CCEW Charity No. 1169896
Company No. CE008386
OSCR Charity No. SC048672

DSDFAMILIES

REPORT AND FINANCIAL STATEMENTS

For the year ended 4 April 2021

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TRUSTEES’ REPORT

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Introduction

The Trustees present their annual report with the financial statements of the charity for the year ended 4 April 2021.

Charity Information

TRUSTEES
Sue Elford (Resigned 3 November 2020)
Kate Davies
Ieuan Hughes
Gareth Hopkins
Susan Chynoweth
Jo Williams
Caroline Sanders (Appointed 6 October 2020)
Parent Representative with exemption permission from the charity commission not to be named

PRINCIPAL ADDRESS
dsdfamilies
61 Dublin Street
Edinburgh
EH3 6NL

REGISTERED CHARITY NUMBER
1169896
SC048672

REGISTERED COMPANY NUMBER
CE008386

INDEPENDENT EXAMINER
Carol Flockhart CA
Chiene + Tait LLP
Chartered Accountants and Independent Examiners
61 Dublin Street
Edinburgh
EH3 6NL

BANKERS
HSBC
118 Princes Street
Edinburgh
EH1 4AA

The Trustees of dsdfamilies present their second report and the financial statements as a charitable incorporated organisation (CIO) for the year ended 4 April 2021.

Objectives and Principal Activities

The purpose of dsdfamilies is to promote good health and social inclusion, of children with DSD (Differences of Sex Development), and to relieve the needs of children with DSD and their families, in particularly, but not exclusively by:

1. providing opportunities for children living with DSD to engage in activities which promote skill development, mental and physical wellbeing and participation in the local and wider community.
2. providing opportunities for the families supporting children to meet for social support and sharing of ideas and resources.
3. assisting in the provision of educational services, equipment and facilities not normally provided by the statutory authorities.
4. promoting understanding and a positive attitude towards DSD within the wider community.

The aims of dsdfamilies are to:

- Bring the experiences and voices of families, children and young people affected by Differences of Sex Development (DSD) into the development and delivery of best practice in care, research, policy, public discourse and professional training.
- Provide a service to families, children and young people living in the UK and Ireland, including a programme of educational tools and resources and access to peer/family-to-family support.
- Be one of the leading advocates for families, children and young people living with DSD in matters relating to support, healthcare and their right to information about their condition.
- Work towards ensuring that children growing up with any type of DSD and their families living in the UK and Ireland are not at a disadvantage due to their condition, whether that relates to equality of opportunity, access to information, access to support or having a say in decision making about the management of their condition.

Achievements and Performance

Few people will ever forget the beginning of this financial year. Our thoughts are with all those who have lost loved ones in the agonising weeks and months that followed, and indeed throughout the financial year.

When Covid-19 hit, we took a moment to re-orientate and adapt to this new reality. However, we are a resilient organisation, with committed trustees, volunteers and freelance staff, providing a highly respected service and addressing an urgent need.
Covid-19 forced healthcare professionals and families to seek support online. Whilst this route was previously limited, this now offered ways to reach young people and families and enable an additional route of how we can directly engage and support this vulnerable group.

The charity has continued to make a significant contribution to the lives of many families across the UK, living with DSD. The following initiatives were driven forward which focused on and supported the key objectives and aims of the charity:

1. Provision of opportunities for greater engagement for young people living with DSD

Our 'Listen to Us' report, published in 2019 highlighted that -above anything else- families and young people want peer support: a chance to connect with and meet others who share similar challenges and questions, in a safe space. Young people stated they needed to meet other young people for peer support, in different ways to suit different people.

Achievements and Performance (*cont'd*)

> *'We got on straight away... I don't know why.... We didn't talk about [our health condition].... but it just felt good' (Young person, 'Listen to Us', 2019)*
>
> *(…) it was the first time our daughter met anyone else whose body had developed like her. She found the experience extremely valuable, to finally meet someone who can actually understand what you're going through and who you can talk honestly with and just be who you are without fear of judgement is a very powerful thing. (Parent, 'Listen to Us', discussing dsdfamilies/GEO focus group posted by dsdfamilies on 18 Feb 2019)*

Covid-19 interrupted our workplans considerably and we had to cancel a series of face-to-face events, and all subsequent in-person activity. We know how anxious our young people can be and moving everything online without adequate support and follow-up in place was not an option.

Covid-19 also wiped out almost all other opportunities that young people had to access peer support when all clinic consultations moved online, reinforcing isolation.

When plans for family and youth events had to be shelved, we began to explore alternative and safe approaches to provide youth support. We were delighted to receive a Comic Relief/MetroCharity grant to kickstart our online peer support in November.

We recruited an experienced youth worker who hit the ground running. We connected her with young people we had been working with, and with healthcare professionals who were working specifically on transition of young people from paediatric to adult care and who were keenly aware of the need for more support.

By January we recruited 5 youth consultants to guide our work. It is vital to us that it is the young people themselves who advise us how best to support children and teens growing up, and to steer our youth work.

Young people living with variations of sex development have told us that what is most useful is: a safe space to talk, peer-led emotional support, and social connections. We are engaging with them around some of the most intimate issues: absence of periods, genital surgery and dilation, mixed sex characteristics, a small penis or penis that looks very different, hospital appointments and physical examinations, infertility, talking to friends and partners…how this makes them feel and discussing skills to negotiate this. Engagement is a steady process of trust building; it takes time and sensitivity.

The next stage of the project (from April 2021) focuses on:

- awareness and recruitment – growing the number of young people we provide a service to, 'normalising' youth work in DSD care, and widening our impact.
- working directly with young people: host monthly group meetings, kickstart a social media presence, increase the number of consultations around our workbook, and deliver, evaluate, and add to our #ExpectToBeAccepted workbook.
- training and management of peer supporters, to work directly with young people, and
- developing a series of podcasts by and for young people

Achievements and Performance (*cont'd*)

We will make specific and target efforts to ensure we can:
- reach young people with all 46,XY, 46,XX and related DSD diagnoses,
- develop a separate workbook for (young) boys with 46,XY DSD.

Feedback from our first cohort of young people includes:

'I would love to continue my involvement. I love the whole idea and would really like to help young people with variations find their confidence and not be discouraged to speak about themselves.'

'Instead of education this focused more on the emotional side of DSD, which is often overlooked when going to doctors. This is as helpful, if not more, than the medical aspect. '

'The whole process was very comfortable and allowed me to voice my opinions. It allowed me to feel like I am making a change and my voice is being heard... This youth project is one of the best things I have heard of that has been proposed to individuals with a sex development variation. I wish I had had this opportunity during my diagnosis.'

2. Provision of social support and sharing of ideas for the families of children with DSD and those involved in their care

In June 2020, dsdfamilies launched two new welcoming Facebook private groups to help families connect. One group is for parents of boys who were born with peno-scrotal hypospadias due to an underlying DSD. The other group is for parents of girls with XY.

Our objective is to create safe online spaces where families can learn from each other, chat, meet other families, share parenting successes and -over time- help support those who are a little behind them on the journey.

The groups are administrated by a dsdfamilies trustee who lives with a DSD, is a mum and an NHS healthcare professional. She is the first person families connect with when requesting to join. The groups are private which means that you can find them on Facebook but you cannot access them unless you have been accepted to join.

By March 2021, and despite minimum 'advertisement', the group for boys has 40 members and the group for girls has 26 members. We are inundated with requests from overseas families to join and could easily treble membership numbers but are for now limiting access to the groups for families living in the UK and Ireland. We really understand the huge need to provide thoughtful, supportive safe spaces to all families but feel that keeping it limited to UK/Ireland for now, and with the capacity that we have to monitor and support, is the right decision.

Often Facebook members, on finding out they live near each other have connected privately and form support 'bubbles'. Equally, we know other families who are uncomfortable joining a Facebook group; we still provide peer support to them too on a smaller scale.

It is important to keep being aware of the limitations of online communications and we will be working to host face-to-face family events as soon as we safely and reasonably can. At heart, what many families want is for their children to connect with other children, and you can only do that with a child-centred play-based programme.

Achievements and Performance (*cont'd*)

> *"The dsdfamilies charity has made it possible for me to join a Facebook group in the past year. Before that, I was aware of the amazing website but really didn't go to it much because I didn't really interact with anyone on the website. The Facebook group for parents of children with a dsd or penal scrotal hypospadias diagnosis has been especially important during this very stressful year dealing with hospital appointments and lockdown due to COVID because I spoke to real people about our children."*
>
> *"Over the past year, I have come to feel like my situation is not isolated because I have been a part of a group of people who know what it is like to have a child with a rare medical condition. The professionals, other parents, and even the children themselves have brought me a sense of community that I never felt before."*
>
> *"dsdfamilies are an essential source of support and information for parents of children with DSDs. Most importantly, they provide connection with other parents, which hospitals and GPs cannot give us. Thanks to the dsdfamilies charity I can talk to other parents and not feel alone, I can navigate my child's developmental milestones in a much more informed and confident manner, and as my child is growing up I can hope that she will meet other children through dsdfamilies and that she will never feel alone. "*

Moving forward:

- Awareness raising: We will continue to raise awareness among healthcare professionals and MDTs in the UK and Ireland about how families value the chance to connect, and raise further awareness of the groups
- Capacity-building: We are exploring setting up a parent steering committee to guide our work, help set charity priorities and also build capacity within the charity
- Centring Connecting: as the Facebook membership grows, we are now beginning to offer Zoom meetings to parents, and hope to revisit family days too (possibly on a regional scale).

3. Provision of educational services, equipment and facilities

a. Nursery leaflet

Led by parents, including a nursery manager, we developed an information leaflet for parents of boys with peno-scotal hysospadias who are looking for nursery places and are concerned about issues around care and maintaining privacy. The leaflet has been reviewed by expert psychologists in the field who tell us it will be hugely beneficial in their practice. The leaflet is being designed by Emily Tulloh who also designed 'Top Tips for Dilation', 'Top Tips for Talking' and 'The Story of Sex Development'.

We are now looking at producing a similar leaflet for girls with genital difference, in collaboration with the 'Living with CAH' group.

b. Supporting illustrations of genital difference for Midwifery e-course

For many parents, the initial experience of learning about having a baby with different sex development can have a big impact in how they feel about DSD and on bonding with their baby. What is said at that time, and the support that is shown, can make a huge difference. At the same time, DSD is rare enough that midwives might only come across newborns once in their career.

Achievements and Performance (*cont'd*)

We contributed to the development of a psychology-informed training resource for midwives who are assisting at the birth of a baby with DSD/ genital difference. The resource, developed by UHBW in conjunction with Royal College of Midwives will include a number of images -funded by dsdfamilies- drawn by artist Rosie Mclay of atypical genitals of a newborn, so as to familiarise the midwife and 'normalise' the atypical appearance. It will give information on how to support the family at that time and in the days after the birth. The resource also draws on the dsdfamilies 'Story of Sex Development' to explain typical and atypical sex development.

c. In October 2020 we instigated the review of the Androgen Insensitivity Syndrome page on the NHS Digital website, which was formally updated in March 2021.

d. We continued to add and develop the dsdfamilies website as well as maintain the dsdteens website. Both websites serves a large UK and international community.

> *"I lost my son in his first year but even now it is still so important to feel like I have a link to other DSD families and know that there is an organisation raising awareness and normalising DSD. I don't think I'd ever felt as alone as when I was handed a baby I'd already named as a girl and told not only was he not, but he wasn't a he yet either, he was just a baby who couldn't even be given an NHS number. Having done IVF as a solo mum I felt like I must have inadvertently allowed my child to become a science experiment, awful ad that sounds I was so shocked I was scared to look. Luckily, I had a DSD specialist who happened to be on site that day but it is no substitute to finding an organisation for parents. I'll continue to stay involved however I can."*

> *"We are so fortunate to have this service. I remember when I first learned of my child's diagnosis back in 2006. I looked it up online and got a pornography site for fetishes and alternative sex interests.... well, you can imagine how shocking and upsetting it was to imagine that this would be my child's future. Parents today are less likely to be directed to such a place based on an internet search because medical professionals refer us to a wholesome supportive website and help us link up with parents of children who are similar to our own. Not only do our children benefit from this charity, but the mental health of the parents does as well."*

4. Promotion of understanding and positive attitudes through being a lead advocate

a. Working with NHS England

In September 2018, following correspondence with dsdfamilies, a review began into the care delivered to children and young people living with differences of sex development. The review takes a two-pronged approach: (a) it focuses on the specific service requirements each Trust needs to provide if it wishes to provide care to children, young people and their families (this is called 'Service Specification) (b) it reviews the 'surgical policy in DSD', in particular relating to the management of genital difference for girls with 46 XX, dsd and for girls with 46XY,dsd and MGD, and to the management of gonads for girls with 46,XY dsd and MGD.

Achievements and Performance (*cont'd*)

In discussions with NHSE and healthcare professionals, dsdfamilies continues to push for a child-centred approach that addresses the real needs of families and young people and takes the long term view: the family and child need psychological support at the same time -if not before- as when endocrine support is given, they need peer support for the growing child and family, and they need accessible, science-based and practical information aimed at living well with these conditions.
In November 2020 a Stakeholder Consultation was launched, providing just under 80 responses. Ellie Magritte, a trustee of dsdfamilies, took part in the review of these responses. A public consultation on the proposed surgical policy is scheduled for late spring/early summer 2021 and the process should conclude in 2022.

b. Working with professionals, in the UK and internationally

During the year we continued to work with professionals both in the UK and internationally on initiatives aimed at improving support and best practice care for children, young people and families. This often included private correspondence with professionals and also a 2-day international event reviewing the 2006 Chicago Consensus statement. Trustees Ellie Magritte and Jo Williams took part.

Professionals from non-English speaking countries understand the hard work we put into developing resources and we are grateful for the £1800 donations to dsdfamilies from the Paris MDT Team, the Japanese Society or Endocrinology and a group of Japanese midwives to enable French and Japanese translations of 'Story of Sex Development' and 'When your baby is born with genitals that look different'.

Because of COVID, all large specialist conferences where we would usually exhibit or speak were cancelled or went online. We are grateful to all professional supporters who included information about dsdfamilies in their presentations.

Our trustee Jo Williams took part in 3 DSD-focused professional events:

I. In December 2020, Jo spoke at the DSD Special Interest Group of the British Society for Paediatric Endocrinology and Diabetes, and introduced our Facebook groups and Youth Project to specialist paediatric endocrinologists from across the UK.
II. In March 2021, Jo gave a keynote presentation at the Scottish DSD managed clinical network educational day for Scottish professionals.
III. Also in March 2021, Jo spoke at the conference of the Royal College of Obstetricians and Gynaecologists.

c. Scottish Government

We continued to challenge the Scottish Government's approach to DSD and submitted evidence against the inclusion of the undefined 'Variations of Sex Characteristics' in a proposed Hate Crime Law. This was also discussed with the Cabinet Secretary for Justice of the Scottish Government. We remain concerned that the Scottish Governments' fragmented and policy-driven approach to different sex development is counterproductive to the real needs of children and young people living with DSD in Scotland. A meeting with NHS Scotland has now been scheduled for the beginning of this financial year.

Achievements and Performance (*cont'd*)

d. Census 2021

During this period, we had a series of meetings with policy advisors in the Office of National Statistics (ONS) and National Records of Scotland (NRS) about the sex questions in the Census 2021 and the way that dsd was misrepresented in this. Correspondence continued with ONS throughout this year, and we insisted on ethical oversight which was granted. The outcome reflected the dsdfamilies position: all reference to 'intersex' was removed from the Guidance to the Census whilst allowing people who wanted to be counted as intersex could include this in an open box. We are particularly looking forward to a follow-up of these discussions and to working with the ONS on producing accurate data around variations of sex development.

e. Twitter

Our Twitter account is a helpful means to raise awareness about differences of sex development and the needs of children, young people and adults growing up with these conditions. It is also useful as a fundraising tool, and we are grateful to the online supporters who have helped us raise over £2000 this year. The Twitter feed can also be visited from our website homepage to maximise access. Current follower numbers are just under 1500.

Finally, we are extremely grateful to Sue Elford, Chair of 'Living with CAH' and founding trustee of dsdfamilies for her years of service. Sue stepped down as a trustee in November 2020 but we look forward to continued partnership in the years to come.

Beneficiaries

Our direct beneficiaries are:

* the children and families throughout the UK who have contacted us directly either through the website, through Facebook or by email for support and advice.
* young people we are supporting through our youth project.

Other direct beneficiaries are attendees of events we speak at, now mostly online: these primarily being doctors and consultants as well as specialist nurses and those with a professional interest in this field. Often, they will ask our views or advice on how to explain something thoughtfully and kindly.

The largest number of beneficiaries are the children and their parents that we rarely meet, and are worldwide, which is not surprising given that many of the e-booklets are freely available in multiple languages including Arabic, Bulgarian, Dutch, English, French, German, Polish, Portuguese, Russian, Swedish, Turkish, Urdu and Japanese (all are available to download from our website). The group accessing this material, as well as the information on our websites, mainly consists of parents, young people, and health professionals.

In the UK and beyond, clinicians use our materials by handing them to families as part of routine care. For example: in Bristol, the specialist DSD Nursing team give all new families our 'When your baby is born with genitals that look different – the first days' booklet. At the first multi-disciplinary meeting the psychologist talks about the importance of open dialogue with children and maintaining parental self-care – this is when our 'Top Tips for Talking' booklet is given. When parents or older children are ready to know more about how and why their body developed as it did the psychologist or the consultant endocrinologist will use the clinical tool 'Story of Sex Development' to explain their unique story to them and provide a bespoke written account. And girls who are ready to move on to the dilation clinic will be given a copy of our booklet 'Top Tips for Dilation'.

Achievements and Performance (*cont'd*)

Our investment in public awareness and understanding sits in between direct and indirect benefit. To raise happy and healthy young people, confident to engage with the world around them, we need that world and that societal narrative to be open to, and understanding of, variations of sex development. That is why we will continue to engage with policymakers, academics, media and third parties and insist on an accurate understanding of variations of sex development and what that means for those living with it, as this work directly feeds into 'successful outcomes' for children, young people and adults living with these hugely diverse conditions in the UK and Ireland.

Strengthening our Fundraising capabilities

This year, we trained up a dedicated fundraiser whose focus is on developing both new and sustainable sources of fundraising. One of these was to set up our first Crowdfunding campaign (with Aviva) which generated almost £1600 to support our work. Another is to engage more with our supporters who are interested in fundraising from a sports activity.

We also started to diversify our fundraising approaches, and in particular to make more use of social media as a channel to help heighten awareness of our work in addition to encouraging income.

Financial Information

The financial position is as shown in the attached financial statements which comply with statutory requirements. The surplus for the period amounted to £5,426 with income totalled £21,857.

Related Parties

There were no transaction with related parties during the period.

Reserves policy

We have agreed to maintain a liquid balance of income equal to at least three months of annual expenditure to meet pay and other standard expenditures, and provide stability for the sustainability of the charity as a whole. There are closing reserves of £9,199. Unrestricted reserves are in surplus by £8,494 as at the period end. £4,000 has been designated at the year end being split £3,000 as detailed in the plans for the future and £1,000 to provide continuity of the youth project. The intention is for these funds to be spent in the year ended 4 April 2022. The Trustees believe they are maintaining an appropriate level of reserves whilst ensuring that excessive funds are not accumulated.

The adequacy of this policy is reviewed annually. The Trustees have identified no significant short or medium-term financial risks to the charity's continued operations.

Plans for the future

The charity believes it is already making a significant contribution to the lives of many young people and their families, and is well positioned to deepen our impact over the next twelve months. Planning is already underway around these areas –

- As the charity continues to grow, we will continue to focus on strengthening governance and safeguarding, admin and financial admin support as well as building our fundraising capabilities. To that end we have designated £3000 of our unreserved income to do this.
- Developing and growing our youth project and services to young people, as directed by them, will be central to our work this year. At the time of writing this report we are delighted to have received part funding enabling us to begin developing a series of Podcasts. To ensure continuity in case of funding shortfalls, we have designated £1000 from our unrestricted income to the youth project. We also look forward to involving young people's voices in the management of dsdfamilies.
- Families want more peer support – this year we will develop dedicated Zoom sessions but also work towards hosting family events again. We will keep working with MDT teams to build confidence and grow understanding of why peer support is so important to the families they care for.

Plans for the future (cont'd)

- We are delighted to welcome our new trustee Dr Caroline Sanders to support our understanding of urological issues, peer support for families, research capacity and youth work.
- The dissemination of our new Nursery resource, along with maintenance and investment in our dsdfamilies and dsdteens websites will remain a focus for us. There is also huge interest in the resource we produced for primary and secondary schools – we have begun to develop that further, including the possibility of training in this area.
- We will continue to promote the voice of children, young people and adults in discussions about care delivery with BSPED, NHS England and NHS Scotland.
- We look forward to continuing our work with NHS England around a Service Specification and a Surgery Policy that centres on the wellbeing of all children. We also look forward to embarking on similar conversations with NHS Scotland, scheduled for early this coming year.
- We are concerned about lack of understanding, poor research and often plain ignorance around variations of sex development – in particular in academia and in information for schools produced by third parties. This risks preventing young people to be open about their conditions or causing trauma whilst in school. We will continue to explore opportunities with various stakeholders -including in education and policy/politics- to promote a can-do, inclusive and confident narrative.

Taxation

The Fund has been recognised by H M Revenue and Customs as a charity for tax purposes. As a result, no liability to taxation is anticipated on any of its income.

Structure, governance and management

Constitution

dsdfamilies is constituted as a charitable incorporated organisation, founded in October 2016 and registered in October 2016 with the Charity Commission for England and Wales, and in August 2018 with OSCR the Scottish Charity Regulator.

Trustees

All the current Trustees were appointed as a result of their lived experience and/or professional expertise in supporting children and young people living with different sex development and their families.
The minimum number of Trustees shall not be less than three nor more than twelve. Appointment and removal is in accordance with the CIO document, which requires that appointment be by way of a resolution passed by majority vote at a meeting of the Trustees.

The charity considers its key management personnel to comprise of the Trustees.

The Board meets three times a year, and gives detailed consideration to monitoring the progress of the Charity in achieving its performance and quality objectives.

Structure, governance and management (cont'd)

The day-to-day operation and management of the charity is shared among the Trustees. The Trustees consider recruitment of new Trustees as the need arises. Applications from suitable candidates would be sought by identifying specific gaps in professional skills and seeking recommendations of professionally qualified candidates, if necessary, placing advertisements in suitable publications.

Applicants would be provided with an information pack outlining the history of the organisation, its structure, activities and objectives, roles and expectations of Trustees plus other supporting information.

A new Trustee would be provided with information on the activities, financing and management structure of the Charity, together with guidance and codes of conduct related to the roles and responsibilities of Trustees.

Statement of Trustees' responsibilities

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 Scotland and in England & Wales requires the Trustees to prepare financial statements for each financial 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 for that period. In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any departures disclosed and explained in the financial statements;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The Trustees are responsible for keeping proper accounting records that 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 requirements of the Charities and Trustee Investment (Scotland) Act 2005 the Charities Accounts (Scotland) Regulations 2006 (as amended), and the Charities Act 2011 and the provisions of the charity's constitution. 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 declare that they have approved the Trustees' Report above.

Signed on behalf of the charity's Trustees on 7/6/21

Gareth Hopkins
Trustee

INDEPENDENT EXAMINER’S REORT TO THE TRUSTEES ON THE FINANCIAL STATEMENTS OF DSDFAMILIES

Independent Examiner's Report to the Trustees of dsdfamilies

I report to the charity trustees on my examination of the financial statements of the charity for the period ended 4 April 2021 which are set out on pages 13 to 17.

This report is made to the Trustees of dsdfamilies, as a body, in accordance with the terms of my engagement. My work has been undertaken to enable me to prepare the financial statements on behalf of the Trustees and to report my opinion as set out below and for no other purpose. To the fullest extent permitted by law, I do not accept or assume responsibility to anyone other than the Trustees and members of dsdfamilies, as a body, for my work or for this report.

Responsibilities and basis of report

As the charity’s trustees you are responsible for the preparation of the financial statements in accordance with the requirements of the Charities and Trustee Investment (Scotland) Act 2005 (the ‘2005 Act’), the Charities Accounts (Scotland) Regulations 2006 (as amended), and the Charities Act 2011 (‘the 2011 Act’).

I report in respect of my examination of the charity’s financial statements carried out under section 44 (1) (c) of the 2005 Act and section 145 of the Act. In carrying out my examination I have followed the requirements of Regulation 11 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and all the applicable Directions given by the Charity Commission under section 145(5)(b) of the 2005 Act.

Independent examiner's statement

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 as required by section 44 (1) (a) of the 2005 Act and Regulation 3 of the Charities Accounts (Scotland) Regulations 2006 (as amended and section 130 of the Act; or
2. the financial statements do not accord with those records; and
3. the accounts do not comply with the accounting requirements of Regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

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 financial statements to be reached.

Carol Flockhart

Carol Flockhart CA
CHIENE + TAIT LLP
Chartered Accountants and Independent Examiners
61 Dublin Street
Edinburgh
EH3 6NL

7 June 2021

RECEIPTS AND PAYMENTS ACCOUNT

For the year ended 4 April 2021

	Note	Unrestricted	Restricted	Total Funds Year ended 4 April 2021	Total Funds Year ended 4 April 2020
		£	£	£	£
Receipts					
Grants received	3	6,245	12,313	18,558	14,881
Donations		3,299	-	3,299	120
Total receipts		9,544	12,313	21,857	15,001
Payments					
Charitable activities	4	4,823	11,608	16,431	12,766
Total payments		4,823	11,608	16,431	12,766
Net (payments)/receipts		4,721	705	5,426	2,235
Transfers to/(from) funds		1,331	(1,331)	-	-
(Deficit)/surplus for the year		6,052	(626)	5,426	2,235

All income and expenditure derive from continuing activities.

The notes on pages 15 to 17 form part of these financial statements

STATEMENT OF BALANCES

At 4 April 2021

	Unrestricted £	Restricted £	Total 2021 £	Total 2020 £
Bank and cash in hand				
Opening balances	2,442	1,331	3,773	1,538
(Deficit)/Surplus for the period	6,052	(626)	5,426	2,235
Closing balances	8,494	705	9,199	3,773
Creditors: Amounts falling due within one period				
Accruals			930	900

Approved by the Trustees on...7/6/21...... and signed on their behalf by the following:-

....

Gareth Hopkins

The notes on pages 15 to 17 form part of these financial statements

NOTES to the FINANCIAL STATEMENTS

For the year ended 4 April 2021

1. Statement of Accounting Policies

Basis of preparation
The financial statements have been prepared on the receipts and payments basis, and comprise a receipts and payments account and statement of balances, as permitted for lower-income charities by section 133 of the Charities Act 2011. Only cash movements during the period are summarised in the receipts and payments account, no recognition being taken of transactions due but not received or paid.

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

Going concern
The financial statements have been prepared on a going concern basis. The Trustees have assessed the Charity's ability to continue as a going concern and have reasonable expectation that the Charity has adequate resources to continue in operational existence for the foreseeable future. Thus, they continue to adopt the going concern basis of accounting in preparing these financial statements.

Funds structure
Unrestricted funds comprise those funds which the Trustees are free to use for any purpose in furtherance of the charitable objects. Trustees have designated funds to specific projects in line with the charitable objects.

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by the donors.

Resources expended
Expenditure is allocated between:-

- expenditure incurred on raising funds;
- expenditure incurred in direct fulfilment of the charity's objectives;

Expenditure is accounted for on a cash basis.

Charitable activities
Costs of charitable activities include the expenses incurred in the furtherance of the charity's objectives.

Support costs
Support costs are those that assist the work of the charity but do not directly represent charitable activities and include office costs, governance costs, administrative payroll costs. They are incurred directly in support of expenditure on the objects of the charity

Irrecoverable VAT
The charity is not registered for VAT and consequently all expenditure is shown inclusive of VAT.

2. Trustees' Remuneration

During the year, two trustees were reimbursed for travel and other expenses incurred on behalf of the charity during the period, totalling £876 (2020: £2,696).

One Trustee also received remuneration of £nil (2020: £3,204) for professional services provided to the charity.

3. Grant income

	Year ended 4 April 2021 £	**Year ended 4 April 2020** £
Edinburgh Children's Hospital Charity	2,227	2,704
Addenbrooke's Charitable Trust	-	2,000
Government Equality Office	-	1,000
University of Michigan	-	7,677
NSS	1,000	1,500
Society of Endocrinology	2,250	-
Comic Relief	9,955	-
Aviva	1,561	-
French Translations	1,065	-
Japanese Translations	500	-
	18,558	14,881

£12,313 (2020: £10,018) of the income relates to restricted funds.

4. Expenditure

	Year ended 4 April 2021 £	**Year ended 4 April 2020** £
Charitable activities:		
Legal & professional fees	13,706	6,635
Printing & postage	-	1,472
Travel & subsistence	250	1,027
Internet & website	757	858
Family days	-	-
Venue hire	-	-
Support costs:		
Insurance	464	464
Bank charges	-	-
Governance costs:		
Independent examination	1,254	2,310
	16,431	12,766

£11,608 (2020: £7,778) of the expenditure relates to restricted funds.

5. Statement of funds

Unrestricted funds

	At 5 April 2020	Income	Expenditure	Transfers	**At 4 April 2021**
	£	£	£	£	£
Designated funds	-	-	-	4,000	4,000
General funds	2,442	9,544	(4,823)	(2,669)	4,494
	2,442	9,544	(4,823)	1,331	8,494

General Fund: represents funds which the Trustees are free to use in accordance with the Charity's constitution, aims and objectives.

Designated Fund: represents funds which the Trustees have designated for an administration and finance position, to work on review policies whilst strengthening safeguards. Along with professional fundraising in order to make the charity sustainable.

Restricted funds

	At 5 April 2020	Income	Expenditure	Transfers	**At 4 April 2021**
	£	£	£	£	£
Society of Endocrinology	151	1,020	(1,020)	(151)	-
Comic Relief	-	8,705	(8,000)	-	705
University of Michigan	(119)	-	-	119	-
NSS	-	550	(550)	-	-
ECHC	1,299	2,038	(2,038)	(1,299)	-
	1,331	12,313	(11,608)	(1,331)	705

Transfers of balances on the Society of Endocrinology and ECHC funds were made to the unrestricted fund at the balance sheet date. The opening balances on these restricted funds were incorrect due to incorrect allocation of expenditure allocated to unrestricted in the prior year.

Society of Endocrinology represents funding from Society of Endocrinology for development of online and printed patient/family support resources.
Comic Relief represents funding for the development a youth project for dsdfamilies.
University of Michigan represents funding to review the information pages of the TRN DSD Decision Making Tool to promote accessibility and ensure it provides answers to the questions families have.
NSS represents funding from NHS National Services Scotland for assisting with the production of education materials.
ECHC represents funding from the Edinburgh Children's Hospital Charity for "What's missing in DSD? Care, connection, conversation."