DRAVET
Syndrome UK

Dravet Syndrome UK

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

Registered charity number: 1128289

CONTENTS

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.

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.

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.

> **“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.”**

Galia Wilson

Galia Wilson
Chair of Trustees

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

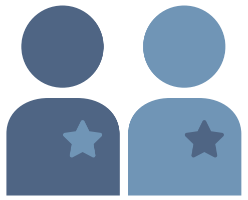
from our 16+ Assistance Fund.

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

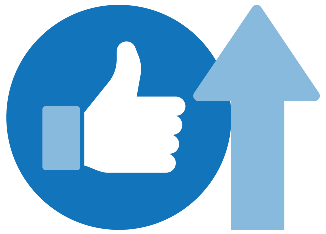
4 scientific conferences to raise awareness among healthcare professionals.

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.

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.

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.

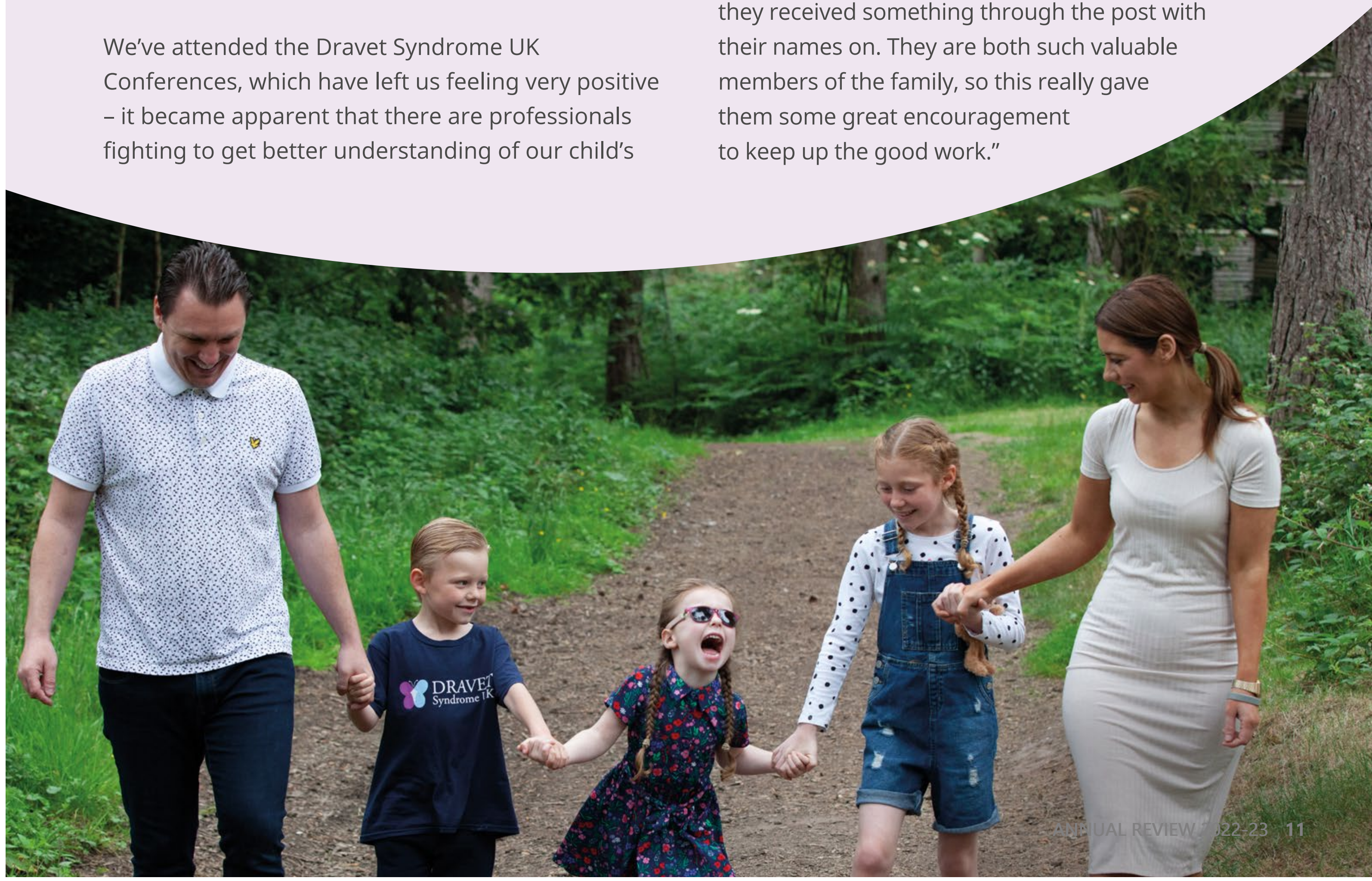
“Although the diagnosis of Dravet Syndrome was difficult, it also made things a lot easier. Because Penny had an early diagnosis, it’s meant that we’ve been supported by Dravet Syndrome UK from the start and that has made such a huge difference to us. The private Facebook forum for parents/carers, for 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.”



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

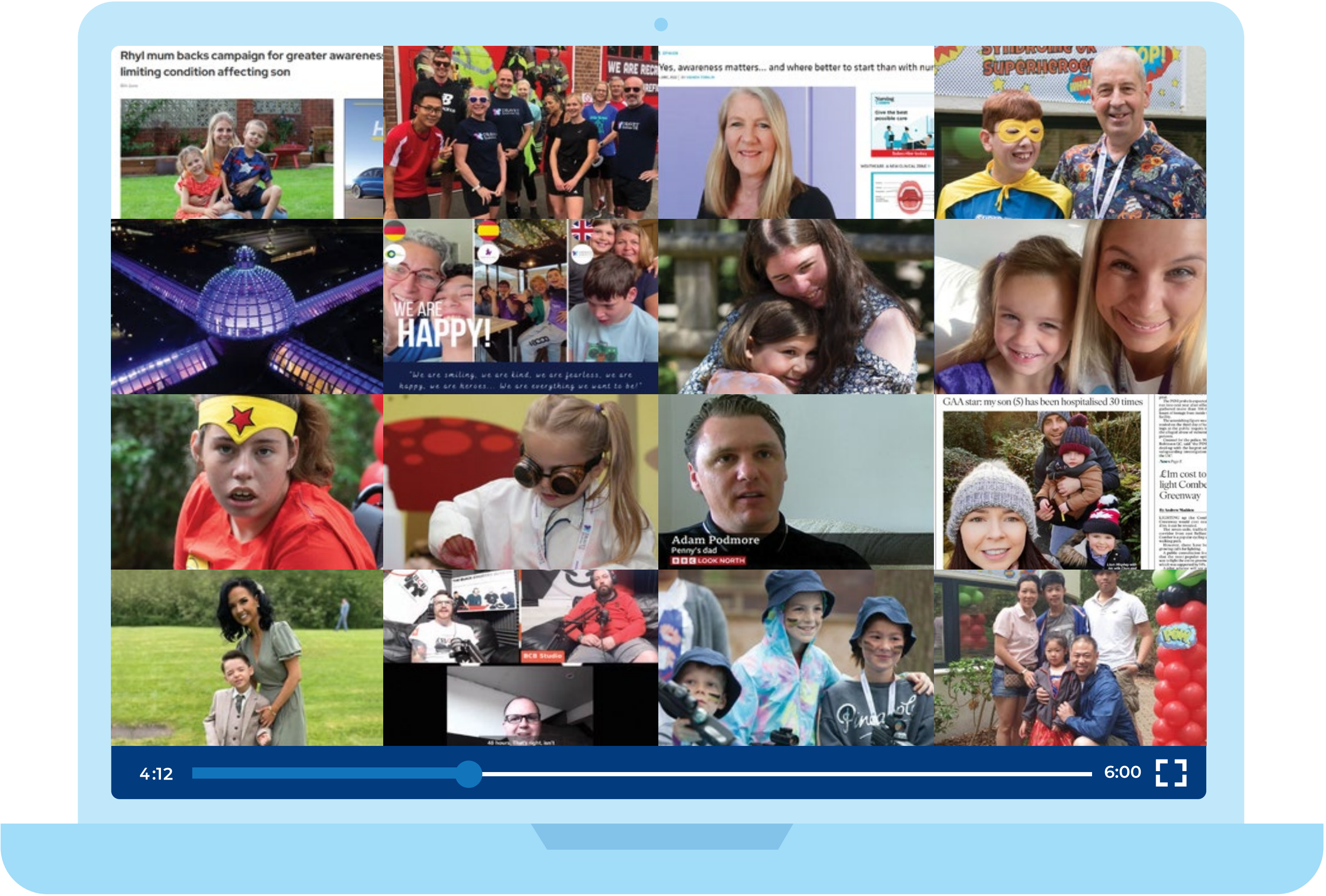
June is Dravet Syndrome Awareness Month. In 2022, we ran our biggest ever press campaign, supporting families to share their experiences with the media. We had coverage in local, national, print and online media, including BBC News Online where we were their eighth most read story on the day after publication.

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.



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.

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.

SCN1A HORIZONS

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:

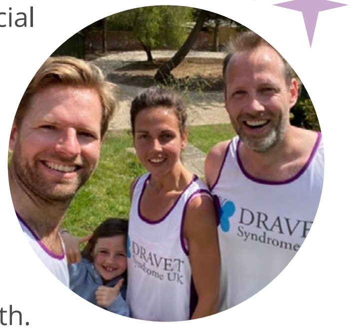
- Supporting recruitment for the SCN1A Horizons Natural History Study – a major research milestone. This co-funded research has the potential to transform our understanding of Dravet Syndrome, encouraging earlier diagnosis and improved, more standardised approaches to treatment.
- Actively seeking partners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

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.

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
6EE6A4843F99485...

K Hughes
Trustee

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
BE9BD1D6C2314D3...
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

		2023			2022
	Note	Unrestricted funds £	Restricted funds £	**Total funds £**	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.

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
6EE6A4843F99485...
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.

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.

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

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

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

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

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.

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

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2023

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.

Dravet Syndrome UK

Management Information

Year Ended 31 January 2023

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

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)

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

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