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

DSDFAMILIES

REPORT AND FINANCIAL STATEMENTS

For the year ended 4 April 2020

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For the year ended 4 April 2020

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DSDFAMILIES

TRUSTEES' REPORT

For the year ended 4 April 2020

Introduction

The Trustees present their annual report with the financial statements of the charity for the year ended 4 April 2020.

Charity Information

TRUSTEES
Julie Alderson (Resigned 6 March 2020)
Sue Elford (Resigned 3 November 2020)
Kate Davies
Ieuan Hughes
Gareth Hopkins (Appointed 3 April 2019)
Susan Chynoweth (Appointed 3 April 2019)
Jo Williams (Appointed 6 March 2020)
Caroline Sanders (Appointed 6 October 2020)
Parent Representative with exemption permission from the charity commission not to be named

PRINCIPAL ADDRESS
dsdfamilies
11 Vine Acre
Monmouth
NP25 3HW

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 2020.

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

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**
    a. At the beginning of this financial year we published **'Listen to Us'**, the largest consultation ever held in the UK. Over an 18-month period, we had been consulting with 194 people comprising of children, young people and adults living with different sex development and their families (dsd is an umbrella name for around 40 heterogeneous congenital conditions that can affect genital and/or reproductive development). The consultation included Family Day events in Bristol, Newport and Manchester. In total, 72 children and young people were engaged in this consultation process.

       The report, and its observations inform our current workplans but also serve to inform key stakeholders in healthcare, government and fundraising bodies of the clearly articulated and shared needs of children, young people and adults living with different sex development and their families.

       To mark the launch of the report we worked with journalist Angela Robson and the **BBC World Service Health Check programme** on a 10 minutes section on the Listen to Us report and living with DSD, including families and a young person who took part in the consultations.

Achievements and Performance (*cont'd*)

b. We included young people in the development of an Annex around Variations of Sex Development for the Scottish Government RSHP Teaching Guidance. We also included the statements made by young people around information and schools and as detailed in our Listen to Us report, including:

✓ They want differences of sex development as part of the curriculum, but not as a 'special' topic, just acknowledged

✓ Want teachers to not generalise - everyone is not the same, not everyone will have periods, be able to have their own children and all bodies are different.

✓ They would like medical appointments outside of school time.

We also developed this booklet in a stand-alone format which you can find here: https://www.dsdfamilies.org/application/files/9915/9223/5625/Info_for_Schools-dsdf.pdf

c. We began to consult informally with young people around the redevelopment of dsdteens, new youth-led content and how to host young people days or camps. The end of the financial year, March 2020 has of course meant that any face-to-face plans had to be postponed. We are now looking at funding for a youth participation officer who can concentrate on shifting this work online and build online networks (with a view to combine face-to-face and online post Covid).

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

- Correspondence with, and telephone support for, families and healthcare professionals seeking advice.
- One of our Trustees and one of our volunteers attended and spoke at the Family Day hosted by the Scottish DSD Clinical Network in Glasgow on 8 June 2019, meeting with various families throughout the day.
- Mumsnet featured charity: in June 2019, Mumsnet highlighted the work of dsdfamilies and featured an article by our Trustee Kate Davies. The following days Kate answered just under 100 questions about all aspects of DSD. This was without doubt the largest 'mainstreaming' initiative we have ever taken part in educating thousands of people but also, crucially, reaching out to many families who are isolated. The event coincided with a huge rise in visitor numbers to our website.
- The success of this event lead to us being the featured again in February 2020. We decided to combine education around sex development with understanding of growing up and living with a DSD. We promoted our new resource, Story of Sex Development, and asked an adult who has been working with dsdfamilies for some time to take over our Twitter account for the week. This was a hugely successful online running from 5 to 9 February 2019, generating 100s of Tweets and many new followers.

3. Provision of educational services, equipment and facilities

Throughout the reporting period, a significant amount of time and effort was put in creating resources to keep up with the demand from families and healthcare professionals and maintaining our existing ones –

a. During this financial year we finalised our new booklet 'The Story of Sex Development' which provides a transformative way to explain typical and atypical sex development alongside each other. As with all our resources it was developed in conjunction with senior healthcare professionals. The booklet was launched at the November 2019 conference of the British Society for Endocrinology. We are grateful to all funding bodies to help us develop this resource and for the funding from Edinburgh Children's Hospital Charity to help us disseminate.

Achievements and Performance (*cont'd*)

b. We instigated the review of NHS Website Information regarding Differences of Sex Development and collaborated on a new version.

c. Consultancy project with DSD-TRN on the 'Family Decision Making Tool'. The DSD-TRN network is a network of 12 large DSD Centres in North America with PI's David Sandberg (Psychology) and Eric Vilain (Genetics). The Network produced a 200 pages Family Decision Making Tool that combines providing general information about DSD, information about conditions and various questionnaires to measure understanding and impact of the decision making tool. dsdfamilies agreed to review all but the condition specific information and personal stories. We produced an initial edited version and involved a small number of families to review. This was followed by a series of online meetings. At the end of this financial year we are awaiting a substantially edited document for one further review by dsdfamilies and with a larger group of families.

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

a. Trustees attended, and spoke at, many conferences throughout the period with the key purposes of disseminating information and engaging with professionals in the field of endocrinology. It is a vital part of our work to attend such events in order to convey the voices of the children and their families, as well as provide an expert source of information –
    i. April 2019: Society for Endocrinology BES *2019* in Brighton
    ii. May 2019: British Society for Paediatric And Adolescent Gynaecology, Edinburgh, with presentation by our parent representative
    iii. November 2019: British Society for Paediatric Endocrinology and Diabetes in Cardiff, with key note by Chair Julie Alderson. This also included a presentation by Dr Danielle Eddy about training for midwives, building on work by dsdfamilies.
    iv. September 2019: European Society for Paediatric Endocrinology in Vienna, including extensive tweeting by Trustee Kate Davies
    v. March 2020: Scottish DSD managed clinical network meeting in Edinburgh, with keynote by Chair Julie Alderson
    vi. We were delighted to co-partner in developing a dedicated session on DSD at the conference of the European Pediatric Psychology Conference in Stockholm, titled: Information sharing, discovery and connection: Enhancing communication exchange among patients, families and health care providers to optimize adjustment and agency, with a focus on differences of sex development (DSD) and application to other paediatric conditions. The conference has had to be postponed because of Covid.
    vii. Several of our Trustees also attended conferences and events with an indirect focus on dsd such as general endocrinology, care in CAH, and specialist nursing in dsd care.
    viii. One of our resources 'Top Tips for Dilation' has been included and referenced in a key textbook for Paediatric and Adolescent Gynaecology, published by Cambridge University Press.

        - Some of our Trustees were invited to meet politicians and Government policy advisors to provide more information – this includes:

    ix. Meetings with Scottish Government policy advisors to discuss information about dsd in schools
    x. Meetings with various MSPs about the 'Listen to Us' report.
    xi. 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 presented in this.
    xii. Meeting with the Scottish Convenor of the Equality and HR Committee

Achievements and Performance (*cont'd*)

Building on the strong foundations laid in the first year of the charity, some of our Trustees were able to dedicate more of their time this year to engagement with the media and on social media to promote greater understanding of dsd –

1. As mentioned above, working with journalist Angela Robson on a piece for BBC World Service Health Check based around our 'Listen to Us' report, including interviews with volunteers from dsdfamilies.
2. Ongoing discussions with various media outlets to inform coverage around Caster Semenya
3. We launched a Twitter account in May and find this is a really good way to raise awareness of needs of children, young people and families – we now have 1000 plus followers, some of whom are now making regular financial donations to dsdfamilies. The Twitter feed can also be visited from our website homepage to maximise access.
    1. Collaboration on an article for Nursery World, published in June 2019
    2. An article in the Scotsman by our parent representative. You can find it here: https://www.scotsman.com/news/opinion/columnists/children-different-sex-development-need-more-help-ellie-magritte-1415038

- We were invited to sit on the NHS Service Specification Working Group and the NHS Policy on DSD Surgery Working Group and attended a series of meetings at Skipton House during the Financial Year.

Beneficiaries

Our **direct beneficiaries are the children and families throughout the UK** who have contacted us directly either through the website or by email for support and advice.

Other direct beneficiaries are the attendees at British and European conferences where on a yearly basis we speak directly to 300-400 professionals: 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 challenging 'cases', or on how to explain something thoughtfully and kindly.

The largest number of beneficiaries are the children and their parents that we never 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 and Urdu (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.

Our materials are disseminated widely via professional meetings and conferences such as the ESPE conferences in Athens (2018) and Vienna (2019) attended by approx. 4000 delegates from all over the world including clinicians, nurses, basic researchers, fellows and trainees. BSPED, where we exhibit annually is attended by approx. 500 endocrine healthcare professionals.

In the UK and beyond clinicians use our materials by handing them to families as part of routine care. For example: in Bristol, UK 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'.

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 £2,235 with income totalled £15,001.

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 £3,773. Unrestricted reserves are in surplus by £2,442 as at the period end. 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, focus can be given to maintaining a strong governance as well as building our fundraising capabilities. We were delighted to welcome two new trustees at the beginning of the financial year to support our strategic development, safeguarding and IT infrastructure needs.
- The 'Story of Sex Development' and its dissemination alongside with maintenance of our websites will be a big focus topic for us
- 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.
- Our main focus will be the translation of the recommendations of the Listen to Us report into a Strategic plan for 2020-2023. Developing our capacity to provide peer support will be integral to that.

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.

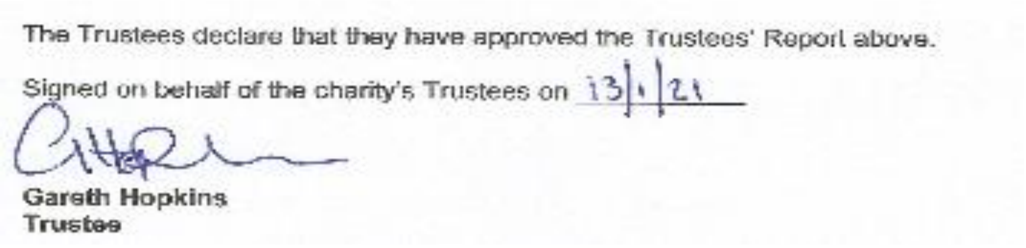
A new Trustee would be provided with information on the activities, financing and management structure of the Charity, together with guidance and codes of conduct related to the roles and responsibilities of Trustees.

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 13/1/21

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 2020 which are set out on pages 9 to 13.

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

13 January 2021

DSDFAMILIES

RECEIPTS AND PAYMENTS ACCOUNT

For the year ended 4 April 2020

	Note	Unrestricted	Restricted	Total Funds Year ended 4 April 2020	Total Funds Year ended 4 April 2019
		£	£	£	£
Receipts					
Grants received	3	4,863	10,018	14,881	4,279
Donations		120	-	120	-
Total receipts		4,983	10,018	15,001	4,279
Payments					
Charitable activities	4	4,988	7,778	12,766	23,704
Total payments		4,988	7,778	12,766	23,704
Net (payments)/receipts		(5)	2,240	2,235	(19,425)
Transfers to/(from) funds		1,060	(1,060)	-	-
(Deficit)/surplus for the year		1,055	1,180	2,235	(19,425)

All income and expenditure derive from continuing activities.

The notes on pages 11 to 13 form part of these financial statements

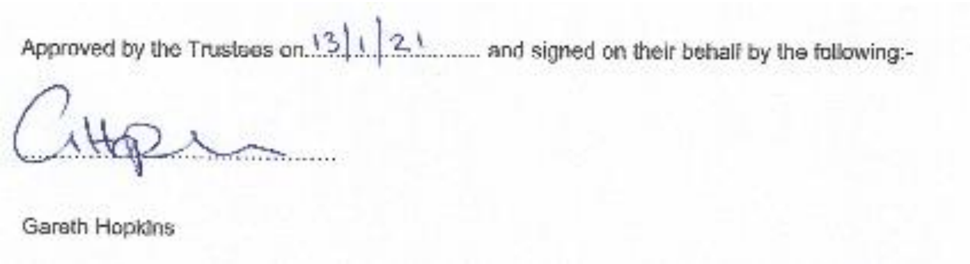
DSDFAMILIES

STATEMENT OF BALANCES

At 4 April 2020

	Unrestricted £	Restricted £	Total 2020 £	Total 2019 £
Bank and cash in hand				
Opening balances	1,387	151	1,538	20,963
(Deficit)/Surplus for the period	1,055	1,180	2,235	(19,425)
Closing balances	2,442	1,331	3,773	1,538

	Total 2020 £	Total 2019 £
Creditors: Amounts falling due within one period		
Accruals	900	1,140



Approved by the Trustees on 13/1/21 and signed on their behalf by the following:-

Gareth Hopkins

The notes on pages 11 to 13 form part of these financial statements

DSDFAMILIES

NOTES to the FINANCIAL STATEMENTS

For the year ended 4 April 2020

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 £2,696 (2019: £683).

One Trustee also received remuneration of £3,204 (2019: nil) for professional services provided to the charity.

3. Grant income

	Year ended 4 April 2020 £	**Year ended 4 April 2019** £
Edinburgh Children's Hospital Charity	2,704	-
Addenbrooke's Charitable Trust	2,000	-
Government Equality Office	1,000	-
University of Michigan	7,677	-
NSS	1,500	-
Society of Endocrinology	-	4,279
	14,881	4,279

£10,018 (2019: £4,279) of the income relates to restricted funds.

4. Expenditure

	Year ended 4 April 2020 £	**Year ended 4 April 2019** £
Charitable activities:		
Legal & professional fees	6,635	11,912
Printing & postage	1,472	290
Travel & subsistence	1,027	5,097
Internet & website	858	3,658
Family days	-	1,777
Venue hire	-	645
Support costs:		
Insurance	464	286
Bank charges	-	39
Governance costs:		
Independent examination	2,310	-
	12,766	23,704

£7,778 (2019: £21,357) of the expenditure relates to restricted funds.

5. Statement of funds

Unrestricted funds

	At 5 April 2019	Income	Expenditure	Transfers	**At 4 April 2020**
	£	£	£	£	£
General funds	1,387	4,983	(4,988)	1,060	2,442

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

Restricted funds

	At 5 April 2019	Income	Expenditure	Transfers	**At 4 April 2020**
	£	£	£	£	£
Government Equality Office	-	1,000	(1,120)	120	-
Society of Endocrinology	151	-	-	–	151
Addenbrooke's Charitable Trust	-	2,000	(1,535)	(465)	-
University of Michigan	-	3,084	(3,203)	–	(119)
NSS	-	1,500	(785)	(715)	-
ECHC	-	2,434	(1,135)	–	1,299
	151	10,018	(7,778)	(1,060)	1,331

Government Equality Office represents funding received in order to co-organise a focus group as part of the previous Children in Need project.
Society of Endocrinology represents funding from Society of Endocrinology for development of online and printed patient/family support resources.
Addenbrooke's Charitable Trust represents funding for the development of a DSD information booklet and clinic visual aids.
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."