to the multiple gene and genetic studies into Dravet Syndrome that are currently taking place. These therapies aim to dramatically improve seizures, and also the intellectual disability and comorbidities associated with this devastating condition.

The first study is led by Dr Rajvindar Karda at University College London. The second study is led by Professor Matthew Wood at the University of Oxford. This research aims to develop a new genetic therapy to increase the amount of "missing" SCN1A protein in someone with Dravet Syndrome.

A joint research project we co-funded with European patient organisations also started in 2022. It looks at **how Dravet Syndrome develops** and how certain cells interact when someone has the condition, with the aim of better understanding why some people respond to certain treatments and others do not.

We are very excited about the SCN1A Horizons Natural History Project, led by Professor Andreas Brunklaus at the University of Glasgow. This is an incredibly important piece of research that will allow us to learn more about the **seizures, intellectual disability and comorbidities** affecting children and adults with Dravet Syndrome. We're co-funding this project and invested £30,000 in 2021-22. This year, Professor Brunklaus and colleagues set up the framework for the study, which will take place in 27 hospitals across the UK. Recruitment will start in 2023.



Professor Andreas Brunklaus

Looking to the future

Our plans for 2023-24 include:

- Supporting recruitment for the SCN1A Horizons Natural History Study – a major research milestone. This co-funded research has the potential to transform our understanding of Dravet Syndrome, encouraging earlier diagnosis and improved, more standardised approaches to treatment.
- Actively seeking partners to fund novel projects that address our research priorities.

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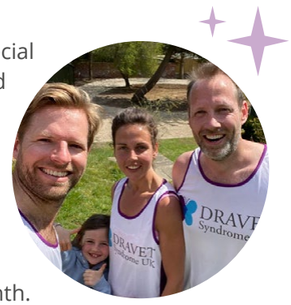
FUNDRAISING FOCUS



Community fundraising

We would like to pay tribute to our amazing community fundraisers, who raised a collective total of **£325,697** in 2022-2023.

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, bell-ringing, wearing purple and much much more, to raise money for Dravet Syndrome UK.



We would like to say a special thank you to Tamara Ward and her husband Mike for raising more than £100,000 in May 2022, through the epic 5K #EveryDayinMay4Dravet challenge and a gala dinner held the same month.

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 2022-23. The company contributed towards our family support, education 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.

Our ongoing partnership with **Kid-A** continued, with their staff team joining us for the Marathon Walk London, raising funds and awareness of Dravet Syndrome.

We were delighted to welcome on board two new corporate partners in 2022-23. Construction industry company **Roofdec** and finance providers **Cubefunder**. Both of these tailored partnerships developed following introductions from employees who have a family connection to Dravet Syndrome. They include sponsorship, employee engagement and efforts to increase awareness of Dravet Syndrome across their business networks.



"We chose to support Dravet Syndrome UK after seeing our colleague and his wife share their daughter's story on BBC Look North during Dravet Syndrome Awareness Month. We all knew the challenges that the family face, but that interview really hit home. We wanted to give back to the charity who has provided support to one of our own."

Jon Barnes Jnr, Managing Director at Roofdec, who took part in the Marathon Walk London in 2022

Industry grants

We are grateful for continued support from the **pharmaceutical industry sector**. In the reporting year, we received restricted grants from companies including **Zogenix** (now part of **UCB**) and **GW Pharma Limited** (now part of **Jazz Pharmaceuticals**) to enable family support and educational projects.

Trusts and foundations

We were delighted to be awarded a £20,000 grant from the **Baily Thomas Charitable Fund** in October 2022. The grant is helping with running costs of our family support services for a year, focusing on learning disability, which affects people with Dravet Syndrome.

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 five-year strategy which will underpin and guide our work through to 2026. It provides a roadmap to help us reach our overall mission, as it has done in 2022-23.

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.

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FINANCIAL REVIEW

Incoming Resources

In 2022/2023 DSUK received **£456,074** (2021/2022: £342,790) in income from the following sources:

£325,697 (2021/2022: £213,001) Community fundraising

£55,563 (2021/2022: £66,500) Industry grants

£47,000 (2021/2022: £45,000) Corporate sponsorship

£22,500 (2021/2022: £7,500) Grants from Trusts/Foundations

£5,314 (2021/2022: £10,789) Income generation

Historically community fundraising has been an important source of income for DSUK, with £209,418 raised in 2019/2020. With the onset of the pandemic it was not possible for the normal community fundraising activities to take place such as marathons, treks etc. meaning only £136,238 was secured in 2020/2021. In 2021/2022 we saw a recovery in community fundraising, which generated £213,001 and this year has seen a further increase to £325,697. Other funding sources continue to ably support the ongoing activities of the charity. XTX Markets generously continue as a corporate sponsor of the charity.

Outgoing Resources

In 2022/2023 DSUK spent **£371,118** (2021/2022: £364,519) 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 Center Parcs weekend)
- Awareness raising materials (e.g. DSUK educational leaflets and videos)
- DSUK merchandise for fundraising events & shop sales
- Research projects focused on the unmet needs of families
- Staff costs with 4 people (3.60 FTE) paid for 133 hours per month on average as at 31st January 2023.

Reserves Policy

Dravet Syndrome UK is required to ensure that free reserves are available in 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 running costs.



Based on our forecast for 2023-2024, six months of operating expenditure would be approximately £316,000. At 31 January 2023, the free reserves of the charity amount to £357,713 net of tangible fixed assets and designated funds, which constitutes the free reserves at that date. (The free reserves at the comparative year-end were £358,959).

As set out in our 5-Year Strategy for 2021-2026 DSUK is currently implementing planned strategic organisational growth. To enable this growth, our estimated expenditure in 2023-2024 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 trustees' annual report was approved on

26 September 2023

and signed on behalf of the Board of Trustees by:

DocuSigned by:
Kelvin Hughes
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K Hughes
Trustee

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Dravet Syndrome UK

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

Year Ended 31 January 2023

I report to the trustees on my examination of the financial statements of Dravet Syndrome UK ('the charity') for the year ended 31 January 2023.

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.

DocuSigned by:
Tim Leeman
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T G Leeman FCA
Independent Examiner

MCABA Limited t/a
Mitchells Chartered Accountants and Business Advisers
91 - 97 Saltergate
Chesterfield
Derbyshire
S40 1LA

Date: 26 September 2023

Dravet Syndrome UK

Statement of Financial Activities (Incorporating Income and Expenditure Account)

Year Ended 31 January 2023

	Note	2023 Unrestricted funds £	2023 Restricted funds £	2023 Total funds £	2022 Total funds £
Income					
Donations and grants	**4**	348,233	102,527	**450,760**	332,001
Charitable activities	**5**	–	–	**–**	6,428
Other trading activities	**6**	3,786	–	**3,786**	2,355
Investment income	**7**	603	–	**603**	6
Other income	**8**	925	–	**925**	2,000
Total income		353,547	102,527	**456,074**	342,790
Expenditure					
Expenditure on raising funds:					
Costs of raising donations and grants	**9**	31,459	4,000	**35,459**	33,640
Costs of other trading activities	**10**	7,495	–	**7,495**	1,083
Expenditure on charitable activities	**11**	241,680	86,484	**328,164**	329,796
Total expenditure		280,634	90,484	**371,118**	364,519
Net income/(expenditure)		72,913	12,043	**84,956**	(21,729)
Transfers between funds		(30,778)	30,778	**–**	–
Net movement in funds		42,135	42,821	**84,956**	(21,729)
Reconciliation of funds					
Total funds brought forward		390,398	14,630	**405,028**	426,757
Total funds carried forward		432,533	57,451	**489,984**	405,028

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 25 to 34 form part of these financial statements.

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Dravet Syndrome UK

Statement of Financial Position

31 January 2023

	Note	2023 £	£	2022 £
Fixed Assets				
Tangible fixed assets	**17**		**1,820**	466
Current Assets				
Stocks	**18**	**10,965**		14,072
Debtors	**19**	**82,236**		32,188
Cash at bank and in hand		**442,720**		398,904
		535,921		445,164
Creditors: amounts falling due within one year	**20**	**47,757**		40,602
Net Current Assets			**488,164**	404,562
Total Assets Less Current Liabilities			**489,984**	405,028
Net Assets			**489,984**	405,028
Funds of the Charity				
Restricted funds			**57,451**	14,630
Unrestricted funds			**432,533**	390,398
Total charity funds	**23**		**489,984**	405,028

These financial statements were approved by the board of trustees and authorised for issue on 26 September 2023 and are signed on behalf of the board by:

DocuSigned by:
Kelvin Hughes
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K Hughes
Trustee

The notes on pages 25 to 34 form part of these financial statements.

Dravet Syndrome UK

Notes to the Financial Statements

Year Ended 31 January 2023

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.

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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 2023

4. Donations and grants

	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**
Seizure monitors	–	–	**–**
16+ grants to beneficiaries	–	–	**–**
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**
	348,233	102,527	**450,760**

	Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £
Donations			
Donations	258,001	–	258,001
Grants			
DSUK conference	–	66,500	66,500
Center Parcs event	–	–	–
Seizure monitors	–	500	500
16+ grants to beneficiaries	–	5,000	5,000
Bereavement grants	–	2,000	2,000
Professional website development	–	–	–
Family support	–	–	–
Fundraising grant	–	–	–
	258,001	74,000	332,001

The trustees confirm that the above restricted income recognised in respect of the DSUK Conference 2021 in the comparative period is compliant with The Association of the British Pharmaceutical Industry Code of Practice.

5. Charitable activities

	Unrestricted Funds £	**Total Funds 2023 £**	Unrestricted Funds £	Total Funds 2022 £
DSUK conference ticket income	–	**–**	6,428	6,428

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6. Other trading activities

	Unrestricted Funds £	**Total Funds 2023 £**	Unrestricted Funds £	Total Funds 2022 £
Merchandise sales	3,786	**3,786**	2,355	2,355

7. Investment income

	Unrestricted Funds £	**Total Funds 2023 £**	Unrestricted Funds £	Total Funds 2022 £
Bank interest receivable	603	**603**	6	6

8. Other income

	Unrestricted Funds £	**Total Funds 2023 £**	Unrestricted Funds £	Total Funds 2022 £
Consultancy services	925	**925**	2,000	2,000

9. Costs of raising donations and grants

	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	–	–	**–**
Just Giving charges	5,975	–	**5,975**
	31,459	4,000	**35,459**

	Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £
Event costs	2,298	–	2,298
Wages and salaries	14,969	–	14,969
Employer's NIC	709	–	709
Pension costs	347	–	347
Fundraising consultancy fees	12,000	–	12,000
Just Giving charges	3,317	–	3,317
	33,640	–	33,640

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2023

10. Costs of other trading activities

	Unrestricted Funds £	**Total Funds 2023 £**	Unrestricted Funds £	Total Funds 2022 £
Opening stock	13,402	**13,402**	14,146	14,146
Merchandise purchases	4,440	**4,440**	339	339
Closing stock	(10,347)	**(10,347)**	(13,402)	(13,402)
	7,495	**7,495**	1,083	1,083

11. Expenditure on charitable activities by activity type

	Activities undertaken directly £	Support costs £	**Total funds 2023 £**	Total fund 2022 £
Research funding	13,651	3,292	**16,943**	117,293
Raising awareness	155,580	37,523	**193,103**	113,351
Supporting families	79,126	19,084	**98,210**	75,600
Governance costs	–	19,908	**19,908**	22,832
	248,357	79,807	**328,164**	329,076

12. Analysis of support costs

	Analysis of support costs - charitable activities £	**Total 2023 £**	Total 2022 £
Staff costs	49,307	**49,307**	20,145
Premises	1,173	**1,173**	1,070
Communications and IT	8,131	**8,131**	9,702
Human resources	591	**591**	361
Finance costs	252	**252**	715
Governance costs	20,353	**20,353**	22,832
	79,807	**79,807**	54,825

13. Net income/(expenditure)

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

	2023 £	2022 £
Depreciation of tangible fixed assets	**463**	229

14. Independent examination fees

	2023 £	2022 £
Fees payable to the independent examiner for:		
Independent examination of the financial statements	**2,850**	2,592

15. Staff costs

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

	2023	2022
	£	£
Wages and salaries	**121,352**	108,163
Social security costs	**10,868**	5,907
Employer contributions to pension plans	**2,331**	2,382
	134,551	116,452

The average head count of employees during the year was 4 (2022: 4).

No employee received employee benefits of more than £60,000 during the year (2022: 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 £48,976 (2022:£25,207).

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 is 1 trustee (2022: 2) that claimed expenses or had their expenses met by the charity as follows:

	2023	2022
	£	£
Travel	**85**	393
Hotel and Subsistence	**239**	–
	324	393

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2023

17. Tangible fixed assets

	Fixtures and fittings	Equipment	**Total**
	£	£	**£**
Cost			
At 1 February 2022	490	3,994	**4,484**
Additions	–	1,817	**1,817**
At 31 January 2023	490	5,811	**6,301**
Depreciation			
At 1 February 2022	489	3,529	**4,018**
Charge for the year	–	463	**463**
At 31 January 2023	489	3,992	**4,481**
Carrying amount			
At 31 January 2023	1	1,819	**1,820**
At 31 January 2022	1	465	466

18. Stocks

	2023	2022
	£	£
Stock of merchandise and consumables	**10,347**	13,402
Monitor stock	**618**	670
	10,965	14,072

19. Debtors

	2023	2022
	£	£
Prepayments and accrued income	**65,686**	32,013
Other debtors	**16,550**	175
	82,236	32,188

20. Creditors: amounts falling due within one year

	2023	2022
	£	£
Accruals and deferred income	**28,141**	33,860
Social security and other taxes	**2,709**	1,979
Other creditors	**16,907**	4,763
	47,757	40,602

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21. Deferred income

	2023 £	2022 £
At 1 February 2022	**26,563**	26,563
Amount released to income	**(26,563)**	–
Amount deferred in year	**21,375**	–
At 31 January 2023	**21,375**	26,563

Deferred income at the year-end relates to funding received in respect of the DSUK Conference to be 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 £2,331 (2022: £2,382).

23. Analysis of charitable funds

Unrestricted funds

	At 1 February 2022 £	Income £	Expenditure £	Transfers £	At 31 January 2023 £
General funds	359,425	353,547	(249,661)	(30,778)	**432,533**
Designated research fund	–	–	–	–	**–**
Designated educational materials fund	30,973	–	(30,973)	–	**–**
	390,398	353,547	(280,634)	(30,778)	**432,533**

	At 1 February 2021 £	Income £	Expenditure £	Transfers £	At 31 January 2022 £
General funds	290,805	268,790	(162,540)	(37,630)	359,425
Designated research fund	50,663	–	(80,000)	29,337	–
Designated educational materials fund	45,000	–	(14,027)	–	30,973
	386,468	268,790	(256,567)	(8,293)	390,398

Unrestricted grants to which entitlement passed to the charity during the 2020/21 financial year were allocated to the provision of educational materials by the trustees, as part of the ongoing drive to raise awareness of Dravet Syndrome. The project was delayed due to the COVID-19 pandemic but this funding was fully spent in the year to 31 January 2023.

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2023

23. Analysis of charitable funds *(continued)*

The Board of Directors have designated further unrestricted funds in the current year for the following planned projects:

- To implement a new Customer Relationship Management (CRM) and Content Management System (CMS) to enable the charity to deliver against its strategic objectives. It is anticipated that this fund will be disbursed by September 2024.
- To support strategic growth through the recruitment of two senior roles; it is anticipated that this fund will be disbursed by January 2024.

Restricted funds

	At 1 February 2022 £	Income £	Expenditure £	Transfers £	At 31 January 2023 £
Conference	–	–	–	–	**–**
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**
	14,630	102,527	(90,484)	30,778	**57,451**

	At 1 February 2021 £	Income £	Expenditure £	Transfers £	At 31 January 2022 £
Conference	–	66,500	(74,793)	8,293	–
Research	–	–	–	–	–
Center Parcs 2022 event	–	–	(933)	–	(933)
Seizure monitors - Nottinghamshire	–	500	–	–	500
16+ grants to beneficiaries	3,464	5,000	(5,934)	–	2,530
Educational videos	36,825	–	(26,292)	–	10,533
Bereavement grants	–	2,000	–	–	2,000
Fundraising	–	–	–	–	–
Center Parcs 2023 event	–	–	–	–	–
Family support	–	–	–	–	–
Website development	–	–	–	–	–
	40,289	74,000	(107,952)	8,293	14,630

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23. Analysis of charitable funds *(continued)*

Transfers of £30,778 (2022: £8,293) have been made during the year from unrestricted funds to specific restricted funds to finance a deficit in respect of projects for which specific funding was received.

In the reporting year, Dravet Syndrome UK, was able to utilise funding from a number of pharmaceutical companies, including a grant from Zogenix to fund further development of the charity's website and from GW/Jazz Pharmaceuticals in respect of the Center Parcs weekend held this year. Funding was also received from The Baily Thomas Charitable Fund for the provision of support for families living with Dravet Syndrome.

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

24. Analysis of net assets between funds

	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	474,991	14,993	**489,984**

	Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £
Tangible fixed assets	466	–	466
Current assets	403,971	41,193	445,164
Creditors less than 1 year	(14,039)	(26,563)	(40,602)
Creditors greater than 1 year	–	–	–
Net assets	390,398	14,630	405,028

25. Related parties

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

The following pages do not form part of the financial statements.

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Dravet Syndrome UK

Detailed Statement of Financial Activities (Incorporating Income and Expenditure Account)

Year Ended 31 January 2023

	2023 £	2022 £
Income		
Donations and grants		
Donations	**372,697**	258,001
DSUK conference	**–**	66,500
Center Parcs event	**26,563**	–
Seizure monitors	**–**	500
16+ grants to beneficiaries	**–**	5,000
Bereavement grants	**2,500**	2,000
Professional website development grant	**25,000**	–
Family support grant	**20,000**	–
Fundraising grant	**4,000**	–
	450,760	332,001
Charitable activities		
DSUK conference ticket income	**–**	6,428
Other trading activities		
Merchandise sales	**3,786**	2,355
Investment income		
Bank interest receivable	**603**	6
Other income		
Consultancy services	**925**	2,000
Total income	**456,074**	342,790

Dravet Syndrome UK

Detailed Statement of Financial Activities (Incorporating Income and Expenditure Account) *(continued)*

Year Ended 31 January 2023

	2023 £	2022 £
Expenditure		
Costs of raising donations and grants		
Event costs	**10,637**	2,298
Wages and salaries	**16,988**	14,969
Employer's NIC	**1,565**	709
Pension costs	**294**	347
Professional fees	**–**	12,000
Just Giving charges	**5,975**	3,317
	35,459	33,640
Costs of other trading activities		
Opening stock	**13,402**	14,146
Merchandise purchases	**4,440**	339
Closing stock	**(10,347)**	(13,402)
	7,495	1,083
Expenditure on charitable activities		
Opening monitors stock	**670**	118
Direct costs including research	**181,908**	193,844
Closing monitors stock	**(618)**	(670)
Wages and salaries	**104,364**	93,194
Employer's NIC	**9,303**	5,198
Pension costs	**2,037**	2,035
Insurance	**1,173**	1,070
Travel costs	**–**	677
Professional fees	**19,237**	22,832
Depreciation	**463**	229
Human resources costs	**591**	361
Computer costs	**7,668**	9,473
Bank charges and admin fees	**252**	715
Training	**1,116**	720
	328,164	329,796
Total expenditure	**371,118**	364,519
Net income/(expenditure)	**84,956**	(21,729)

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GET INVOLVED

Find out more about how you can support Dravet Syndrome UK:



MAKE A DONATION

To give a one-off gift or set up a regular donation, go to **dravet.org.uk/make-a-donation**



FUNDRAISE

For a whole host of events and fundraising ideas, go to **dravet.org.uk/fundraising**



SHOP

Check out our Dravet Syndrome merchandise at **dravet.org.uk/shop**



PARTNER WITH US

To find out how we can work together, contact us on **info@dravet.org.uk**

DRAVET Syndrome UK

Hope for families with life-limiting epilepsy

www.dravet.org.uk

Dravet Syndrome UK
PO Box 756
Chesterfield
S43 9EB
Tel: 01246 912 421
Email: info@dravet.org.uk

@DravetSyndromeUK
@DravetUK
Dravet Syndrome UK

Registered charity number: 1128289

Design: www.adeptdesign.co.uk

DRAVET SYNDROME UK

England & Wales - Charity number 1128289

Accounts

DocuSign Envelope ID: 54A8EAB4-30C3-4BF4-81BB-017DD03E5C46

CHARITY REGISTRATION NUMBER: 1128289

Dravet Syndrome UK

Unaudited Financial Statements

31 January 2022

MCABA Limited t/a Mitchells
Chartered Accountants
91 - 97 Saltergate
Chesterfield
Derbyshire
S40 1LA

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Dravet Syndrome UK

Financial Statements

Year Ended 31 January 2022

	Pages
Trustees' annual report	**1 to 19**
Independent examiner's report to the Trustees	**20**
Statement of financial activities (incorporating income and expenditure account)	**21**
Statement of financial position	**22**
Notes to the financial statements	**23 to 32**
The following pages do not form part of the financial statements	
Detailed statement of financial activities (incorporating income and expenditure account)	**34 to 35**

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Dravet Syndrome UK

Trustees' Annual Report

Year Ended 31 January 2022

The trustees present their report and the unaudited financial statements of the charity for the year ended 31 January 2022.

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
Independent examiner	T G Leeman FCA MCABA Limited t/a Mitchells Chartered Accountants 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.

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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").

To fund medical research projects into Dravet Syndrome and other related genetic sodium channel epilepsies that will benefit the sufferers of Dravet Syndrome;

To raise awareness and provide education to families and the medical community about Dravet Syndrome;

To support families affected by Dravet Syndrome in the UK.

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.

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Achievements and performance

Introduction

The following narrative details the ways in which Dravet Syndrome UK has been able to make a positive difference to those affected by Dravet Syndrome during the period from 1st February 2021 to 31st January 2022.

Dravet Syndrome is a life-long, life-limiting and devastating genetic neurological condition, occurring in one in every 15,000 live births in the UK. In around 85% of cases, the condition is caused by a mutation in a gene known as SCN1A.

Dravet Syndrome is characterised by complex epilepsy (causing severe, frequent and treatment-resistant seizures), learning disability (severe-to-profound in 80% of cases) and a spectrum of associated conditions including autism, ADHD, challenging behaviour, and difficulties with speech, mobility, feeding and sleep. Severe, frequent, life-threatening seizures necessitate 24/7 supervision and care, and close access to emergency medical attention. Care requirements, learning disability and associated conditions mean most children with Dravet Syndrome cannot attend mainstream school or live independently as adults.

In 2021/22, Dravet Syndrome UK (DSUK) has continued its vital mission - to improve the lives of those affected by Dravet Syndrome through support, education, and medical research.

During this reporting period, the COVID-19 pandemic has continued to pose significant challenges. For many families living with Dravet Syndrome, the pandemic has increased existing difficulties, such as access to care and respite, and isolation from support networks. For DSUK, COVID-19 restrictions, especially in the first half of the year, significantly disrupted usual events and fundraising activities.

With thanks to the continued support of our fundraisers and generosity of our donors, corporate sponsors and other industry partners, we are pleased to report that DSUK has been able to make considerable progress in delivering against our charitable aims, despite the continued challenges of COVID-19.

As in the previous year, we remained open throughout, without recourse to furlough and provided increased family support to meet additional needs arising from the pandemic. In addition, we continued delivering established activities for the benefit of families living with Dravet Syndrome, as defined in our charitable objects and in keeping the following areas:

- Family support
- Raising awareness and educating professionals
- Funding medical research

Below the Trustees report on the charity's activities, outputs and outcomes against each of these thematic areas. They also report on DSUK's income, expenditure, reserves and future plans.

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Achievements and performance ***(continued)***

Publication of DSUK's first strategy

In February 2021, we published our first 5-Year Strategy (developed by the Trustees and Director in the previous reporting period). This strategy marks an important milestone in our charity's journey.

From a group of 30 families who came together looking for mutual support in 2008, to a registered charity helping over 550 families with support, education and research services underpinned by a world class Medical Advisory Board, we have come a long way. Now we are looking ahead to the next stage in our development.

The strategy shapes what we do and the way we do it. We want to reach more families, to deliver research that puts family needs first, to improve awareness and understanding amongst professionals, particularly in adult neurology and social services, and to give families the tools and support needed to assert their rights.

Our strategy is underpinned by four overarching objectives:

1) Every Family Counts

Every UK family living with Dravet Syndrome will be aware of DSUK and the support available, be enabled to access this support as required, and know that all activities and research are driven by the things that count the most to them.

2) Leaders in the Field

DSUK will lead the conversation about Dravet Syndrome in the UK, making the best possible use of its 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.

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Achievements and performance ***(continued)***

Family Support

In 2021/22 DSUK directly supported over 550 families living with Dravet Syndrome in the UK, including 463 people living with Dravet Syndrome and 612 parents/carers, with 33 new families registering with DSUK in the reporting period. This figure is slightly lower than the 41 new families who registered in 2020/2021, which is likely due to a general decrease in new diagnoses due to the impact of the pandemic.

DSUK provided emotional, practical, and emotional support including the following:

Coronavirus resource hub
Seizure monitor fund
16+ assistance fund
Bereavement fund
1:1 emotional/practical support
Closed Facebook group
Center Parcs grant
Super siblings award

More information about each of these activities follows below.

Coronavirus Resource Hub

In 2020/2021 we undertook a wide range of new activities to meet the pressing needs of families through the pandemic. This work was continued in 2021/2022 and included:

The re-allocation of 65% of our Family Support Manager's time to providing 1:1 emotional and practical support to families living with Dravet Syndrome.

A regularly updated web-based resource hub guidance and resources to assist families, informed and approved by our Medical Advisory Board. Increased provision for our 16+ assistance fund) providing equipment and items vital for stimulation and entertainment as families shielded and day centres remained closed (see below for more details). Publication of two reports providing important evidence on the impact of COVID-19 among children and adults with DS, including the impact of shielding and (latterly) vaccinations (in adults); "The impact of COVID-19 in Dravet Syndrome: a UK survey" and "The impact of SARS-CoV-2 vaccination in Dravet Syndrome: a UK survey".

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Achievements and performance ***(continued)***

Seizure Monitor Fund

38 seizure monitors were awarded in the reporting period.

Children and adults with Dravet Syndrome need 24/7 supervision, due to the risk of life-threatening seizures, and the learning disability and other difficulties associated with this condition. Seizure monitors are not routinely funded by health or social care but can play a vital role in helping families manage the day-to-day challenges of living with Dravet Syndrome.

Seizure monitors provide an early alert to seizures, thus enabling prompt emergency treatment and potentially reducing risks of brain damage and death. In addition, they also help provide some respite and reassurance for caregivers, therefore improving quality of life.

In this reporting period, DSUK awarded 38 seizure monitors to families, including 36 new monitors and 2 replacement monitors. These were primarily new families who had recently joined DSUK. Although a lower number of awards than the previous year (47 monitors given), this is closely linked to the number of new families registering with DSUK, which dropped in 2020/2021 due to the impact of the pandemic on diagnosis.

Seizure monitor awards included:

o 8 Pulse Oximeter Machines
o 1 MedPage Epileptic Seizure Monitors
o 6 Video Monitors
o 9 Nightwatch Monitors
o 14 Fingertip Pulse Oximeters

As in previous years family feedback was overwhelmingly positive. The following verbatim quote is from a mum to an 11-year-old boy with Dravet Syndrome. It describes the benefits a seizure monitor can bring, making a positive difference to quality of life for all the family.

"We would like to say a huge thankyou to DSUK. We received our video monitor and fingertip oximeter today, the whole application was so straight forward it almost seemed untrue, nothing in our life's has been so simple! We always seem to be fighting for help but not this time.

We chose a video monitor as our son, who is 11 now, has been connected to my hip since his first seizure at 7 months old and his diagnosis of Dravet at aged 5. I always need to have eyes on him, and he can't be in a room without me for fear of a seizure I won't hear or see. This video monitor will enable me to allow him some independence in our home and give his big sister (who's lost out on a lot of mum time over the years) some one-on-one time.

I will be able to sit with my daughter in the kitchen and help her with her GCSE school work, whilst my son can go up to his room and play as he likes to do after school. But now I won't have to follow him and sit on his floor and watch him, I will be able to stay with his sister, whilst still having eyes on him. I can't tell you all how much this will improve our family's quality of life, I will get time with my eldest and my son will get some free time from his helicopter mum...maybe it might even help with my sleepless nights, and he can move out of my bed and sleep in his own bed.

Thankyou DSUK so much! I can't explain what this means to us, but I have a weight lifted off my shoulders and feel like we can live a somewhat 'normal' life."

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Achievements and performance ***(continued)***

16+ Assistance Fund

27 assistance grants for people with Dravet Syndrome aged 16+ were awarded.

Transitioning to adult services, when a young person with Dravet Syndrome reaches the age of 16 and beyond, encompasses significant changes in the organisation of care. Families consistently tell us of their challenges accessing funding for this support. DSUK offers a non-means tested 16+ Assistance Fund. Families can apply for any items of equipment or assistance that will improve the life for the person aged 16+ with Dravet Syndrome. In making this award DSUK aims to improve the quality of life and life chances for people living with Dravet Syndrome and reduce the financial burden on families, who would otherwise need to pay for these items themselves.

In this reporting period DSUK made 27 awards, just slightly lower than the 31 awards made in the previous year, reflecting an overall increase in demand for the 16+ grant compared to years before the pandemic. The is driven partly by needs arising from COVID-19, as people applied for IT and mobility equipment to compensate for the loss of normal daily activities, and partly by an increasing number of adult patients on our database (either joining us as adults or reaching 16 years of age).

Thanks to £5,000 of grant funding from the Pears Foundation/DCMS we were able to meet part of this increased demand, with funding awarded for young people aged 16 to 25 years living in England.

Overall 16+ grants were awarded as follows:

o 9 x IT equipment (e.g. iPads)
o 6 x Indoor furniture (e.g. suitable chairs)
o 6 x Mobility equipment
o 4 x Garden items (e.g. sensory garden)
o 2 x Other

On receipt of the grant, parents/carers are asked to complete a voluntary feedback survey. Although only six people responded during the reporting period, the feedback was universally positive. All rated their overall experience of DSUK's 16+ Assistance Fund service as 'very good'. 5 respondents 'strongly agreed' and 1 'agreed' that the 16+ Fund had a positive impact on their child's health, wellbeing and overall quality of life. 5 respondents rated the likelihood of accessing the same support without the assistance of DSUK as 'very difficult' and 1 as 'difficult'.

Below are verbatim comments highlighting how the 16+ grant has helped improve the lives and well-being of young people with Dravet Syndrome:

"A very big thankyou from our son for his grant for the TV. These past 18 months have been very hard as he hasn't been able to attend his day centre since the start of the pandemic because he is extremely vulnerable to Covid. The TV has helped him through these tough times of Covid, isolation and his kidney transplant. It has helped with entertainment and relaxing during dialysis treatment, whilst waiting for the kidney transplant. It is also now helping him through his recovery. Having the TV has definitely made his isolation periods and recovery easier."

"We are very grateful for all the help you give as all other funding stops when your child turns 18 this is so kind and much appreciated."

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Achievements and performance ***(continued)***

Bereavement Fund

DSUK offers a Bereavement Fund up to the value of £1,000 to support families coping with the recent loss of a loved one with Dravet Syndrome. As with our other funds it is non-means tested and open to those registered with DSUK within 6 months of their child's passing.

Thankfully, there were no bereavements among DSUK's registered families in the 2021/2022 reporting period and therefore no grants were given.

DSUK is extremely grateful to St. James' Place Charitable Foundation for a grant of £2,000 towards our Bereavement Fund, received during the reporting period. Thanks to the generosity of St. James' Place these funds will be available as and when required; £2,000 will help a minimum of 2 families during their time of need.

1:1 Emotional/Practical Support

69 families supported through 1:1 emotional/practical support.

During this reporting period, DSUK maintained the decision taken after the onset of COVID-19 to allocate 65% of the Family Support Manager's role to providing 1:1 emotional and practical support to families living with Dravet Syndrome Our Family Support Manager is also a parent to an adult daughter with Dravet Syndrome.

As an outcome 69 families were supported on 80 separate occasions. Only 10% of these points of contact were logged as COVID-19 related (compared to 67% the previous year). Out of the other points of contact, the top reasons for seeking DSUK support were: 14% lack of support from social care, 11% stress and anxiety, 7.5% information on symptoms (including seizures, sleeping issues, and learning disability) and 7.5% school/education issues.

The Family Support Manager was available to provide emotional support and practical assistance, which included writing letters of support (e.g. to assist with challenges accessing social care) and signposting.

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 social isolation and anxiety.

Below are quotes from two parents and a social worker, illustrating the difference that DSUK's support has made to them:

"Sharing many common difficulties as we do, it was really nice to have a chat. It helps to alleviate some of the anxieties just talking to someone who really understands the many problems that arise caring for a daughter with Dravet." (Parent)

*"We wanted to let you know that your letter was a huge turning point and a massive help to us as our Local Authority have decided to change minds and name **our preferred special school** on our daughter's Education, Health and Care Plan (EHCP)! I want to thank you so very much for all your help and really appreciate your letter and how quick you were. We are truly grateful and cannot thank you enough." (Parent)*

"I found out today that my client's application for Continuing Healthcare was successful. Thank you for your advice and information about Dravet Syndrome. My client would not have got the funding if it hadn't been for the advice given and the information on the DSUK website." (Social Worker)

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Achievements and performance ***(continued)***

Closed Facebook Group

384 people benefitted from being members of our closed Facebook Group.

Every DSUK registered family is invited to join our closed Facebook Group. This group is a safe moderated space for families to ask questions, share experiences and access support from other Dravet families. In managing this group DSUK aims to improve knowledge and understanding of Dravet Syndrome as well as reducing feelings of social isolation and loneliness.

In 2021/2022 DSUK saw the number of members grow from 372 to 384 people, representing over 60% of all parents/carers registered with DSUK during the reporting period. On average the group has 4 to 5 new posts a day covering a wide range of topics including discussion on: seizure types, seizure medication, other therapies (e.g. physio), benefits and social care, EHCPs and special schools, residential care options and more besides.

The group also provides a safe space for families to share the highs and lows of caring for someone with Dravet Syndrome, enabling people to access peer support.

Below are quotes from parents, highlighting the beneficial impact of the closed Facebook Group on their daily lives:

"The Facebook group is invaluable really, for the resource of other families and what they've been through, and advice on things that you're going through. You'll always find somebody else with who's had some similar experience and has some really great advice on the forum."

"Even if you're feeling a bit shy and you don't want to ask anything, it's really nice just to see the posts … which, you know, to other people might be something really small. So, for example, somebody might post on there, 'we managed to go out and have a really good day at the beach', which to a normal family that would just seem why is that important? Whereas to us, we know that a day out at the beach means really hot weather that could trigger seizures. So even if you don't want to partake, you get a sense of kind of belonging just through reading other people's stories".

Center Parcs Grant

Each year DSUK holds a weekend away at Center Parcs in Nottinghamshire, bringing families living with Dravet Syndrome together to share experiences/knowledge and to have a much-needed holiday. In arranging this holiday DSUK aims to reduce the social isolation and loneliness experienced by many families living with Dravet Syndrome, by connecting them with a new support network of Dravet families.

Unfortunately, due to the restrictions associated with the ongoing COVID-19 pandemic, it was necessary to once again postpone the Center Parcs weekend planned for June 2021. Families were understanding and measures were put in place to transfer the bookings already made to the following year.

Following a two-year delay, the DSUK Family Weekend Away to Center Parcs finally took place in June 2022. However, as the event falls outside the reporting period for this document, it will be included in next year's Annual Report.

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Achievements and performance ***(continued)***

Super Sibling Awards

15 Super Sibling Awards given during the reporting period.

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.

They also need to adapt to the day-to-day pressures of living with Dravet Syndrome: the fact that there are times when plans are cancelled, holidays are not possible, sleepovers just too intense and the simple fact that their mum and dad are stressed, worried and exhausted. They may also experience those feelings of isolation or guilt that often go alongside the pressures of living with a disabled sibling.

Each year, just before Christmas, we announce our annual 'Super Sibling' awards as a way to give special recognition to siblings and say thank you for all that they do. In making these awards DSUK aims to contribute positively to sibling mental well-being.

In the reporting period, DSUK received 15 Super Sibling Award nominations from parents/carers. Every nominated sibling was awarded a personalised 'Super Sibling' certificate, medal and £50 amazon gift voucher so they could treat themselves to something special.

Below is a quote from a parent, highlighting the beneficial impact of receiving a Super Sibling Award:

“We are so proud of Ella, who really embodies what it means to be a super sibling. We tell her all the time how fabulously she deals with it all - it really brings it home to her for it to be recognised by those outside of her family.”

In addition to the Super Sibling Awards, we also updated our 'Supporting Siblings' with useful information for caregivers on how to support siblings, as well as providing real-life sibling case studies from some of our registered families.

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Achievements and performance *(continued)*

Education

During 2021/22, DSUK contributed to improving awareness and understanding of Dravet Syndrome through the following educational activities.

Marketing and Communications Strategy

A Marketing and Communication strategy and implementation plan was developed in alignment with DSUK's overall 5-Year Strategy, supporting our 4 strategic objectives:

- Every Family Counts
- Leaders in the Field
- Support for Professionals
- Empowerment of Families

The overall objective of the Marketing and Communications implementation plan is to expand the reach of DSUK's communications to key audiences, including families living with Dravet Syndrome, medical professionals and the broader community of supporters and sponsors.

In July 2021, to support with the implementation of the expanded Marketing and Communications remit and fundraising capability, DSUK hired a new part-time staff member, Natalie Perkins, as Marketing, Communications and Fundraising Manager, reporting to the existing Head of Marketing and Communications, Claire Eldred.

Educational campaigns

International or national awareness days/weeks offer DSUK opportunities to communicate educational priorities, especially with regard to improving diagnosis of Dravet Syndrome.

During 2021/2022, we leveraged multiple occasions run social media campaigns aimed at educating both professional and public audiences, via facts about Dravet Syndrome, case studies, educational videos and information to encourage diagnosis, including our 'Could it be Dravet Syndrome?' Diagnosis Guide for Professionals.

Key awareness dates included Rare Diseases Day in February, achieving a social media reach of over 23,000, and Purple Day in March, achieving a social media reach of over 42,000.

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Achievements and performance *(continued)*

Educational campaigns *(continued)*

Our flagship educational campaign took place in June 2021. DSUK has traditionally leveraged International Dravet Syndrome Awareness Day on 23rd June as a key opportunity to raise the profile of this condition among wider audiences. In 2021, we took the decision to align for the first time with our US colleagues in marking the entirety of June as Dravet Syndrome Awareness Month, in addition to the International day on 23rd June. Our month-long campaign was themed 'Every Family Counts' (in line with our strategic objective) and involved a series of activities, including:

- Facts, case studies and other information shared via social media, gaining an overall reach of over 153,000 people
- 'Could it be Dravet Syndrome?' factsheet shared on our website and social media, downloaded over 355 times
- The introduction of a new Remembrance Day on 15th June dedicated to those loved ones lost to Dravet Syndrome. The overall response from families was very positive. Social media posts had a combined reach of over 15,000 and the website received 276 visits - the biggest spike of the month.
- An awareness video, 'Every Family Counts', shared on social media and YouTube. The objective of the video, featuring 5 children and adults living with Dravet Syndrome, was to both encourage diagnosis and let families with the condition know about the different ways DSUK can provide support. The video was subsequently a runner up in Charity Film's People's Choice Award and has gained over 5,500 views on YouTube, making it the second most-watched video on our YouTube channel
- A Twitter Takeover on 23rd June by Trustee and Children's Epilepsy Nurse Specialist, Neil Williamson, resulting in 11,000 impressions just on this day, over 200 engagements, 95 likes and 23 retweets - the most interaction recorded in a single day since we launched our @DravetUK Twitter account.

COVID-19 publications

In the reporting period, we continued our pioneering work in contributing to scientific knowledge about the impact of COVID-19 among people with Dravet Syndrome. Our initial publication, 'The impact of COVID-19 in Dravet syndrome: A UK survey' by Simona Balestrini et al., was published in the in peer-review medical journal, Acta Neurologica Scandinavica.

In February 2021, we conducted a second survey of our registered families to gather information about how the COVID-19 vaccinations affect young people and adults living with Dravet Syndrome. There was very little data about the impact of vaccinations on this group, so although the survey sample is relatively small (8 people), it provided a unique contribution to evolving scientific knowledge of how coronavirus affects our community.

Key findings from the survey include:

- Overall, the results of the survey suggest that the SARS-CoV-2 vaccines are safe and well tolerated in people with DS, as they are in most people without DS.
- Mild, short term side effects were fatigue, fever, pain at the injection site, aching or headache are common after vaccination in people with, and without, DS
- In the majority of people with DS, COVID-19 vaccines do not appear to be associated with an increase in the frequency or duration of seizures, even in those who develop fever post-vaccination.

These survey findings provided the basis for a second publication, 'The impact of SARS-CoV-2 vaccination in Dravet Syndrome: a UK survey' by Lisa M. Clayton et al., which was published in peer-review medical journal, Epilepsy & Behaviour.

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Achievements and performance ***(continued)***

Webinars

In 2021/2022 we held two educational webinars for caregivers and one for professionals:

Parent/Carer Webinar: Managing Behaviours that Challenge (March 2021)
Dr Penny Williams, Speech and Language Therapist and Annemarie Sims, Occupational Therapist, from Evelina London Children's Hospital neurodevelopment team, discussed behaviours that challenge, including why these behaviours occur in children and adults with Dravet Syndrome and strategies for managing these behaviours. The webinar was recorded and made available on our YouTube channel. It has received over 230 views.

Parent/Carer Webinar: Gene Therapies and UK Clinical Trials (June 2021) This webinar provided an overview of current treatments, introduced developmental gene therapies and provided information about new clinical trials planned for the UK. The aim was to provide caregivers with more information about these developmental therapies and what to expect from a future clinical trial, so that they can make an informed choice about whether they would want to take part, should the opportunity be available. The webinar was recorded and made available on our YouTube channel. It has received over 260 views.

Professional Webinar: Gene Therapies and UK Clinical Trials (June 2021) Led by Professor Helen Cross (Chair of DSUK's Medical Advisory Board and Dr Andreas Brunklaus (Royal Hospital for Children, Glasgow), this webinar provided an overview of current and development therapies for Dravet Syndrome for Healthcare Professionals to ensure that they were informed and equipped with relevant information to be able to answer patient/caregiver enquiries. The webinar was recorded and made available on our YouTube channel. It has received over 430 views.

Social Media

Social media is an important platform for raising awareness and understanding of Dravet Syndrome. DSUK has an active social media presence, posting on platforms between 3-5 times per week on a variety of topics including our educational priorities, family case studies, fundraising stories and other news relevant to the Dravet Syndrome community.

During 2021/2022, DSUK's posts across our four social media platforms (Facebook, Instagram, Twitter and LinkedIn) had a combined overall reach of over 800,000.

Website

In 2021/2022, more than 30,000 people (an increase of over 7,500 compared to the previous year) visited our website and benefited from its educational content. 87% of these were new visitors to the website. Overall, the top-5 most viewed pages (in addition to the home page) were 'What is Dravet Syndrome' (7,000+ views), 'About Dravet Syndrome', (4,000+ views), 'About us' (2,000+ views), 'Dravet Syndrome Symptoms' (1,800+ views) and 'Treatments and Outcomes' (1,800+ views).

Key website updates during this period included:

- Continued updates to COVID-19 hub including information about vaccines and return to schooling/day care (1,600+ views)
- Updates and new case studies added to the 'Dravet Journeys' section, sharing real-life experiences from families living with Dravet Syndrome (1,800+ views)
- A new 'Events' section to make it easier for people to find information about our events, including our biennial Conference (6,700+ views).

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Achievements and performance ***(continued)***

External conferences

2 major conferences attended, reaching paediatricians, neurologists and specialist nurses, and a high-profile audience of decision makers interested in public health policies.

Every year DSUK attends the major UK and international paediatric, neurology and epilepsy conferences to raise awareness and improve understanding of Dravet Syndrome amongst paediatricians, neurologists, specialist nurses and other key stakeholders. Due to the coronavirus pandemic, many congresses that DSUK would usually attend were cancelled or changed to a virtual event. As a result, DSUK attended two major conferences in the reporting period:

- Epilepsy and Climate Change Conference (EPiCC)

DSUK's Chair and Trustee, Galia Wilson gave a 10-minute talk on the impact of climate change on Dravet Syndrome, at the EPiCC meeting on 25th November, on the invitation of Professor Sanjay Sisodiya, one of the Conference organisers. This talk was an opportunity to raise awareness of Dravet Syndrome among a high-profile audience (including public health professionals as well as environmental specialists), as well as providing an important contribution in highlighting real-life, lived experience of how climate change can affect vulnerable individuals, such as those living with Dravet Syndrome.

- British Paediatric Neurology Association (BPNA)

DSUK hosted a virtual stand at the UK's most high-profile paediatric neurology congress. This included a short presentation with educational messages around the diagnosis of Dravet Syndrome and the 'Could it be Dravet Syndrome?' Diagnosis Guide. In addition, we interacted virtually with attending clinicians from across the UK.

Expert meetings with stakeholders

Throughout the reporting period, DSUK participated in numerous meetings with a range of stakeholders involved in the provision and development of current and future treatments for Dravet Syndrome, including those from the rare diseases sectors, other charities with an interest in epilepsy/neurological conditions, the pharmaceutical industry, and the NHS / National Institute for Health and Care Excellence (NICE).

DSUK Biennial Conference

Since 2010 we have been holding a two-day biennial DSUK Conference bringing together world-leading experts to educate professionals and caregivers on the latest developments in Dravet Syndrome. During the reporting period, we held our fifth biennial conference, which took place on 19th-20th November in Birmingham. This was our first virtual conference for Professionals and first hybrid event for Parents/Carers, ensuring we could reach a wide audience of clinicians and families despite the restrictions of COVID-19.

Both meetings were chaired by Professor Helen Cross and featured sessions led by members of DSUK's Medical Advisory Board and guest speakers.

The Professional Day is the only scientific meeting in the UK that is dedicated to furthering knowledge about Dravet Syndrome. The 2021 Professional Conference was endorsed by the European Academy of Neurology, with CPD points from RCP and RPCH. By live-streaming and enabling an on-demand viewing option, we reached nearly 200 professionals - improving understanding of Dravet Syndrome, enabling earlier diagnosis and aiming to provide accessible pathways to the best possible treatment and care for all ages.

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Achievements and performance ***(continued)***

The Parent/Carer Day, held on day two, is a great opportunity for families to meet others living with Dravet Syndrome and to hear directly from expert guest speakers. In 2021, due to Covid-19 restrictions, we were only able to host a limited number of caregivers at the conference venue. Around 60 parents and carers were able to join the conference in Birmingham, with more than 90 participants accessing the online event

Feedback from our 2021 Conferences was overwhelmingly positive. Out of those who gave feedback to the Professional Conference, 87% of respondents agreed the event fully or greatly met their learning needs, 75% said education received at the conference would significantly impact their clinical practice and 100% rated the quality of CPD education as very good or excellent.

Comments include:
- "Thank you for such a thought provoking and informative conference. Very relevant to practice and beneficial to improving care."
- "Fantastic conference - very well planned and informative. Very accessible being online."

Out of those who gave feedback on the Parent/Carer Conference, 90% rated it as very good or excellent and 76% agreed the conference would have a positive impact on the care and support they provide for their children with Dravet Syndrome.

Comments include:
- "Very pleased with the organisation and agenda. Thank you DSUK and all contributors."
- "Always great to get the latest research and developments and the opportunity to ask questions."

Research

In 2021/2022 DSUK spent £80,000 on novel research into Dravet Syndrome.

As part of the new five-year Strategy, DSUK updated its research priorities to ensure that all funded projects are focused on the needs of families. In 2021, we were pleased to be able to award grants for three diverse and innovative research projects.

- Genetic therapy to address the underlying causes of Dravet Syndrome

In April 2021, in partnership with Great Ormond Street Children's Charity, DSUK awarded funding for a novel gene therapy project for Dravet Syndrome, led by Professor Matthew Wood at the University of Oxford. DSUK contributed £50,000 towards the research grant. Around 85% of individuals with Dravet Syndrome have a mutation in the SCN1A gene. SCN1A is an important protein for controlling the activity of brain cells. If not enough protein is produced this can lead to seizures, intellectual disability and the spectrum of comorbidities that we see in Dravet Syndrome. Professor Wood's research aims to develop a new genetic therapy to increase the amount of "missing" SCN1A protein. It's an exciting and complementary addition to the multiple gene and genetic therapies currently being explored for Dravet Syndrome. These therapies aim to dramatically improve seizures, and also the intellectual disability and comorbidities associated with this devastating condition.

- Advancing knowledge of the pathophysiology of Dravet Syndrome

In July 2021, DSUK partnered with four additional European patient organisations (Gruppo Famiglie Dravet ONLUS, Apoyo Dravet, Dravet Syndrom e.V, Stichting Dravet Syndroom Nederland/Vlaanderen and Swiss Dravet Syndrome Association (SDSA), contributing £20,000 towards a 2-year research grant.

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Achievements and performance ***(continued)***

The overarching goal of the selected project is to study a new mechanism in the pathophysiology of Dravet Syndrome, neuron-oligodendrotyte interactions. Led by a team at the Hertie Institute for Clinical Brain Research (HIH) at University Hospital Tübingen, this project has the potential to significantly advance understanding of Dravet Syndrome and inform a wide range of future studies.

(Note: Dravet Syndrome charities globally committed €125,000 in total to this call, of which DSUK committed £20,000. This expenditure was undertaken in the previous reporting period of 2020/2021, although the grant was not awarded until the current reporting period, hence its inclusion here).

- Natural History Project for standardised and better care

In November 2021, DSUK partnered with the University of Glasgow to co-fund the SCN1A Horizons Natural History Study, contributing £30,000 towards a 4-year project. The lead investigator for this project is Professor Andreas Brunklaus, who is also a member of DSUK's Medical Advisory Board.

The Natural History Project aims to characterise all aspects of Dravet Syndrome via regular, standardised clinical assessments involving 300 patients of all ages across the UK between 2021-2025. It is hoped that the study and its outcomes will ultimately enable standardised and better care that is more closely tailored to the needs of individuals with Dravet Syndrome than current approaches.

In addition to these co-funded projects, DSUK also initiated several independent research projects, in partnership with individual members of its Medical Advisory Board, in order to address unmet needs of caregivers and families living with Dravet Syndrome.

- COVID-19 and Dravet Syndrome

As reported above (page 12) in February 2021, we conducted a second survey of our registered families to gather information about how the COVID-19 vaccinations affect young people and adults living with Dravet Syndrome. There was very little data about the impact of vaccinations on this group, so although the survey sample is relatively small (8 people), it provided a unique contribution to evolving scientific knowledge of how coronavirus affects our community. The resulting study, 'The impact of SARS-CoV-2 vaccination in Dravet Syndrome: a UK survey' by Lisa M. Clayton et al., was published in peer-review medical journal, Epilepsy & Behaviour in November 2021.

- DSUK Family Survey

In November/December 2021, DSUK conducted a wide-ranging survey among registered parents/carers, covering core topics affecting families, including diagnosis, medical care, and social care. The response exceeded our expectations with 165 parent/carers completing the survey, representing around 30% of all families registered with us. Out of the 165 responses, 35% (58) were caring for adults aged 18 and over. We are currently working with members of our Medical Advisory Board to review findings and develop educational material to raise awareness of unmet needs.

- DSUK Gastrostomy Survey

In January 2022, DSUK conducted a survey among its registered parents/carers devised with Medical Advisory Board member, Professor Sanjay Sisodiya and Dr Lisa Clayton. The aim was to explore issues relating to feeding, eating, swallowing and weight loss in Dravet Syndrome and to examine attitudes and responses to Gastrostomy. The data is currently being reviewed and future publications are anticipated.

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Financial review

Incoming Resources

In 2021/2022 DSUK received £342,790 in income from the following sources

£ 213,001	Community fundraising
£ 66,500	Industry grants
£ 45,000	Corporate sponsorship
£ 7,500	Grants from Trusts/Foundations
£ 10,789	Income generation

Historically community fundraising has been an important source of income for DSUK, with £209,418 raised in 2019/2020. With the onset of the pandemic it was not possible for the normal community fundraising activities to take place such as marathons, treks etc. meaning only £136,238 was secured in 2020/2021. In 2021/2022 we saw a recovery in community fundraising, which generated £213,001. Last year saw a growth in grants from trusts/foundations in response to the pandemic but this year this has reduced from £26,225 to £7,500. XTX Markets generously continue as a corporate sponsor of the charity and have again provided us with £30,000 of funding. Additionally Novayct have provided a grant of £15,000 during the year.

Outgoing Resources

In 2021/2022 DSUK spent £364,519 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
- Awareness raising activities (e.g. DSUK Biennial conference)
- Awareness raising materials (e.g. DSUK educational leaflets and videos)
- DSUK merchandise for fundraising events & shop sales
- Staff costs with 4 people (3.18 FTE) paid for 119 hours as at 31st January 2022.

Reserves Policy

Dravet Syndrome UK is required to ensure that free monies are available in each financial year to meet any reasonably foreseeable contingency.

The trustees have determined that 'free' reserves should ideally be at least six months of normal operating expenditure, which is considered by the trustees to amount to around £244,000 based on estimated expenditure for 2022/2023. At 31 January 2022, the unrestricted reserves of the charity amounted to £389,432, net of tangible fixed assets, of which £30,973 has been designated by the trustees for educational materials, leaving free reserves of £358,459 at that date, compared to £290,805 at the previous year-end date. It is anticipated that the designated fund balances relating to educational materials as at 31 January 2022 will be fully expended by 31 January 2023.

Looking ahead to 2022/2023, the Trustees will be continuing DSUK's 5-year Strategy for 2021 to 2026. In order to deliver this strategy, the Trustees plan to invest at least £44,000 of available free reserves in order to lay the foundations for organisational growth.

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Plans for future periods

In this reporting period the Board of Trustees approved DSUK's first five-year strategy for 2021 to 2026, which was launched in February 2021. This strategy aims to reach more families, to deliver research that puts family needs first, to improve awareness and understanding amongst professionals, particularly in adult neurology and social services, and to give families the tools and support needed to assert their rights.

Underpinning the strategy are four overarching objectives

1. Every Family Matters
   Every UK family living with Dravet Syndrome will be aware of DS UK and the support available, be enabled to access this support as required, and know that all activities and research are driven by the things that matter most to them.

2 Leaders in the Field
   DSUK will lead the conversation about Dravet Syndrome in the UK, making the best possible use of its 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.

We have come a long way supporting children and adults with Dravet Syndrome but there is further to go. Families are still waiting too long for a diagnosis. We do not know enough about the comorbidities of Dravet Syndrome and the spectrum nature of the condition. Transition into adult health care services remains challenging and many families struggle to access the statutory support to which they are entitled. We know we have given ourselves a lot to do but we believe this is the right time to move forward and, more importantly, this is the right way for us to support everyone who lives with Dravet Syndrome and all its challenges.

With our families behind us and a strong and committed team of staff, trustees and medical advisors we are ready and excited to get on with this work. To deliver this strategy we will be putting robust plans in place, particularly to secure the resources needed to achieve our ambitions while also being responsive to the uncertainties of these times. In 2021/22 we will be designating our free reserves to enable this growth and as such will have an income to expenditure deficit as we bring our reserves in line with our reserves policy.

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Plans for future periods ***(continued)***

There is so much to be hopeful for as we look ahead, and the next 5 years is just the next milestone, not the end of the road. We are really excited by the possibilities of the coming years. There are gene therapies on the horizon, and other new treatments in development, as well as all the work we are planning with this new strategy. We look forward with confidence, excitement and hope that DSUK can and will make a difference for every family living with Dravet Syndrome in the UK.

The Trustees' annual report was approved on 07 October 2022 and signed on behalf of the board of trustees by:

DocuSigned by:
Kelvin Hughes
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K Hughes
Trustee and Treasurer

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Dravet Syndrome UK

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

Year Ended 31 January 2022

I report to the trustees on my examination of the financial statements of Dravet Syndrome UK ('the charity') for the year ended 31 January 2022.

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.

DocuSigned by:
Tim Leeman
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T G Leeman FCA
Independent Examiner

MCABA Limited t/a
Mitchells Chartered Accountants
91 - 97 Saltergate
Chesterfield
Derbyshire
S40 1LA

Date: 12 October 2022

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Dravet Syndrome UK

Statement of Financial Activities (Incorporating Income and Expenditure Account)

Year Ended 31 January 2022

	Note	2022 Unrestricted funds £	2022 Restricted funds £	2022 **Total funds** £	2021 Total funds £
Income					
Donations and grants	**4**	258,001	74,000	**332,001**	336,806
Charitable activities	**5**	6,428	–	**6,428**	–
Other trading activities	**6**	2,355	–	**2,355**	7,286
Investment income	**7**	6	–	**6**	59
Other income	**8**	2,000	–	**2,000**	920
Total income		268,790	74,000	**342,790**	345,071
Expenditure					
Expenditure on raising funds:					
Costs of raising donations and grants	**9**	33,640	–	**33,640**	20,176
Costs of other trading activities	**10**	1,083	–	**1,083**	4,490
Expenditure on charitable activities	**11**	221,844	107,952	**329,796**	281,146
Total expenditure		256,567	107,952	**364,519**	305,812
Net (expenditure)/income		12,223	(33,952)	**(21,729)**	39,259
Transfers between funds		(8,293)	8,293	**–**	–
Net movement in funds		3,930	(25,659)	**(21,729)**	39,259
Reconciliation of funds					
Total funds brought forward		386,468	40,289	**426,757**	387,498
Total funds carried forward		390,398	14,630	**405,028**	426,757

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 23 to 32 form part of these financial statements.

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Dravet Syndrome UK

Statement of Financial Position

31 January 2022

	Note	2022 £	£	2021 £
Fixed Assets				
Tangible fixed assets	**18**		**466**	104
Current Assets				
Stocks	**19**	**14,072**		14,264
Debtors	**20**	**32,188**		81,825
Cash at bank and in hand		**398,904**		363,363
		445,164		459,452
Creditors: amounts falling due within one year	**21**	**40,602**		6,236
Net Current Assets			**404,562**	453,216
Total Assets Less Current Liabilities			**405,028**	453,320
Creditors: amounts falling due after more than one year	**22**		**–**	26,563
Net Assets			**405,028**	426,757
Funds of the Charity				
Restricted funds			**14,630**	40,289
Unrestricted funds			**390,398**	386,468
Total charity funds	**25**		**405,028**	426,757

These financial statements were approved by the board of trustees and authorised for issue on 07 October 2022 and are signed on behalf of the board by:

DocuSigned by:
Kelvin Hughes
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K Hughes
Trustee

The notes on pages 23 to 32 form part of these financial statements.

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Dravet Syndrome UK

Notes to the Financial Statements

Year Ended 31 January 2022

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

Whilst the global economy has been significantly impacted by the effect of the COVID-19 pandemic, the management and trustees realigned their strategy and working practices to meet the demands arising from an ever-changing environment and continue to adapt in response to change. 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.

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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.

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4. Donations and grants

	Unrestricted Funds £	Restricted Funds £	**Total Funds 2022 £**
Donations			
Donations	258,001	–	**258,001**
Grants			
DSUK conference	–	66,500	**66,500**
Seizure monitors	–	500	**500**
Educational materials	–	–	**–**
Others	–	–	**–**
Educational videos	–	–	**–**
COVID-19 assistance	–	–	**–**
16+ grants to beneficiaries	–	5,000	**5,000**
Bereavement grants	–	2,000	**2,000**
	258,001	74,000	**332,001**

	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £
Donations			
Donations	180,281	10,957	191,238
Grants			
DSUK conference	–	–	–
Seizure monitors	–	9,817	9,817
Educational materials	30,000	–	30,000
Others	1,553	–	1,553
Educational videos	–	36,825	36,825
COVID-19 assistance	52,518	9,855	62,373
16+ grants to beneficiaries	–	5,000	5,000
Bereavement grants	–	–	–
	264,352	72,454	336,806

The trustees confirm that the above restricted income recognised in respect of the DSUK Conference 2019 is compliant with The Association of the British Pharmaceutical Industry Code of Practice.

5. Charitable activities

	Unrestricted Funds £	**Total Funds 2022 £**	Unrestricted Funds £	Total Funds 2021 £
DSUK conference ticket income	6,428	**6,428**	–	–

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6. Other trading activities

	Unrestricted Funds £	**Total Funds 2022 £**	Unrestricted Funds £	Total Funds 2021 £
Merchandise sales	2,355	**2,355**	7,286	7,286

7. Investment income

	Unrestricted Funds £	**Total Funds 2022 £**	Unrestricted Funds £	Total Funds 2021 £
Bank interest receivable	6	**6**	59	59

8. Other income

	Unrestricted Funds £	**Total Funds 2022 £**	Unrestricted Funds £	Total Funds 2021 £
Consultancy services	2,000	**2,000**	920	920

9. Costs of raising donations and grants

	Unrestricted Funds £	**Total Funds 2022 £**	Unrestricted Funds £	Total Funds 2021 £
Event costs	2,298	**2,298**	146	146
Wages and salaries	14,969	**14,969**	16,635	16,635
Employer's NIC	709	**709**	1,110	1,110
Pension costs	347	**347**	372	372
Fundraising consultancy fees	12,000	**12,000**	–	–
Just Giving charges	3,317	**3,317**	1,913	1,913
	33,640	**33,640**	20,176	20,176

10. Costs of other trading activities

	Unrestricted Funds £	**Total Funds 2022 £**	Unrestricted Funds £	Total Funds 2021 £
Opening stock	14,146	**14,146**	4,716	4,716
Merchandise purchases	339	**339**	13,920	13,920
Closing stock	(13,402)	**(13,402)**	(14,146)	(14,146)
	1,083	**1,083**	4,490	4,490

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11. Expenditure on charitable activities by activity type

	Activities undertaken directly	Support costs	**Total funds 2022**	Total fund 2021
	£	£	**£**	£
Research funding	85,529	31,764	**117,293**	106,407
Education and raising awareness	113,122	229	**113,351**	43,113
Supporting families	75,600	–	**75,600**	111,930
Governance costs	–	22,832	**22,832**	18,676
	274,251	54,825	**329,076**	280,126

12. Analysis of support costs

	Analysis of support costs - charitable activities	**Total 2022**	Total 2021
	£	**£**	£
Staff costs	20,145	**20,145**	13,886
Premises	1,070	**1,070**	485
Communications and IT	9,702	**9,702**	7,938
Human resources	361	**361**	1,509
Finance costs	715	**715**	104
Governance costs	22,832	**22,832**	18,675
	54,825	**54,825**	42,597

13. Net (expenditure)/income

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

	2022	2021
	£	£
Depreciation of tangible fixed assets	**229**	216

14. Auditors remuneration

	2022	2021
	£	£
Fees payable for the audit of the financial statements	**–**	4,200

15. Independent examination fees

	2022	2021
	£	£
Fees payable to the independent examiner for:		
Independent examination of the financial statements	**2,592**	–

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16. Staff costs

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

	2022	2021
	£	£
Wages and salaries	**108,163**	116,757
Social security costs	**5,907**	7,331
Employer contributions to pension plans	**2,382**	2,477
	116,452	126,565

The average head count of employees during the year was 4 (2021: 4).

No employee received employee benefits of more than £60,000 during the year (2021: 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 £25,207 (2021:£52,371).

17. 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 2 trustees (2021: 1) that have claimed expenses or had their expenses met by the charity as follows:

	2022	2021
	£	£
Travel	**393**	–
Sundry	**–**	8
	393	8

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18. Tangible fixed assets

	Fixtures and fittings £	Equipment £	**Total £**
Cost			
At 1 February 2021	490	3,403	**3,893**
Additions	–	591	**591**
At 31 January 2022	490	3,994	**4,484**
Depreciation			
At 1 February 2021	489	3,300	**3,789**
Charge for the year	–	229	**229**
At 31 January 2022	489	3,529	**4,018**
Carrying amount			
At 31 January 2022	1	465	**466**
At 31 January 2021	1	103	104

19. Stocks

	2022 £	2021 £
Stock of merchandise and consumables	**13,402**	14,146
Finished goods and goods for resale	**670**	118
	14,072	14,264

20. Debtors

	2022 £	2021 £
Prepayments and accrued income	**32,013**	81,765
Other debtors	**175**	60
	32,188	81,825

21. Creditors: amounts falling due within one year

	2022 £	2021 £
Accruals and deferred income	**33,860**	774
Social security and other taxes	**1,979**	2,780
Other creditors	**4,763**	2,682
	40,602	6,236

22. Creditors: amounts falling due after more than one year

	2022 £	2021 £
Accruals and deferred income	**–**	26,563

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23. Deferred income

	2022	2021
	£	£
At 1 February 2021	**26,563**	–
Amount deferred in year	**–**	26,563
At 31 January 2022	**26,563**	26,563

Deferred income at the year-end relates the delayed Center Parcs event now scheduled to be held in June 2022.

24. 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 £2,382 (2021: £2,477).

25. Analysis of charitable funds

Unrestricted funds

	At 1 February 2021	Income	Expenditure	Transfers	**At 31 January 2022**
	£	£	£	£	**£**
General funds	290,805	268,790	(162,540)	(37,630)	**359,425**
Designated research fund	50,663	–	(80,000)	29,337	**–**
Designated educational materials fund	45,000	–	(14,027)	–	**30,973**
	386,468	268,790	(256,567)	(8,293)	**390,398**

	At 1 February 2020	Income	Expenditure	Transfers	At 31 January 2021
	£	£	£	£	£
General funds	263,243	224,036	(196,474)	–	290,805
Designated research fund	109,255	18,581	(77,173)	–	50,663
Designated educational materials fund	15,000	30,000	–	–	45,000
	387,498	272,617	(273,647)	–	386,468

The trustees designate a proportion of unrestricted funds received by the charity each year for the purpose of funding of medical research into Dravet Syndrome.

Unrestricted grants to which entitlement passed to the charity during the 2020/21 financial year were allocated to the provision of educational materials by the trustees, as part of the ongoing drive to raise awareness of Dravet Syndrome. The project was delayed due to the COVID-19 pandemic but is now ongoing.

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25. Analysis of charitable funds *(continued)*

Restricted funds

	At 1 February 2021 £	Income £	Expenditure £	Transfers £	**At 31 January 2022 £**
Conference	–	66,500	(74,793)	8,293	**–**
Research	–	–	–	–	**–**
Center Parcs event	–	–	(933)	–	**(933)**
Seizure monitors - Nottinghamshire	–	500	–	–	**500**
COVID-19 assistance	–	–	–	–	**–**
16+ grants to beneficiaries	3,464	5,000	(5,934)	–	**2,530**
Educational videos	36,825	–	(26,292)	–	**10,533**
Bereavement grants	–	2,000	–	–	**2,000**
	40,289	74,000	(107,952)	8,293	**14,630**

	At 1 February 2020 £	Income £	Expenditure £	Transfers £	At 31 January 2021 £
Conference	–	–	–	–	–
Research	–	10,957	(10,957)	–	–
Center Parcs event	–	–	–	–	–
Seizure monitors - Nottinghamshire	–	9,817	(9,817)	–	–
COVID-19 assistance	–	9,855	(9,855)	–	–
16+ grants to beneficiaries	–	5,000	(1,536)	–	3,464
Educational videos	–	36,825	–	–	36,825
Bereavement grants	–	–	–	–	–
	–	72,454	(32,165)	–	40,289

Transfers of £8,293 (2021: £ nil) have been made during the year from unrestricted funds to finance a deficit in respect of the biennial DSUK Conference.

In the reporting year, Dravet Syndrome UK, received sponsorship funding for the DSUK Biennial Conference from multiple pharmaceutical companies (including Biocodex, Encoded Therapeutics, GW/Jazz Pharmaceuticals, Liva Nova, Stoke Therapeutics and Zogenix) as well as from its corporate partner, XTX Markets. The charity also received restricted grants to support a variety of educational and family support projects from the pharmaceutical industry sector and from XTX Markets.

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26. Analysis of net assets between funds

	Unrestricted Funds £	Restricted Funds £	**Total Funds 2022 £**
Tangible fixed assets	466	–	**466**
Current assets	403,971	41,193	**445,164**
Creditors less than 1 year	(14,039)	(26,563)	**(40,602)**
Creditors greater than 1 year	–	–	**–**
Net assets	390,398	14,630	**405,028**

	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £
Tangible fixed assets	104	–	104
Current assets	419,163	40,289	459,452
Creditors less than 1 year	(6,236)	–	(6,236)
Creditors greater than 1 year	(26,563)	–	(26,563)
Net assets	386,468	40,289	426,757

27. Related parties

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

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Dravet Syndrome UK

Management Information

Year Ended 31 January 2022

The following pages do not form part of the financial statements.

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Dravet Syndrome UK

Detailed Statement of Financial Activities (Incorporating Income and Expenditure Account)

Year Ended 31 January 2022

	2022	2021
	£	£
Income		
Donations and grants		
Donations	**258,001**	191,238
DSUK conference	**66,500**	–
Seizure monitors	**500**	9,817
Educational materials	**–**	30,000
Others	**–**	1,553
Educational videos	**–**	36,825
COVID-19 assistance	**–**	62,373
16+ grants to beneficiaries	**5,000**	5,000
Bereavement grants	**2,000**	–
	332,001	336,806
Charitable activities		
DSUK conference ticket income	**6,428**	–
Other trading activities		
Merchandise sales	**2,355**	7,286
Investment income		
Bank interest receivable	**6**	59
Other income		
Consultancy services	**2,000**	920
Total income	**342,790**	345,071

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Dravet Syndrome UK

Detailed Statement of Financial Activities (Incorporating Income and Expenditure Account) *(continued)*

Year Ended 31 January 2022

	2022 £	2021 £
Expenditure		
Costs of raising donations and grants		
Event costs	**(2,298)**	(146)
Wages and salaries	**(14,969)**	(16,635)
Employer's NIC	**(709)**	(1,110)
Pension costs	**(347)**	(372)
Professional fees	**(12,000)**	–
Just Giving charges	**(3,317)**	(1,913)
	(33,640)	(20,176)
Costs of other trading activities		
Opening stock	**(14,146)**	(4,716)
Merchandise purchases	**(339)**	(13,920)
Closing stock	**13,402**	14,146
	(1,083)	(4,490)
Expenditure on charitable activities		
Opening monitors stock	**(118)**	(6,424)
Direct costs including research	**(193,844)**	(136,444)
Closing monitors stock	**670**	118
Wages and salaries	**(93,194)**	(100,122)
Employer's NIC	**(5,198)**	(6,221)
Pension costs	**(2,035)**	(2,105)
Insurance	**(1,070)**	(485)
Travel costs	**(677)**	–
Professional fees	**(22,832)**	(18,676)
Depreciation	**(229)**	(216)
Human resources costs	**(361)**	(1,509)
Computer costs	**(9,473)**	(8,042)
Bank charges and admin fees	**(715)**	–
Training	**(720)**	(1,020)
	(329,796)	(281,146)
Total expenditure	**(364,519)**	(305,812)
Net (expenditure)/income	**(21,729)**	39,259

DRAVET SYNDROME UK

England & Wales - Charity number 1128289

Accounts

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CHARITY REGISTRATION NUMBER: 1128289

Dravet Syndrome UK

Financial Statements

31 January 2021

MCABA Limited t/a Mitchells
Chartered accountants
91-97 Saltergate
Chesterfield
Derbyshire
S40 1LA

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Dravet Syndrome UK

Financial Statements

Year Ended 31 January 2021

	Pages
Trustees' annual report	1 to 15
Independent auditor's report to the members	16 to 19
Statement of financial activities (incorporating income and expenditure account)	20
Statement of financial position	21
Notes to the financial statements	22 to 31

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Dravet Syndrome UK

Trustees' Annual Report

Year Ended 31 January 2021

The trustees present their report and the financial statements of the charity for the year ended 31 January 2021.

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 (Appointed 1 September 2020)
Auditor	MCABA Limited t/a Mitchells Chartered Accountants & Statutory Auditor 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.

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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").

To fund medical research projects into Dravet Syndrome and other related genetic sodium channel epilepsies that will benefit the sufferers of Dravet Syndrome;

To raise awareness and provide education to families and the medical community about Dravet Syndrome;

To support families affected by Dravet Syndrome in the UK.

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.

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Achievements and performance

In 2020/21 Dravet Syndrome UK (DSUK), along with other UK charities, faced an unprecedented challenge with the onset of the coronavirus pandemic. The need for support for families living with Dravet Syndrome increased significantly, at the same time as our capacity to fundraise was severely restricted by social distancing measures.

We are proud to report that DSUK met the coronavirus challenge, remaining open at all times without recourse to furlough, and increasing family support to meet additional needs arising from the pandemic. Whilst we saw a 37% drop in community fundraising, we were able to meet this challenge thanks to exceptional COVID-19 funding from the National Lottery Community Fund, Pears Foundation/DCMS, our corporate sponsor and other industry partners. We also benefited from growth in giving via Facebook and a generous individual donation of £25,000.

During this reporting period, the Board of Trustees developed and signed off DSUK's first 5-year strategy, with implementation from 1st February 2021. This ambitious strategy aims to reach more families living with Dravet Syndrome, deliver research that puts family needs first, improve awareness and understanding of the condition amongst professionals, particularly in adult neurology and social services, and to give families the tools and support needed to assert their rights.

Alongside the above we continued delivering established activities for the benefit of families living with Dravet Syndrome, as defined in our charitable objects and in keeping the following areas:

1. Support
2. Education
3. Research

Below the Trustees report on the charity's activities, outputs and outcomes against each of these thematic areas. They also report on DSUK's income, expenditure, reserves and future plans.

Support

In 2020/21 DSUK directly supported nearly 500 families living with Dravet Syndrome in the UK, with 41 new families registering with DSUK compared to 26 families registered in 2019/20. This support included the following

1. Coronavirus resource hub
2. Seizure monitor fund
3. 16+ assistance fund
4. Bereavement fund
5. 1:1 emotional/practical support
6. Center Parcs grant
7. Super siblings award

Coronavirus Resource Hub

In response to the coronavirus pandemic we undertook a wide range of new activities to meet the pressing needs of families through this crisis. This included: the re-allocation of 40% of our Family Support Manager's time to providing 1:1 emotional and practical support to families living with Dravet Syndrome, the establishment of a COVID-19 resource hub with a Q&A informed by DSUK's medical advisory board, the launch of a webinar series on the medical implications of COVID-19 and COVID-19 vaccines on people living with Dravet Syndrome, the commissioning of a film titled "Living with Dravet Syndrome in COVID-19 lockdown" watched 1300 times at the time of writing this report, the launch of a COVID-19 family survey which was accepted for publication in the Neurologica Scandinavica, social activities with a virtual quiz and more besides.

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Achievements and performance *(continued)*

Seizure Monitor Fund

47 seizure monitors awarded with 43 families benefiting.

Seizure monitors are vital to alarm families to seizures so emergency treatment can be given quickly enough. Unfortunately, these monitors are not routinely funded by health or social care. DSUK offers a non-means tested seizure monitor fund, aiming to reduce the risk of brain damage and death and improve the quality of life and life chances for people with Dravet Syndrome.

In this reporting period DSUK awarded 47 seizure monitors, a significant increase on the 32 seizure monitors in the previous year. These awards included:

o 11 Pulse Oximeter Machines
o 10 MedPage Epileptic Seizure Monitors
o 13 Baby Pixel Monitors
o 13 Fingertip Pulse Oximeters

During this reporting period we were extremely grateful to receive a £10k grant from the DM Thomas Foundation for Young People for 14 Pulse Oximeters, which DSUK purchased in the reporting period. We were also pleased to start offering families an additional monitor, called the NightWatch, to choose from following extensive parent/carer testing. The NightWatch monitor consists of a comfortable wireless armband that closely monitors heart rate and motion while the wearer is lying in bed. When NightWatch detects a potentially severe seizure, a warning is transmitted to a caregiver via a wireless signal from the arm module to the corresponding base station alerting the parent or carer.

As in previous years family feedback was overwhelmingly positive and includes the following quotes:

"We recently requested if it was possible to get a pulse oximeter for our daughter who has Dravet Syndrome. We have just received a pulse oximeter (we cannot believe it was so quick). We are honestly lost for words and cannot thank you and the charity enough for your support in supplying this piece of vital equipment. This amazing piece of equipment will make a huge difference to helping monitor <redacted> through the night and also when she has seizures as we can accurately test her pulse rate and oxygen levels. The quality of the device is also a surprise at how good it is, as we know how expensive they are. Please accept our heartfelt thanks from our family for your support".

"The nightwatch is working as I expected. I really like it and now <redacted> can sleep in his own bed which I am glad I can now give his new baby sibling more time. Thanks a lot, the nightwatch has made my nighttime so much easier".

16+ Assistance Fund

31 assistance grants for people with Dravet aged 16+ awarded with 31 families benefitting.

Transitioning to adult services, when a young person with Dravet Syndrome reaches the age of 16 and beyond, encompasses significant changes in the organisation of care. Families consistently tell us of their challenges accessing funding for this support. DSUK offers a non-means tested 16+ Assistance Fund. Families can apply for any items of equipment or assistance that will improve the life for the person aged 16+ with Dravet Syndrome. In making this award DSUK aims to improve the quality of life and life chances for people living with Dravet Syndrome and reduce the financial burden on families, who would otherwise need to pay for these items themselves.

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Achievements and performance *(continued)*

In this reporting period DSUK made 31 awards, a significant increase on the 13 awards made in the previous year. This increased demand was in large part driven by increased need arising from COVID-19, as people applied for IT and mobility equipment to compensate for the loss of normal daily activities. With thanks to £5k of grant funding from the Pears Foundation/DCMS we were able to meet part of this increased demand, with funding awarded for young people aged 16 to 25 years living in England. Overall 16+ grants were awarded as follows:

o 8 x IT equipment (e.g. iPads)
o 8 x Indoor furniture (e.g. suitable chairs)
o 4 x Mobility equipment
o 3 x Home cooling systems
o 2 x Garden items (e.g. sensory garden)
o 6 x Other

In this reporting period we've had a significant amount of positive feedback including the following:

"It was very exciting to receive the wonderful sensory equipment for <Redacted> from Dravet UK. We send our sincere thanks to everyone for these amazing items made possible by the 16+ Assistance Fund. <Redacted> has been shielding with us, her mum and dad since March when the day centre she attended closed due to coronavirus. <Redacted> is not able to walk or communicate with us and being very limited in what she can do, it has been difficult keeping her occupied throughout the past thirty weeks. These very special sensory items are giving more variety to her day. Thank you so much to all at Dravet UK for the happiness you are giving <Redacted> with these lovely and very stimulating sensory items".

"Just wanted to thank you for the 16+ assistance grant you gave us for <Redacted>.<Redacted> is already getting so much enjoyment from the screen and projector. Once again thank you for enabling us to provide <Redacted> with something that will bring him joy and stimulation".

Bereavement Fund

3 bereavement grants awarded benefitting 3 families.

DSUK offers a Bereavement Fund up to the value of £1,000 to support families coping with the recent loss of a loved one with Dravet Syndrome. As with our other funds it is non-means tested and open to those registered with DSUK within 6 months of their child's passing.

2020/21 sadly saw the passing of 3 people with Dravet Syndrome to whom DSUK subsequently made a bereavement award of £1,000 per family. All the families expressed their gratitude for this award and told us what a difference it made to have their financial burdens eased during their grieving.

"Thank you, the money went into my account late this afternoon and it's covered the cost of a beautiful white horse and carriage for her funeral, something I said I always wanted for her if ever she sadly passed away, and never ever thought I would be able to afford. I am so very grateful for you providing me with the funds to be able to afford this for my darling daughter".

1:1 Emotional/Practical Support

71 families supported through 1:1 emotional/practical support

At the onset of COVID-19 a decision was taken to allocate 40% of the Family Support Managers role to providing 1:1 emotional and practical support to families living with Dravet Syndrome. Historically DSUK has responded to enquiries to the charity from parents and carers, as and when. With thanks to a £10k grant from the National Lottery Coronavirus Community Support Fund it was possible for DSUK to promote the availability of 1:1 support from the Family Support Manager.

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Achievements and performance *(continued)*

As an outcome 71 families were supported on 161 separate occasions with 67% of these points of contact being logged as COVID-19 related. Of all the points of contact the top six reasons for seeking DSUK support were: 18% stress and anxiety, 9% social isolation and loneliness, 4% lack of support from social care, 3% COVID-19 symptoms, 3% seizures and 3% school/education issues. The Family Support Manager was available to provide emotional support and practical assistance, which included writing letters of support (e.g. to assist with challenges accessing social care) and signposting.

The 1:1 emotional and practical support provided during this time has been incredibly impactful. Below are two quotes from parents to illustrate the difference this support meant to them:

"you have made me feel so much better"

"Thank you so much it's good to know you and the team are all there for us"

Center Parcs Grant

Each year DSUK holds a weekend away at Center Parcs in Nottinghamshire bringing Dravet families together to share experiences/knowledge and also to have a much-needed holiday. In arranging this holiday DSUK aims to reduce the social isolation and loneliness experienced by many families living with Dravet Syndrome, by connecting them with a new support network of Dravet families.

With great sadness it was necessary to postpone the Center Parcs weekend planned for June 2020 due to the COVID-19 pandemic. Families were understanding and measures were put in place to transfer the bookings already made to a future date. This was originally planned for June 2021 but at the time of writing this report had been further postponed to June 2022.

Super Sibling Award

18 Super Sibling Awards awarded and 18 people benefitted.

Siblings of those diagnosed with Dravet Syndrome experience a wide range of pressures; plans cancelled, holidays not possible, sleepovers being too intense and more besides. Parents often speak about the many, amazing little things that these brothers and sisters do for everyone in the family. Unfortunately, the demands of everyday life mean siblings rarely get the recognition they deserve. DSUK's annual Super Sibling award is for these young, unsung heroes of the Dravet family.

In December 2020 DSUK received 18 Super Sibling Award nominations from parents/carers. Every sibling was recognised with a personalised certificate, trophy and £40 amazon gift voucher so they could treat themselves to something special. In making these awards DSUK aims to contribute positively to sibling mental well-being, by recognising their achievements as a Super Sibling.

"<Redacted> have asked me to thank you for their lovely gifts, the trophies really did put a smile on their faces sometimes words aren't enough but these gifts say it all. It can be so difficult for the siblings of our warriors and they are all just amazing. A massive thank you."

"Thank you dravet syndrome for my lovely gifts! It means so much to me. I can not thank you enough for picking me as a winner. I love my sister and she is my dravet warrior. Thank you again"

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Achievements and performance *(continued)*

Closed Facebook Group

372 people benefitted from being members of our closed Facebook Group.

Every DSUK registered family is invited to join our closed Facebook Group. This group is a safe moderated space for families to ask questions, share experiences and access support from other Dravet families. In managing this group DSUK aims to improve knowledge and understanding of Dravet Syndrome as well as reducing feelings of social isolation and loneliness.

In 2020/21 DSUK saw the number of members grow from 349 to 372 people. On average the group has 4 to 5 new posts a day covering a wide range of topics including discussion on: seizure types, seizure medication, other therapies (e.g. physio), benefits and social care, EHCPs and special schools, residential care options and more besides. The group also provides a safe space for families to share the highs and lows of caring for someone with Dravet, enabling people to access peer support.

Education

During 2021/21, DSUK contributed to improving awareness and understanding of Dravet Syndrome through the following educational activities.

Marketing and Communications Strategy

This year saw a step-change in DSUK's approach. In March 2021, Claire Eldred was appointed as Head of Marketing and Communications with a remit to expand the reach of DSUK's communications to key audiences, including families living with Dravet Syndrome, medical professionals and the broader community of supporters and sponsors.

With this appointment, we identified some key educational priorities around which to focus our communications effort during 2020/2021. These included:

- The impact of COVID-19 - with information and guidance for families and healthcare professionals via our website, social media platforms and webinars. We also undertook the only UK survey to examine the understand the risks, impact and outcome of COVID-19 in people affected by Dravet Syndrome, which is now published in the peer-review journal, Acta Neurologica Scandinavica

- New and emerging treatments for Dravet Syndrome - including submitting testimonies and participating in meetings with NHS appraisal committees for the use of cannabidiol in Scotland and fenfluramine in England and Wales.

- The genetics of Dravet Syndrome - we identified some information gaps around genetics in our educational materials, and also some common misconceptions (e.g. a lack of awareness that Dravet Syndrome is a clinical rather than genetic diagnosis), and addressed these via our website, social media and a webinar dedicated to this topic.

- Continuing to improve diagnosis - although improving, especially among children, there is still much to achieve in terms of improving diagnosis and treatment outcomes. Consistently throughout 2020/2021, we raised awareness on signs of Dravet Syndrome, the importance of early diagnosis and benefits of genetic testing at any age.

In addition to implementing these educational priorities, we developed a comprehensive 5-year marketing and communications plan, with activities aligned to DSUK's overall strategy.

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Achievements and performance *(continued)*

Educational campaigns

International or national awareness days/weeks offer DSUK opportunities to communicate educational priorities, especially with regard to improving diagnosis of Dravet Syndrome. During 2020/2021, we leveraged three events in particular to drive awareness campaigns:

- Rare Diseases Day (February) - 'Paige's Story', DSUK's short film about a family living with Dravet Syndrome was shortlisted for the People's Vote award for the Rare Diseases Film Festival. Although 'Paige's Story' did not win top prize, our social media campaign encouraging people to vote and share the video was very successful, reaching more than 111,250 people with messages about Dravet Syndrome.

- National Epilepsy Awareness Week (May) - the theme in 2020 was #morethanseizures. DSUK shared facts about Dravet Syndrome throughout the week that reached nearly 29,000 people, helping to educate the epilepsy community, as well as broader audiences, about signs of Dravet Syndrome.

- International Dravet Syndrome Awareness Day (June) - our key educational campaign for 2020/2021 involved a series of activities taking place on this global day dedicated to Dravet Syndrome. Our #DravetTogether video, highlighting DSUK's support for families during the pandemic, was watched over 640 times on YouTube, reached more than 14,500 people on social media. Our 'Five Facts' post reached 58,741 and overall on social media we reached just under 100,000 people with educational messages about Dravet Syndrome.

Webinars

Five educational webinars were held benefitting nearly 2,000 parents/carers who attended or watched a recorded version on our YouTube channel

- Dravet Syndrome in the COVID-19 pandemic (April 2020) with Professor Helen Cross
- Dravet Syndrome & Family Wellness during COVID-19 (April 2020) with Neil Williamson
- Dravet Syndrome during COVID-19 - Focus on Adults (April 2020) with Professor Sanjay Sisodiya and Fiona Scolding QC
- Understanding the Genetics of Dravet Syndrome (September 2020) with Dr Andreas Brunklaus
- COVID-19 and Dravet Syndrome: Latest updates including Vaccines (January 2021) with Professor Helen Cross and Professor Sanjay Sisodiya

Leaflets and Video Projects

In 2021 we initiated two major educational initiatives:

- Updating DSUK's educational leaflets including the Family Guide and HCP Diagnosis Guide to bring these up to date with the latest knowledge about Dravet Syndrome. With the Family Guide in particular, this involved significantly extending the scope of the original leaflet (created in 2013). The leaflets are currently in draft form with plans to launch in the latter part of 2021

- Planning for a series of educational videos to educate and engage audiences in different aspects of living with Dravet Syndrome, including short films to raise awareness (e.g. around International Dravet Syndrome Awareness Day), case studies featuring children and adults with Dravet Syndrome and talking heads videos with our Medical Advisory Board.

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Achievements and performance *(continued)*

Website

In 2020-2021, more than 22,500 people visited our website and benefited from its educational content. 87% of these were new visitors to the website. Overall, the most viewed pages (in addition to the home page) were 'What is Dravet Syndrome' (5,000+ views), 'About Dravet Syndrome', (4,000+ views), 'Dravet Journeys'(4,000+ views) and 'COVID-19 Advice and Guidance' (3,500+ views). Key updates during this period included:

- COVID-19 hub containing advice and guidance about COVID-19, family wellness during the pandemic and information about grants and other support services provided by DSUK during the pandemic (3500+ views)

- A 'Genetics of Dravet Syndrome' online resource (870+ views)

- An expansion to the 'Siblings' section of the website with additional advice and case studies (285 views)

- Updates and new case studies added to the 'Dravet Journeys' section, sharing real-life experiences from families living with Dravet Syndrome (4000+ views)

Social media

Social media is an important platform for raising awareness and understanding of Dravet Syndrome. DSUK has an active social media presence, posting on platforms between 3-5 times per week on a variety of topics including our educational priorities, family case studies, fundraising stories and other news relevant to the Dravet Syndrome community.

During 2020-2021, DSUK's posts across our four social media platforms (Facebook, Instagram, Twitter and LinkedIn) had a combined overall reach of nearly one million and a gain of more than 1,000 new followers since January 2020. Our most impactful posts during 2020-2021 corresponded to our educational priorities, with posts on COVID-19 guidance, treatments advances, the genetics of Dravet Syndrome and improving diagnosis garnering the greatest reach and engagement across target audiences.

Welcome packs

41 families benefited from receiving DSUK welcome packs.

Every Dravet family that registers with DSUK receives a welcome pack containing educational leaflets, including our 68 page "Family Guide to Dravet Syndrome". This book contains medical information on seizures, as well as the co-morbid conditions that many Dravet patients face. It also contains information on schooling, respite and many other issues faced by families who are caring for someone diagnosed with the condition including transition to adulthood. In 2020/21 we sent out 41 free welcome packs to UK parents/carers with a confirmed diagnosis of Dravet Syndrome.

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Achievements and performance *(continued)*

External conferences

2 major conferences attended, reaching paediatricians, neurologists and specialist nurses.

Every year DSUK attends the major UK and international paediatric, neurology and epilepsy conferences to raise awareness and improve understanding of Dravet Syndrome amongst paediatricians, neurologists and specialist nurses. Due to the coronavirus pandemic, many congresses that DSUK would usually attend were cancelled or changed to a virtual event. The two major congresses we attended were the virtual AES (American Epilepsy Society) meeting in December 2020 and the virtual BPNA (British Paediatric Neurology Association) meeting in January 2021.

- AES - The conference featured 60 studies relevant to Dravet Syndrome. We attended and reviewed the most relevant scientific sessions and presentations, updating our key educational messages accordingly.

- BPNA - As well as attending key scientific sessions, DSUK hosted a virtual stand with educational messages around the diagnosis of Dravet Syndrome and we interacted with 213 clinicians. Our Chair of Trustees, Galia Wilson-John presented at a symposium alongside our Medical Advisory Board members, Professor Helen Cross and Dr Andreas Brunklaus. We also took part in a meeting with 15 other charities to discuss key issues in childhood neurology and making sure the patient voice is heard. In addition, we live-tweeted from the event and published a wrap-up blog post on our website, reaching just under 10,000 people with educational messages from the conference.

Medical Advisory Board

All of DSUK's educational activities informed by the charity's Medical Advisory Board chaired by Professor Helen Cross of Great Ormond Street Hospital. In this reporting period we were extremely pleased to announce three new members to the Board with the aim of adding experience in general adult neurology and neuropsychology as well of ensuring continuity in having a nursing perspective with Neil Williamson stepping back from the Medical Advisory Board to become a DSUK Trustee. As an outcome we made the following appointments in January 2021: Amanda Tomalin, Paediatric Epilepsy Clinical Nurse Specialist, Evelina; Dr Julia Aram, Consultant Neurologist, Brighton and Sussex; and Professor Mike Kerr, Retired Clinical Professor, Dept. of Psychological Medicine and Clinical Neurosciences, Cardiff.

Research

In 2020/21 DSUK spent £88,130 on novel research into Dravet Syndrome. This included providing funding for novel gene therapy as described below.

In this reporting period DSUK participated in a research call with Great Ormond Street Hospital Charity and Sparks Charity. As an outcome funding totalling £248,000 was awarded to a novel gene therapy project led by Dr Raj Karda. Gene therapy is a technology that aims to deliver gene elements to augment or modulate the expression of a patients mutated gene, to ameliorate disease pathology. One of the most common ways to do this is to use a vehicle (known as a "vector") to deliver therapeutic genes to cells. A major barrier to progressing gene therapy for Dravet Syndrome is that SCN1A, as a very large gene, is too big to deliver via a standard, single vector. The funded project identified an innovative solution to this barrier, using a pioneering gene editing technology (known as CRISPR) to split the SCN1A gene in half and use two vectors to deliver therapy treatment to a mouse model of Dravet Syndrome. Excitingly, the research showed it is possible to split SCN1A and recombine it within the mouse model. Although the gene therapy itself did not prove effective in treating the mice, the project made important progress in understanding the behaviour and expression of SCN1A, and DSUK's funding was an invaluable springboard to future research, enabling the team to further refine their approach via ongoing, follow-up research projects.

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Achievements and performance *(continued)*

COVID-19 and Dravet Syndrome

At the outset of the pandemic DSUK led an initiative with Professor Sanjay Sisodiya and Dr Simona Balestrini to gather a snapshot of the impact of the virus on people with Dravet Syndrome to inform care and treatment. DSUK initiated a survey with families, which led to report being produced by Professor Sisodiya and Dr Balestrini that was published on the DSUK website. 116 families responded to the survey of which 74% were in respect of children and 26% in respect of adults. Key findings from the survey include:

- 'Extremely vulnerable' status for risk of severe forms of COVID-19 was given to 43% people with Dravet Syndrome by a GP or neurologist

- Even if not deemed 'extremely vulnerable', families adhered to shielding, with 91% of respondents shielding their child/adult at the family home during lockdown

- Symptoms compatible with COVID-19 were reported in 19% of individuals (with no significant difference between children and adults with Dravet Syndrome)

- Among symptomatic individuals, only 4 had a (swab) test, none of which was positive; one person had antibody testing (but not swab testing), which was positive for COVID-19

- There were no deaths and, in most cases, the outcome of infection was 'benign' (only 5% required hospitalisation due to severity of symptoms and all recovered)

- Seizure worsening was reported (increased seizure frequency or duration or both) in 50% of those who developed possible or probable COVID-19 symptoms

- The presence of comorbidities, including susceptibility to respiratory infections, swallowing difficulties, and spinal abnormalities, was not significantly associated with the presentation of COVID-19 symptoms

Global call for Dravet Syndrome research

In 2020/21 for the first time DSUK participated in a global research call led by the Associazione Gruppo Famiglie Dravet (GFD), an Italian Dravet Syndrome patient advocacy charity dedicated to supporting the highest quality basic or clinical research on Dravet Syndrome. This call solicits innovative explorative projects that are not currently funded by other agencies became of their preliminary nature. Dravet Syndrome charities globally committed €125,000 in total to this call, of which DSUK committed £20,000. Fourteen research proposals were shortlisted and at the time of writing this report, these short-listed projects are being assessed.

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Financial review

Incoming Resources

In 2020/21 DSUK received £345,071 in income from the following sources

£136,238	Community fundraising
£119,343	Industry grants
£55,000	Corporate sponsorship
£26,225	Grants from Trusts/Foundations
£8,265	Income generation

Historically community fundraising has been an important source of income for DSUK, with £209,418 raised in 2019/20. With the onset of the pandemic it was not possible for the normal community fundraising activities to take place such as marathons, treks etc. meaning only £136,238 was secured. Whilst DSUK saw growth in giving via Facebook (e.g. birthday fundraisers) this did not compensate for loss of income via JustGiving, which typically accounts for in-person challenge events. In response DSUK sought to drive virtual fundraising campaigns at key points of the year including International Dravet Syndrome Awareness Month, International Epilepsy and Tuesday Giving over Christmas.

Despite the sharp drop in income from community fundraising DSUK was able to hold up its income by increasing income from other sources. Grants from the National Lottery, Pears/DMCS and DM Thomas Foundation for Young People contributed to growth in grant income from £11,689 in 2019/20 to £26,225 in 2020/21. Additional support also came in the form of a one-off grant from XTX Markets of £25,000 in addition to £30,000 that the company generously gives to DSUK as a corporate sponsor, a £25,000 exceptional payment from an individual donor, growth in online shop sales following investment in new stock (including branded face masks and leisure wear) and industry grants from GW Pharma, Zogenix, Encoded and Biocodex.

Outgoing Resources

In 2020/21 DSUK spent £305,812 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
- Awareness raising activities (e.g. DSUK educational webinars)
- Awareness raising materials (e.g. DSUK educational leaflets)
- DSUK merchandise for fundraising events & shop sales
- Staff costs with 4 people (2.93 FTE) paid for 117 hours as at 31st January 2021.

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Financial review *(continued)*

Reserves Policy

Dravet Syndrome UK is required to ensure that free monies are available in each financial year to meet any reasonably foreseeable contingency.

The trustees have determined that 'free' reserves should ideally be at least six months of normal operating expenditure, which is considered by the trustees to amount to around £232,000 based on estimated expenditure for 2021/22. At 31 January 2021, the unrestricted reserves of the charity amounted to £386,468, of which £95,663 has been designated by the trustees for research purposes and for educational materials, leaving free reserves of £290,805 at that date, compared to £263,243 at the previous year-end date. It is anticipated that the designated funds balances relating to educational materials and research as at 31 January 2021 will be fully expended by 31 January 2022.

Looking ahead to 2021/22, the trustees will be launching DSUK's 5-year Strategy for 2021 to 2026. In order to deliver this strategy, the Trustees will be investing at least £45,000 of available free reserves in order to lay the foundations for organisational growth.

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Plans for future periods

In this reporting period the Board of Trustees approved DSUK's first five-year strategy for 2021 to 2026, which was launched in February 2021. This strategy aims to reach more families, to deliver research that puts family needs first, to improve awareness and understanding amongst professionals, particularly in adult neurology and social services, and to give families the tools and support needed to assert their rights.

Underpinning the strategy are four overarching objectives

- 1. Every Family Matters

Every UK family living with Dravet Syndrome will be aware of DS UK and the support available, be enabled to access this support as required, and know that all activities and research are driven by the things that matter most to them.

- 2. Leaders in the Field

DSUK will lead the conversation about Dravet Syndrome in the UK, making the best possible use of its 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.

We have come a long way supporting children and adults with Dravet Syndrome but there is further to go. Families are still waiting too long for a diagnosis. We do not know enough about the comorbidities of Dravet Syndrome and the spectrum nature of the condition. Transition into adult health care services remains challenging and many families struggle to access the statutory support they are entitled to. We know we have given ourselves a lot to do but we believe this is the right time to move forward and, more importantly, this is the right way for us to support everyone who lives with Dravet Syndrome and all its challenges.

With our families behind us and a strong and committed team of staff, trustees and medical advisors we are ready and excited to get on with this work. To deliver this strategy we will be putting robust plans in place, particularly to secure the resources needed to achieve our ambitions while also being responsive to the uncertainties of these times. In 2021/22 we will be designating our free reserves to enable this growth and as such will have an income to expenditure deficit as we bring our reserves in line with our reserves policy. In taking this approach we will be better placed to grow income from trusts and foundations from 2022/23 onwards as many donors precluding applications from charities in excess of their reserves policy.

There is so much to be hopeful for as we look ahead, and the next 5 years is just the next milestone, not the end of the road. We are really excited by the possibilities of the coming years. There are gene therapies on the horizon, and other new treatments in development, as well as all the work we are planning with this new strategy. We look forward with confidence, excitement and hope that DSUK can and will make a difference for every family living with Dravet Syndrome in the UK.

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Trustees' responsibilities statement

The trustees are responsible for preparing the trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England and Wales requires the charity trustees to prepare financial statements for each year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, of the charity for that period.

In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the applicable Charities SORP;
- make judgments and accounting estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charity's transactions and disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the applicable Charities (Accounts and Reports) Regulations, and the provisions of the Trust Deed. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The trustees' annual report was approved on 9 July 2021 and signed on behalf of the board of trustees by:

K Hughes
Trustee

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Dravet Syndrome UK

Independent Auditor's Report to the Members of Dravet Syndrome UK

Year Ended 31 January 2021

Opinion

We have audited the financial statements of Dravet Syndrome UK (the 'charity') for the year ended 31 January 2021 which comprise the statement of financial activities (incorporating income and expenditure account), statement of financial position and the related notes, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including FRS 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 January 2021 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice;
- have been prepared in accordance with the requirements of the Charities Act 2011.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and the provisions available for small entities, in the circumstances set out below, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

In common with many other charities we use our auditors to assist in the preparation of the statutory financial statements. We also engage our auditors to provide bookkeeping and payroll preparation services.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

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Other information

The other information comprises the information included in the annual report, other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charity and its environment obtained in the course of the audit, we have not identified material misstatements in the trustees' report.

We have nothing to report in respect of the following matters in relation to which the Charities Act 2011 requires us to report to you if, in our opinion:

- the information given in the trustees' report is inconsistent in any material respect with the financial statements; or
- adequate accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the trustees' responsibilities statement, the trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

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Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at https: www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

Auditor's responsibilities for detecting irregularities, including fraud

The objectives of our audit are: to identify and assess the risks of material misstatement of the financial statements due to fraud and error; to obtain sufficient appropriate audit evidence regarding the assessed risks of material misstatement due to fraud and error; and to respond appropriately to those risks. Owing to the inherent limitations of an audit, there is an unavoidable risk that material misstatements in the financial statements may not be detected, even though the audit is properly planned and performed in accordance with the ISAs (UK).

In identifying and assessing risks of material misstatement in respect of irregularities, including fraud and non-compliance with laws and regulations, our procedures included the following:

- We obtained an understanding of the legal and regulatory frameworks applicable to the charity and the sector in which they operate. We determined that the following laws and regulations were most significant; the Charities Act 2011, health & safety law and employment law.

- We obtained an understanding of how the charity is complying with those legal and regulatory frameworks by making inquiries to relevant members of the management team. We corroborated our inquiries though our review of trustee and management meeting minutes and inquiry into legal fees incurred in the year.

- We assessed the susceptibility of the charity's financial statements to material misstatement, including how fraud might occur. Audit procedures performed by the engagement team included:

 - Identifying the controls management has in place to prevent and detect fraud and assessing the operation of these controls

 - Understanding of how those charged with governance considered and addressed the potential for override of controls or other inappropriate influence over the financial reporting process

 - Identifying and testing journal entries, in particular any journal entries that were large or unusual in nature

 - Assessing the extent of compliance with the relevant laws and regulations governing the charity and the sector it operates within. This included a review of any potential breaches during the year and since the year end; and

 - Challenging assumptions and judgements made by management in its significant accounting estimates.

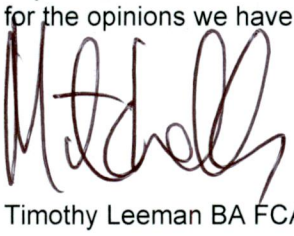
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Auditor's responsibilities for detecting irregularities, including fraud (continued)

There are inherent limitations in the audit procedures above and the further removed that non-compliance with laws and regulations is from the events and transactions reflected in the financial statements, the less likely we would become aware of it. The risk of not detecting a material misstatement due to fraud is higher than the risk of not detecting one resulting from error as fraud may involve deliberate concealment by means of, for example, forgery, intentional misrepresentations or through collusion.

Use of our report

This report is made solely to the charity's members, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.



Timothy Leeman BA FCA (Senior Statutory Auditor)

For and on behalf of
MCABA Limited t/a Mitchells
Chartered accountants & statutory auditor
91-97 Saltergate
Chesterfield
Derbyshire
S40 1LA

Date: 14/July/2021.

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Dravet Syndrome UK

Statement of Financial Activities (Incorporating Income and Expenditure Account)

Year Ended 31 January 2021

	Note	2021 Unrestricted funds £	2021 Restricted funds £	2021 Total funds £	2020 Total funds £
Income					
Donations	**4**	264,352	72,454	**336,806**	339,931
Charitable activities	**5**	–	–	**–**	14,751
Other trading activities	**6**	7,286	–	**7,286**	3,407
Investment income	**7**	59	–	**59**	111
Other income	**8**	920	–	**920**	–
Total income		272,617	72,454	**345,071**	358,200
Expenditure					
Expenditure on raising funds:					
Costs of raising donations and legacies	**9**	20,176	–	**20,176**	21,172
Costs of other trading activities	**10**	4,490	–	**4,490**	1,433
Expenditure on charitable activities	**11**	248,981	32,165	**281,146**	342,828
Total expenditure		273,647	32,165	**305,812**	365,433
Net income/(expenditure) and net movement in funds		(1,030)	40,289	**39,259**	(7,233)
Reconciliation of funds					
Total funds brought forward		387,498	–	**387,498**	394,731
Total funds carried forward		386,468	40,289	**426,757**	387,498

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 22 to 31 form part of these financial statements.

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Dravet Syndrome UK

Statement of Financial Position

31 January 2021

	Note	2021 £	2021 £	2020 £
Fixed Assets				
Tangible fixed assets	18		104	320
Current Assets				
Stocks	19	14,264		11,140
Debtors	20	81,825		39,433
Cash at bank and in hand		363,363		345,498
		459,452		396,071
Creditors: amounts falling due within one year	21	6,236		8,893
Net Current Assets			453,216	387,178
Total Assets Less Current Liabilities			453,320	387,498
Creditors: amounts falling due after more than one year	22		26,563	–
Net Assets			426,757	387,498
Funds of the Charity				
Restricted funds			40,289	–
Unrestricted funds			386,468	387,498
Total charity funds	25		426,757	387,498

These financial statements were approved by the board of trustees and authorised for issue on 9 July 2021 and are signed on behalf of the board by:

Kelvin Hughes

K Hughes
Trustee

The notes on pages 22 to 31 form part of these financial statements.

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Dravet Syndrome UK

Notes to the Financial Statements

Year Ended 31 January 2021

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

Whilst the global economy has been significantly impacted by the effect of the COVID-19 pandemic, the management and trustees have realigned their strategy and working practices to meet the demands arising from an ever-changing environment and continue to adapt in response to change. The trustees have prepared and reviewed forecasts 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.

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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.

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4. Donations

	Unrestricted Funds £	Restricted Funds £	**Total Funds 2021 £**
Donations			
Donations	180,281	10,957	**191,238**
Donated services and facilities	–	–	**–**
Grants			
Grants receivable – DSUK conference	–	–	**–**
Grants receivable - Center Parcs event	–	–	**–**
Grants receivable - monitors	–	9,817	**9,817**
Grants receivable - educational materials	30,000	–	**30,000**
Grants receivable - others	1,553	–	**1,553**
Grants receivable - educational videos	–	36,825	**36,825**
Grants receivable - COVID-19 assistance	52,518	9,855	**62,373**
Grants receivable - 16+ grants to beneficiaries	–	5,000	**5,000**
	264,352	72,454	**336,806**

	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £
Donations			
Donations	232,653	185	232,838
Donated services and facilities	1,500	–	1,500
Grants			
Grants receivable – DSUK conference	30,000	40,000	70,000
Grants receivable - Center Parcs event	–	9,843	9,843
Grants receivable - monitors	–	10,000	10,000
Grants receivable - educational materials	15,000	–	15,000
Grants receivable - others	750	–	750
Grants receivable - educational videos	–	–	–
Grants receivable - COVID-19 assistance	–	–	–
Grants receivable - 16+ grants to beneficiaries	–	–	–
	279,903	60,028	339,931

The trustees confirm that the above restricted income recognised in respect of the DSUK Conference 2019 is compliant with The Association of the British Pharmaceutical Industry Code of Practice.

5. Charitable activities

	Unrestricted Funds £	**Total Funds 2021 £**	Unrestricted Funds £	Total Funds 2020 £
Fundraising events income	–	**–**	14,751	14,751

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6. Other trading activities

	Unrestricted Funds £	**Total Funds 2021 £**	Unrestricted Funds £	Total Funds 2020 £
Merchandise sales	7,286	**7,286**	3,407	3,407

7. Investment income

	Unrestricted Funds £	**Total Funds 2021 £**	Unrestricted Funds £	Total Funds 2020 £
Bank interest receivable	59	**59**	111	111

8. Other income

	Unrestricted Funds £	**Total Funds 2021 £**	Unrestricted Funds £	Total Funds 2020 £
Consultancy services	920	**920**	–	–

9. Costs of raising donations and legacies

	Unrestricted Funds £	**Total Funds 2021 £**	Unrestricted Funds £	Total Funds 2020 £
Event costs	146	**146**	7,312	7,312
Wages and salaries	16,635	**16,635**	10,015	10,015
Employer's NIC	1,110	**1,110**	–	–
Pension costs	372	**372**	–	–
Just Giving charges	1,913	**1,913**	3,845	3,845
	20,176	**20,176**	21,172	21,172

10. Costs of other trading activities

	Unrestricted Funds £	**Total Funds 2021 £**	Unrestricted Funds £	Total Funds 2020 £
Opening stock	4,716	**4,716**	5,634	5,634
Purchases	13,920	**13,920**	515	515
Closing stock	(14,146)	**(14,146)**	(4,716)	(4,716)
	4,490	**4,490**	1,433	1,433

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11. Expenditure on charitable activities by activity type

	Activities undertaken directly £	Support costs £	**Total funds 2021 £**	Total fund 2020 £
Research funding	97,087	9,320	**106,407**	98,456
Raising awareness	39,337	3,776	**43,113**	129,647
Supporting families	102,125	9,805	**111,930**	100,594
Governance costs	–	19,696	**19,696**	14,131
	238,549	42,597	**281,146**	342,828

12. Analysis of support costs

	Analysis of support costs - charitable activities £	**Total 2021 £**	Total 2020 £
Staff costs	13,886	**13,886**	7,342
Premises	485	**485**	2,087
Communications and IT	7,938	**7,938**	56,756
Human resources	1,509	**1,509**	840
Finance costs	104	**104**	117
Governance costs	18,675	**18,675**	12,631
	42,597	**42,597**	79,773

13. Net income/(expenditure)

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

	2021 £	2020 £
Depreciation of tangible fixed assets	**216**	512

14. Auditors remuneration

	2021 £	2020 £
Fees payable for the audit of the financial statements	**4,200**	–

15. Independent examination fees

	2021 £	2020 £
Fees payable to the independent examiner for:		
Independent examination of the financial statements	–	2,330

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16. Staff costs

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

	2021	2020
	£	£
Wages and salaries	**116,757**	73,422
Social security costs	**7,331**	3,320
Employer contributions to pension plans	**2,477**	861
	126,565	77,603

The average head count of employees during the year was 4 (2020: 3).

No employee received employee benefits of more than £60,000 during the year (2020: 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 £52,371 (2020: £22,149).

17. Trustee remuneration and expenses

A former trustee, T Finch, is employed as a Family Support Manager by the charity. In this capacity she received remuneration of £15,462 during her tenure as a trustee in the comparative period. No other Trustee was remunerated through the charity either in the comparative year or the year under review.

Three trustees (2020: 1) have claimed expenses or had their expenses met by the charity as follows:

	2021	2020
	£	£
Travel	**154**	–
Sundry	**908**	8
	1,062	8

18. Tangible fixed assets

	Fixtures and fittings	Equipment	**Total**
	£	£	**£**
Cost			
At 1 February 2020 and 31 January 2021	490	3,403	**3,893**
Depreciation			
At 1 February 2020	489	3,084	**3,573**
Charge for the year	–	216	**216**
At 31 January 2021	489	3,300	**3,789**
Carrying amount			
At 31 January 2021	1	103	**104**
At 31 January 2020	1	319	320

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19. Stocks

	2021	2020
	£	£
Stock of merchandise and consumables	**14,146**	4,716
Monitor stock	**118**	6,424
	14,264	11,140

20. Debtors

	2021	2020
	£	£
Prepayments and accrued income	**81,765**	39,163
Other debtors	**60**	270
	81,825	39,433

21. Creditors: amounts falling due within one year

	2021	2020
	£	£
Accruals and deferred income	**774**	2,863
Social security and other taxes	**2,780**	2,197
Other creditors	**2,682**	3,833
	6,236	8,893

22. Creditors: amounts falling due after more than one year

	2021	2020
	£	£
Accruals and deferred income	**26,563**	–

23. Deferred income

	2021	2020
	£	£
At 1 February 2020	**–**	49,843
Amount released to income	**–**	(49,843)
Amount deferred in year	**26,563**	–
At 31 January 2021	**26,563**	–

Deferred income at the year-end relates the delayed Center Parcs event now scheduled to be held in June 2022.

24. 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 £2,477 (2020: £861).

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25. Analysis of charitable funds

Unrestricted funds

	At 1 February 2020 £	Income £	Expenditure £	**At 31 January 2021 £**
General funds	263,243	224,036	(196,474)	**290,805**
Designated fund - research	109,255	18,581	(77,173)	**50,663**
Designated fund - educational materials	15,000	30,000	–	**45,000**
	387,498	272,617	(273,647)	**386,468**

	At 1 February 2019 £	Income £	Expenditure £	At 31 January 2020 £
General funds	252,550	244,905	(234,212)	263,243
Designated fund - research	142,181	38,267	(71,193)	109,255
Designated fund - educational materials	–	15,000	–	15,000
	394,731	298,172	(305,405)	387,498

The trustees designate a proportion of unrestricted funds received by the charity each year for the purpose of funding of medical research into Dravet Syndrome.

Unrestricted grants to which entitlement passed to the charity prior to the close of the 2020/21 financial year have been allocated by the trustees to the provision of educational materials in the 2021/22 financial year, as part of the ongoing drive to raise awareness of Dravet Syndrome. The project has been delayed due to the COVID-19 pandemic.

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25. Analysis of charitable funds *(continued)*

Restricted funds

	At 1 February 2020 £	Income £	Expenditure £	**At 31 January 2021 £**
Restricted fund - conference	–	–	–	–
Restricted fund - research	–	10,957	(10,957)	–
Restricted fund - Center Parcs event	–	–	–	–
Restricted fund - monitors	–	9,817	(9,817)	–
Restricted fund - COVID-19 assistance	–	9,855	(9,855)	–
Restricted fund - 16+ grants to beneficiaries	–	5,000	(1,536)	**3,464**
Restricted fund - educational videos	–	36,825	–	**36,825**
	–	72,454	(32,165)	**40,289**

	At 1 February 2019 £	Income £	Expenditure £	At 31 January 2020 £
Restricted fund - conference	–	40,000	(40,000)	–
Restricted fund - research	–	185	(185)	–
Restricted fund - Center Parcs event	–	9,843	(9,843)	–
Restricted fund - monitors	–	10,000	(10,000)	–
Restricted fund - COVID-19 assistance	–	–	–	–
Restricted fund - 16+ grants to beneficiaries	–	–	–	–
Restricted fund - educational videos	–	–	–	–
	–	60,028	(60,028)	–

26. Analysis of net assets between funds

	Unrestricted Funds £	Restricted Funds £	**Total Funds 2021 £**
Tangible fixed assets	104	–	**104**
Current assets	419,163	40,289	**459,452**
Creditors less than 1 year	(32,799)	–	**(32,799)**
Net assets	386,468	40,289	**426,757**

	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £
Tangible fixed assets	320	–	320
Current assets	396,071	–	396,071
Creditors less than 1 year	(8,893)	–	(8,893)
Net assets	387,498	–	387,498

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27. Related parties

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