

CHARITY REGISTRATION NUMBER: 1128289

**Dravet Syndrome UK
Financial Statements
31 January 2021**

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

Dravet Syndrome UK
Financial Statements
Year Ended 31 January 2021

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Dravet Syndrome UK

Trustees' Annual Report

Year Ended 31 January 2021

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

Reference and administrative details

Registered charity name	Dravet Syndrome UK
Charity registration number	1128289
Principal office	PO Box 756 Chesterfield Derbyshire S43 9EB
The trustees	K Hughes G Wilson-John J D R Lloyd N Williamson (Appointed 1 September 2020)
Auditor	MCABA Limited t/a Mitchells Chartered Accountants & Statutory Auditor 91-97 Saltergate Chesterfield Derbyshire S40 1LA

Structure, governance and management

Governing Document

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

Trustees Selection Methods

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

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2021

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 2021

Achievements and performance

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

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

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

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

1. Support
2. Education
3. Research

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

Support

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

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

Coronavirus Resource Hub

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

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2021

Achievements and performance *(continued)*

Seizure Monitor Fund

47 seizure monitors awarded with 43 families benefiting.

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

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

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

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

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

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

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

16+ Assistance Fund

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

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

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2021

Achievements and performance *(continued)*

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

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

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

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

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

Bereavement Fund

3 bereavement grants awarded benefitting 3 families.

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

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

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

1:1 Emotional/Practical Support

71 families supported through 1:1 emotional/practical support

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

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2021

Achievements and performance *(continued)*

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

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

"you have made me feel so much better"

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

Center Parcs Grant

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

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

Super Sibling Award

18 Super Sibling Awards awarded and 18 people benefitted.

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

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

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

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

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2021

Achievements and performance *(continued)*

Closed Facebook Group

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

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

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

Education

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

Marketing and Communications Strategy

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

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

- The impact of COVID-19 - with information and guidance for families and healthcare professionals via our website, social media platforms and webinars. We also undertook the only UK survey to examine the understand the risks, impact and outcome of COVID-19 in people affected by Dravet Syndrome, which is now published in the peer-review journal, *Acta Neurologica Scandinavica*
- New and emerging treatments for Dravet Syndrome - including submitting testimonies and participating in meetings with NHS appraisal committees for the use of cannabidiol in Scotland and fenfluramine in England and Wales.
- The genetics of Dravet Syndrome - we identified some information gaps around genetics in our educational materials, and also some common misconceptions (e.g. a lack of awareness that Dravet Syndrome is a clinical rather than genetic diagnosis), and addressed these via our website, social media and a webinar dedicated to this topic.
- Continuing to improve diagnosis - although improving, especially among children, there is still much to achieve in terms of improving diagnosis and treatment outcomes. Consistently throughout 2020/2021, we raised awareness on signs of Dravet Syndrome, the importance of early diagnosis and benefits of genetic testing at any age.

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

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2021

Achievements and performance *(continued)*

Educational campaigns

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

- Rare Diseases Day (February) - 'Paige's Story', DSUK's short film about a family living with Dravet Syndrome was shortlisted for the People's Vote award for the Rare Diseases Film Festival. Although 'Paige's Story' did not win top prize, our social media campaign encouraging people to vote and share the video was very successful, reaching more than 111,250 people with messages about Dravet Syndrome.
- National Epilepsy Awareness Week (May) - the theme in 2020 was #morethanseizures. DSUK shared facts about Dravet Syndrome throughout the week that reached nearly 29,000 people, helping to educate the epilepsy community, as well as broader audiences, about signs of Dravet Syndrome.
- International Dravet Syndrome Awareness Day (June) - our key educational campaign for 2020/2021 involved a series of activities taking place on this global day dedicated to Dravet Syndrome. Our #DravetTogether video, highlighting DSUK's support for families during the pandemic, was watched over 640 times on YouTube, reached more than 14,500 people on social media. Our 'Five Facts' post reached 58,741 and overall on social media we reached just under 100,000 people with educational messages about Dravet Syndrome.

Webinars

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

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

Leaflets and Video Projects

In 2021 we initiated two major educational initiatives:

- Updating DSUK's educational leaflets including the Family Guide and HCP Diagnosis Guide to bring these up to date with the latest knowledge about Dravet Syndrome. With the Family Guide in particular, this involved significantly extending the scope of the original leaflet (created in 2013). The leaflets are currently in draft form with plans to launch in the latter part of 2021
- Planning for a series of educational videos to educate and engage audiences in different aspects of living with Dravet Syndrome, including short films to raise awareness (e.g. around International Dravet Syndrome Awareness Day), case studies featuring children and adults with Dravet Syndrome and talking heads videos with our Medical Advisory Board.

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2021

Achievements and performance *(continued)*

Website

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

- COVID-19 hub containing advice and guidance about COVID-19, family wellness during the pandemic and information about grants and other support services provided by DSUK during the pandemic (3500+ views)
- A 'Genetics of Dravet Syndrome' online resource (870+ views)
- An expansion to the 'Siblings' section of the website with additional advice and case studies (285 views)
- Updates and new case studies added to the 'Dravet Journeys' section, sharing real-life experiences from families living with Dravet Syndrome (4000+ views)

Social media

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

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

Welcome packs

41 families benefited from receiving DSUK welcome packs.

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

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2021

Achievements and performance *(continued)*

External conferences

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

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

- AES - The conference featured 60 studies relevant to Dravet Syndrome. We attended and reviewed the most relevant scientific sessions and presentations, updating our key educational messages accordingly.
- BPNA - As well as attending key scientific sessions, DSUK hosted a virtual stand with educational messages around the diagnosis of Dravet Syndrome and we interacted with 213 clinicians. Our Chair of Trustees, Galia Wilson-John presented at a symposium alongside our Medical Advisory Board members, Professor Helen Cross and Dr Andreas Brunklaus. We also took part in a meeting with 15 other charities to discuss key issues in childhood neurology and making sure the patient voice is heard. In addition, we live-tweeted from the event and published a wrap-up blog post on our website, reaching just under 10,000 people with educational messages from the conference.

Medical Advisory Board

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

Research

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

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

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2021

Achievements and performance *(continued)*

COVID-19 and Dravet Syndrome

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

- 'Extremely vulnerable' status for risk of severe forms of COVID-19 was given to 43% people with Dravet Syndrome by a GP or neurologist
- Even if not deemed 'extremely vulnerable', families adhered to shielding, with 91% of respondents shielding their child/adult at the family home during lockdown
- Symptoms compatible with COVID-19 were reported in 19% of individuals (with no significant difference between children and adults with Dravet Syndrome)
- Among symptomatic individuals, only 4 had a (swab) test, none of which was positive; one person had antibody testing (but not swab testing), which was positive for COVID-19
- There were no deaths and, in most cases, the outcome of infection was 'benign' (only 5% required hospitalisation due to severity of symptoms and all recovered)
- Seizure worsening was reported (increased seizure frequency or duration or both) in 50% of those who developed possible or probable COVID-19 symptoms
- The presence of comorbidities, including susceptibility to respiratory infections, swallowing difficulties, and spinal abnormalities, was not significantly associated with the presentation of COVID-19 symptoms

Global call for Dravet Syndrome research

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

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2021

Financial review

Incoming Resources

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

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

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

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

Outgoing Resources

In 2020/21 DSUK spent £305,812 delivering its charitable objectives.

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

- o Seizure monitors, 16+ Assistance Fund and Bereavement Grant
- o Awareness raising activities (e.g. DSUK educational webinars)
- o Awareness raising materials (e.g. DSUK educational leaflets)
- o DSUK merchandise for fundraising events & shop sales
- o Staff costs with 4 people (2.93 FTE) paid for 117 hours as at 31st January 2021.

Dravet Syndrome UK
Trustees' Annual Report *(continued)*
Year Ended 31 January 2021

Financial review *(continued)*

Reserves Policy

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

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

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

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2021

Plans for future periods

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

Underpinning the strategy are four overarching objectives

- 1. Every Family Matters

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

- 2. Leaders in the Field

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

- 3. Support for Professionals

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

- 4. Empowerment of Families

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

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

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

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

Dravet Syndrome UK

Trustees' Annual Report *(continued)*

Year Ended 31 January 2021

Trustees' responsibilities statement

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

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

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

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

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

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



K Hughes
Trustee

Dravet Syndrome UK

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

Year Ended 31 January 2021

Opinion

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

In our opinion the financial statements:

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

Basis for opinion

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

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

Conclusions relating to going concern

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

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

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

Dravet Syndrome UK

Independent Auditor's Report to the Members of Dravet Syndrome UK *(continued)*

Year Ended 31 January 2021

Other information

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

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

We have nothing to report in this regard.

Matters on which we are required to report by exception

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

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

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

Responsibilities of trustees

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

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

Dravet Syndrome UK

Independent Auditor's Report to the Members of Dravet Syndrome UK *(continued)*

Year Ended 31 January 2021

Auditor's responsibilities for the audit of the financial statements

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

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

Auditor's responsibilities for detecting irregularities, including fraud

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

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

- We obtained an understanding of the legal and regulatory frameworks applicable to the charity and the sector in which they operate. We determined that the following laws and regulations were most significant; the Charities Act 2011, health & safety law and employment law.
- We obtained an understanding of how the charity is complying with those legal and regulatory frameworks by making inquiries to relevant members of the management team. We corroborated our inquiries through our review of trustee and management meeting minutes and inquiry into legal fees incurred in the year.
- We assessed the susceptibility of the charity's financial statements to material misstatement, including how fraud might occur. Audit procedures performed by the engagement team included:
 - Identifying the controls management has in place to prevent and detect fraud and assessing the operation of these controls
 - Understanding of how those charged with governance considered and addressed the potential for override of controls or other inappropriate influence over the financial reporting process
 - Identifying and testing journal entries, in particular any journal entries that were large or unusual in nature
 - Assessing the extent of compliance with the relevant laws and regulations governing the charity and the sector it operates within. This included a review of any potential breaches during the year and since the year end; and
 - Challenging assumptions and judgements made by management in its significant accounting estimates.

Dravet Syndrome UK

Independent Auditor's Report to the Members of Dravet Syndrome UK *(continued)*

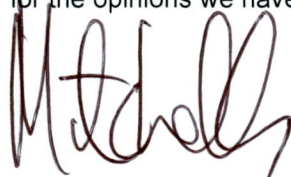
Year Ended 31 January 2021

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

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

Use of our report

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



Timothy Leeman BA FCA (Senior Statutory Auditor)

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

Date:

14/Jul/2021.

Dravet Syndrome UK

Statement of Financial Activities (Incorporating Income and Expenditure Account)

Year Ended 31 January 2021

		Unrestricted funds	2021 Restricted funds	Total funds	2020 Total funds
	Note	£	£	£	£
Income					
Donations	4	264,352	72,454	336,806	339,931
Charitable activities	5	—	—	—	14,751
Other trading activities	6	7,286	—	7,286	3,407
Investment income	7	59	—	59	111
Other income	8	920	—	920	—
Total income		<u>272,617</u>	<u>72,454</u>	<u>345,071</u>	<u>358,200</u>
Expenditure					
Expenditure on raising funds:					
Costs of raising donations and legacies	9	20,176	—	20,176	21,172
Costs of other trading activities	10	4,490	—	4,490	1,433
Expenditure on charitable activities	11	248,981	32,165	281,146	342,828
Total expenditure		<u>273,647</u>	<u>32,165</u>	<u>305,812</u>	<u>365,433</u>
Net income/(expenditure) and net movement in funds		<u>(1,030)</u>	<u>40,289</u>	<u>39,259</u>	<u>(7,233)</u>
Reconciliation of funds					
Total funds brought forward		387,498	—	387,498	394,731
Total funds carried forward		<u>386,468</u>	<u>40,289</u>	<u>426,757</u>	<u>387,498</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 22 to 31 form part of these financial statements.

Dravet Syndrome UK
Statement of Financial Position
31 January 2021

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

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



K Hughes
Trustee

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

Dravet Syndrome UK

Notes to the Financial Statements

Year Ended 31 January 2021

1. General information

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

2. Statement of compliance

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

3. Accounting policies

Basis of preparation

The financial statements have been prepared on the historical cost basis.

The financial statements are prepared in sterling, which is the functional currency of the entity.

The charity meets the definition of a public benefit entity under FRS102.

Going concern

Whilst the global economy has been significantly impacted by the effect of the COVID-19 pandemic, the management and trustees have realigned their strategy and working practices to meet the demands arising from an ever-changing environment and continue to adapt in response to change. The trustees have prepared and reviewed forecasts and are confident that these show that the charity is able to operate within its available resources and meet its liabilities as they fall due for the foreseeable future. Accordingly, the trustees consider it appropriate to continue to adopt the going concern basis of accounting in preparing the financial statements.

Judgements and key sources of estimation uncertainty

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

Fund accounting

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

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2021

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 2021

4. Donations

	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £
Donations			
Donations	180,281	10,957	191,238
Donated services and facilities	—	—	—
Grants			
Grants receivable – DSUK conference	—	—	—
Grants receivable - Center Parcs event	—	—	—
Grants receivable - monitors	—	9,817	9,817
Grants receivable - educational materials	30,000	—	30,000
Grants receivable - others	1,553	—	1,553
Grants receivable - educational videos	—	36,825	36,825
Grants receivable - COVID-19 assistance	52,518	9,855	62,373
Grants receivable - 16+ grants to beneficiaries	—	5,000	5,000
	<u>264,352</u>	<u>72,454</u>	<u>336,806</u>
	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £
Donations			
Donations	232,653	185	232,838
Donated services and facilities	1,500	—	1,500
Grants			
Grants receivable – DSUK conference	30,000	40,000	70,000
Grants receivable - Center Parcs event	—	9,843	9,843
Grants receivable - monitors	—	10,000	10,000
Grants receivable - educational materials	15,000	—	15,000
Grants receivable - others	750	—	750
Grants receivable - educational videos	—	—	—
Grants receivable - COVID-19 assistance	—	—	—
Grants receivable - 16+ grants to beneficiaries	—	—	—
	<u>279,903</u>	<u>60,028</u>	<u>339,931</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 2021 £	Unrestricted Funds £	Total Funds 2020 £
Fundraising events income	—	—	14,751	14,751

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2021

6. Other trading activities

	Unrestricted Funds	Total Funds 2021	Unrestricted Funds	Total Funds 2020
	£	£	£	£
Merchandise sales	<u>7,286</u>	<u>7,286</u>	<u>3,407</u>	<u>3,407</u>

7. Investment income

	Unrestricted Funds	Total Funds 2021	Unrestricted Funds	Total Funds 2020
	£	£	£	£
Bank interest receivable	<u>59</u>	<u>59</u>	<u>111</u>	<u>111</u>

8. Other income

	Unrestricted Funds	Total Funds 2021	Unrestricted Funds	Total Funds 2020
	£	£	£	£
Consultancy services	<u>920</u>	<u>920</u>	<u>—</u>	<u>—</u>

9. Costs of raising donations and legacies

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

10. Costs of other trading activities

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

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2021

11. Expenditure on charitable activities by activity type

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

12. Analysis of support costs

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

13. Net income/(expenditure)

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

	2021 £	2020 £
Depreciation of tangible fixed assets	<u>216</u>	<u>512</u>

14. Auditors remuneration

	2021 £	2020 £
Fees payable for the audit of the financial statements	<u>4,200</u>	<u>—</u>

15. Independent examination fees

	2021 £	2020 £
Fees payable to the independent examiner for: Independent examination of the financial statements	<u>—</u>	<u>2,330</u>

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2021

16. Staff costs

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

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

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

No employee received employee benefits of more than £60,000 during the year (2020: None).

Key Management Personnel

Key management personnel include all persons that have authority and responsibility for planning, directing and controlling the activities of the charity. The total compensation paid to key management personnel for services provided to the charity was £52,371 (2020: £22,149).

17. Trustee remuneration and expenses

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

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

	2021 £	2020 £
Travel	154	–
Sundry	908	8
	<u>1,062</u>	<u>8</u>

18. Tangible fixed assets

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

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2021

19. Stocks

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

20. Debtors

	2021	2020
	£	£
Prepayments and accrued income	81,765	39,163
Other debtors	60	270
	<u>81,825</u>	<u>39,433</u>

21. Creditors: amounts falling due within one year

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

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

	2021	2020
	£	£
Accruals and deferred income	26,563	—

23. Deferred income

	2021	2020
	£	£
At 1 February 2020	—	49,843
Amount released to income	—	(49,843)
Amount deferred in year	26,563	—
At 31 January 2021	<u>26,563</u>	<u>—</u>

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

24. Pensions and other post-retirement benefits

Defined contribution plans

The amount recognised in income or expenditure as an expense in relation to defined contribution plans was £2,477 (2020: £861).

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2021

25. Analysis of charitable funds

Unrestricted funds

	At 1 February 2020 £	Income £	Expenditure £	At 31 January 2021 £
General funds	263,243	224,036	(196,474)	290,805
Designated fund - research	109,255	18,581	(77,173)	50,663
Designated fund - educational materials	15,000	30,000	—	45,000
	<u>387,498</u>	<u>272,617</u>	<u>(273,647)</u>	<u>386,468</u>
	At 1 February 2019 £	Income £	Expenditure £	At 31 January 2020 £
General funds	252,550	244,905	(234,212)	263,243
Designated fund - research	142,181	38,267	(71,193)	109,255
Designated fund - educational materials	—	15,000	—	15,000
	<u>394,731</u>	<u>298,172</u>	<u>(305,405)</u>	<u>387,498</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 prior to the close of the 2020/21 financial year have been allocated by the trustees to the provision of educational materials in the 2021/22 financial year, as part of the ongoing drive to raise awareness of Dravet Syndrome. The project has been delayed due to the COVID-19 pandemic.

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2021

25. Analysis of charitable funds *(continued)*

Restricted funds

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

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

26. Analysis of net assets between funds

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

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

Dravet Syndrome UK

Notes to the Financial Statements *(continued)*

Year Ended 31 January 2021

27. Related parties

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