

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
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Dravet Syndrome UK
Financial Statements
Year Ended 31 January 2022

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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.

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2022

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.

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2022

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.

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2022

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.

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2022

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".

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2022

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."

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2022

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. This 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."

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2022

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)

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2022

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.

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2022

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.

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2022

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.

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2022

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 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.

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2022

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).

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2022

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.

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2022

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.

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2022

Achievements and performance *(continued)*

The overarching goal of the selected project is to study a new mechanism in the pathophysiology of Dravet Syndrome, neuron-oligodendrocyte 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.

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2022

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.

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2022

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.

Dravet Syndrome UK
Trustees' Annual Report *(continued)*
Year Ended 31 January 2022

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

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.

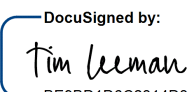
Independent examiner's statement

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:

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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

Dravet Syndrome UK

Statement of Financial Activities (Incorporating Income and Expenditure Account)

Year Ended 31 January 2022

			2022		2021
	Note	Unrestricted funds £	Restricted funds £	Total funds £	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		<u>268,790</u>	<u>74,000</u>	<u>342,790</u>	<u>345,071</u>
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		<u>256,567</u>	<u>107,952</u>	<u>364,519</u>	<u>305,812</u>
Net (expenditure)/income		<u>12,223</u>	<u>(33,952)</u>	<u>(21,729)</u>	<u>39,259</u>
Transfers between funds		(8,293)	8,293	—	—
Net movement in funds		<u>3,930</u>	<u>(25,659)</u>	<u>(21,729)</u>	<u>39,259</u>
Reconciliation of funds					
Total funds brought forward		386,468	40,289	426,757	387,498
Total funds carried forward		<u>390,398</u>	<u>14,630</u>	<u>405,028</u>	<u>426,757</u>

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

All income and expenditure derive from continuing activities.

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

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:

6EE6A4843F99485...
K Hughes
Trustee

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

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.

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2022

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 2022

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
	<u>258,001</u>	<u>74,000</u>	<u>332,001</u>
	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	–	–	–
	<u>264,352</u>	<u>72,454</u>	<u>336,806</u>

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	<u>6,428</u>	<u>6,428</u>	<u>–</u>	<u>–</u>

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2022

6. Other trading activities

	Unrestricted Funds	Total Funds 2022	Unrestricted Funds	Total Funds 2021
	£	£	£	£
Merchandise sales	<u>2,355</u>	<u>2,355</u>	<u>7,286</u>	<u>7,286</u>

7. Investment income

	Unrestricted Funds	Total Funds 2022	Unrestricted Funds	Total Funds 2021
	£	£	£	£
Bank interest receivable	<u>6</u>	<u>6</u>	<u>59</u>	<u>59</u>

8. Other income

	Unrestricted Funds	Total Funds 2022	Unrestricted Funds	Total Funds 2021
	£	£	£	£
Consultancy services	<u>2,000</u>	<u>2,000</u>	<u>920</u>	<u>920</u>

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	<u>3,317</u>	<u>3,317</u>	<u>1,913</u>	<u>1,913</u>
	<u>33,640</u>	<u>33,640</u>	<u>20,176</u>	<u>20,176</u>

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	<u>(13,402)</u>	<u>(13,402)</u>	<u>(14,146)</u>	<u>(14,146)</u>
	<u>1,083</u>	<u>1,083</u>	<u>4,490</u>	<u>4,490</u>

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2022

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
	<u>274,251</u>	<u>54,825</u>	<u>329,076</u>	<u>280,126</u>

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
	<u>54,825</u>	<u>54,825</u>	<u>42,597</u>

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	–

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2022

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
	<u>116,452</u>	<u>126,565</u>

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
	<u>393</u>	<u>8</u>

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2022

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

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2022

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
	<u>386,468</u>	<u>268,790</u>	<u>(256,567)</u>	<u>(8,293)</u>	<u>390,398</u>

	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
	<u>387,498</u>	<u>272,617</u>	<u>(273,647)</u>	<u>–</u>	<u>386,468</u>

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.

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2022

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
	<u>40,289</u>	<u>74,000</u>	<u>(107,952)</u>	<u>8,293</u>	<u>14,630</u>

	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	–	–	–	–	–
	<u>–</u>	<u>72,454</u>	<u>(32,165)</u>	<u>–</u>	<u>40,289</u>

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.

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2022

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.

Dravet Syndrome UK
Management Information
Year Ended 31 January 2022

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 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	—
	<u>332,001</u>	<u>336,806</u>
 Charitable activities		
DSUK conference ticket income	<u>6,428</u>	<u>—</u>
 Other trading activities		
Merchandise sales	<u>2,355</u>	<u>7,286</u>
 Investment income		
Bank interest receivable	<u>6</u>	<u>59</u>
 Other income		
Consultancy services	<u>2,000</u>	<u>920</u>
 Total income	<u><u>342,790</u></u>	<u><u>345,071</u></u>

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)
	<u>(33,640)</u>	<u>(20,176)</u>
 Costs of other trading activities		
Opening stock	(14,146)	(4,716)
Merchandise purchases	(339)	(13,920)
Closing stock	13,402	14,146
	<u>(1,083)</u>	<u>(4,490)</u>
 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)
	<u>(329,796)</u>	<u>(281,146)</u>
 Total expenditure	<u><u>(364,519)</u></u>	<u><u>(305,812)</u></u>
 Net (expenditure)/income	<u><u>(21,729)</u></u>	<u><u>39,259</u></u>