DSDFAMILIES

England & Wales · Charity number 1169896

Details

Status	Registered
Legal form	CIO
Registered	2016-10-25
Register	View on the Charity Commission register

Contact

Address	61 Dublin Street Edinburgh EH3 6NL
Phone	07855719968
Email	info@dsdfamilies.org
Website	www.dsdfamilies.org

Activities

Objects: TO PROMOTE GOOD HEALTH AND SOCIAL INCLUSION, OF CHILDREN WITH DSD (DIFFERENCES OFSEX DEVELOPMENT), AND TO RELIEVE THE NEEDS OF CHILDREN WITH DSD AND THEIRFAMILIES, IN PARTICULARLY, BUT NOT EXCLUSIVELY BY:(I) PROVIDING OPPORTUNITIES FOR CHILDREN LIVING WITH DSD TO ENGAGE INACTIVITIES WHICH PROMOTE SKILL DEVELOPMENT, MENTAL AND PHYSICALWELLBEING AND PARTICIPATION IN THE LOCAL AND WIDER COMMUNITY.(II) PROVIDING OPPORTUNITIES FOR THE FAMILIES SUPPORTING CHILDREN TO MEET FORSOCIAL SUPPORT AND SHARING OF IDEAS AND RESOURCES(III) ASSISTING IN THE PROVISION OF EDUCATIONAL SERVICES, EQUIPMENT ANDFACILITIES NOT NORMALLY PROVIDED BY THE STATUTORY AUTHORITIES(IV) PROMOTING UNDERSTANDING AND A POSITIVE ATTITUDE TOWARDS DSD WITHINTHE WIDER COMMUNITY.

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), through opportunities for greater engagement in activities, provision of educational resources and promotion of understanding and positive attitudes.

Classification

- **How:** Provides Services, Provides Advocacy/advice/information, Acts As An Umbrella Or Resource Body
- **What:** The Advancement Of Health Or Saving Of Lives, Disability, Human Rights/religious Or Racial Harmony/equality Or Diversity
- **Who:** Children/young People, Other Defined Groups

Geography

- Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-04-04	£4,779	£18,842	-	-
2024-04-04	£17,003	£10,018	-	-
2023-04-04	£19,807	£9,941	-	-
2022-04-04	£16,279	£16,422	-	-
2021-04-04	£18,558	£16,431	-	-

Trustees

Name	Role	Appointed
Dilyana Tosheva		2021-07-05
Dr Jo Williams		2020-06-06
Ieuan Arwel Hughes		2017-06-06
Rebecca Jones		2024-09-24

DSDFAMILIES

England & Wales - Charity number 1169896

Accounts

dsdfamilies

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

DSDFAMILIES
REPORT AND FINANCIAL STATEMENTS
For the year ended 5 April 2025

DSDFAMILIES

REPORT AND FINANCIAL STATEMENTS

For the year ended 5 April 2025

Contents	**Pages**

Introduction

The Trustees present their annual report with the charity's financial statements for the year ended 5 April 2025.

Charity Information

TRUSTEES

Ieuan Hughes
Jo Williams
Caroline Sanders (until 1 April 2025)
Dilyana Tosheva
Bex Pritchard (from 1 October 2024)
Parent Trustee (from 1 October 2024)

PRINCIPAL ADDRESS
dsdfamilies
11, Pittway Avenue
Shipston On Stour
Warwickshire
CV36 4DG

REGISTERED CHARITY NUMBER
1169896
SC048672

REGISTERED COMPANY NUMBER
CE008386

BANKERS
HSBC
118 Princes Street
Edinburgh
EH1 4AA

DSDFAMILIES TRUSTEES' REPORT

The Trustees of dsdfamilies present their seventh report and the financial statements as a charitable incorporated organisation (CIO) for the year ended 5 April 2025.

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 support the needs of children with DSD and their families, in particular, but not exclusively by:

1. Providing opportunities for children with DSD to engage in activities promoting 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 providing educational services, equipment, and facilities not normally/usually provided by the statutory authorities.
4. Promoting understanding and a positive attitude towards DSD within the wider community.

The aims of dsdfamilies are to:

- Incorporate the experiences and voices of families, children, and young people affected by Differences of Sex Development (DSD) into the development and delivery of best practices 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 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

We are pleased to present our seventh annual report, showcasing the sustained and meaningful impact our charity has made on the lives of children, young people, and families across the UK and internationally.

Before celebrating this year's achievements, we wish to highlight the vital restructuring and reinforcement of our organisational framework. Since its inception, dsdfamilies has relied heavily on volunteers—an approach that enabled remarkable global influence but often obscured the true cost and value associated with delivering our services.

In the past financial year, the departure of several long-serving volunteers and trustees exposed a structural vulnerability. While volunteer contributions—and trustee involvement—remain foundational, we recognised the need to formally acknowledge and resource key operational areas: service delivery, sustainability, training, peer support, volunteer and youth-ambassador coordination, web development and IT support, policy formulation, and strategic communications.

Responding to this, we made several strategic appointments:

1. **Susanne Lambert**, recruited at the beginning of the financial year, now serves as Project Manager, dedicating five days per month. She supports our youth work, administers the Thriving Mind grant programme, and oversees general communications, IT, web development, and administrative tasks.

2. **Ellie Magritte**, a former trustee, was appointed in September 2024 as a Consultant and Acting Director. Ellie leads trustee training and development, fortifies our organisational foundation, and provides governance support. Her primary focus includes addressing current debates surrounding Differences of Sex Development (DSD) in the context of sport and enhancing societal understanding of DSD.
3. In September 2024, two new trustees joined our Board:

- **Bex**, appointed as Secretary, will champion peer support initiatives and coordinate intimate, in-person community events.
- A **parent trustee**, with dedicated responsibility for fundraising.

Finally, following a comprehensive skills audit of our trustees, we will recruit two additional board members in the 2025–26 financial year:

- One to uphold and enhance the sustainability and quality of our peer support programme.
- A second to reinforce organisational infrastructure and operational capacity.

In keeping with our commitment to diversity and breadth of expertise, future trustee recruitment will extend beyond the DSD community.

These strategic 'people investments' affirm our confidence that dsdfamilies now possesses the breadth of skills required to thrive, expand, and continue its vital work.

We would also like to express our deepest gratitude to **Dr Caroline Sanders**, who has served as a trustee for five years. Caroline's dedication was pivotal in the development of our services, the successful acquisition of the Thriving Mind grant, and the execution of key initiatives. Her steadfast leadership, during both this and the previous financial year, guided us gracefully through periods of change and growth.

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The following initiatives were driven forward, which focused on and supported the charity's key objectives and aims.

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

Social Media

Our young ambassadors have continued to develop a social media presence on the Instagram account YourPace.dsd. They decide entirely independently on content. They liaise with other young people (and sometimes parents), reaching out to them and providing peer support.

We know that we will likely support a wider 'incognito' audience because young people (and their families) will keep dsd private and not 'follow' the account. Our young ambassadors continue to help disseminate our school brochure and the Notepad Resource. Together, we are reaching out to DSD teams in the UK and Europe to grow the number of young people who are aware of our service, normalise youth work in dsd, and widen their impact.

Thriving Mind supported youth-centered work.

Our youth work, supported by the Thriving Mind grant, continues to be shaped by the following outcomes from our 23-24 collaboration with the Centre for Appearance Research (CAR):

1. Peer-to-Peer Engagement

Peer-to-peer support is a vital component of psychosocial care for young people with differences in sex development (DSD) in the UK. However, such support remains underdeveloped. To achieve

person-centred care, support services must be accessible, meaningful, and inclusive, fostering genuine connections among peers. There's a pressing need to address the underrepresentation of ethnic and racial groups in these support networks.

- While online peer support is beneficial for some, it should complement, not replace, face-to-face interactions. A hybrid approach is essential to meet diverse needs.
- Parents require robust support systems and networks to navigate the challenges of assisting their children towards wellness and well-being.

2. Integrating Peer Support into Clinical Settings

Advocating for peer support should extend beyond community spaces into clinical environments. Engaging in dialogue with DSD teams across the UK is crucial to understand their perspectives on peer support and to explore how they can enhance and sustain these initiatives.

3. Addressing Educational Challenges

Educational settings can pose significant challenges, potentially leading to recurring trauma for young individuals with DSD. Currently, there is a lack of psychosocial strategies that connect healthcare providers, educators, and peer support networks for these young people and their families.

- Establishing partnerships with secondary education champions is vital to integrate DSD-related content into Relationships, Sex, and Health Education (RSHE), particularly in alignment with the 2020 guidance.
- Updating and enhancing the dsdteens website is a strategic approach to disseminate information and facilitate ongoing knowledge transfer activities.

As a charity, we have greatly benefited from the organisational support and training provided by Thriving Minds. It has enabled us to support our young ambassadors and offer training opportunities, including a dedicated Thriving Minds weekend for young people. This support has significantly helped us build confidence and resilience.

In addition to managing the Instagram account, our young people have worked on redevelopment and expansion of the dsdteens website. They are currently collaborating with the MRKH charity to plan the development of new bite-sized information about absent periods, infertility, and different ways of forming a family, which can become part of the RSHE curriculum in the UK.

Finally, our young ambassadors are also keen to have a greater presence in non-DSD public environments to help ‘normalise’ and ‘mainstream’ DSD.

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

Our Facebook groups continue to grow and provide opportunities for families to 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. Some 150 families are now connected in this way.

The groups are administered by a family trustee who lives with a DSD, is a mum, and is an NHS healthcare professional. She is the first person families contact 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.

Often, Facebook members from the UK and Ireland, when they find out they live near each other, connect privately and form support bubbles.

The groups continue to receive a large number of international requests to join. We remain confident that the geographical and cultural connections are part of creating an accessible, low-barrier, non-political environment. Trustees will continue to evaluate this.

Of course, we know other families who are uncomfortable joining a Facebook group; we still provide

peer support on a smaller scale, often via email or phone. We also know from feedback that our youth-led Instagram account attracts parents, too, who find the positive and can-do approach of our youth ambassadors inspiring.

Since Autumn 2024, we have been running a series of facilitated parents' hangouts via Zoom. The sessions are held in the evening or occasionally on weekends, lasting 1.5 hours. There is always a parent present, along with someone from the dsdfamilies team to co-facilitate.

The group provides an informal space for conversation, sharing, and connection. Topics discussed include diagnosis, navigating the healthcare system, supporting teenagers with a DSD within broader teen issues, deciding who to share information with and trust, and how to talk with your child about their DSD. The group sizes vary, with an average of 4 to 8 participants.

Some quotes:

> ***The opportunity to speak with other families has been a huge help in not feeling so alone. Sometimes it can feel like you're the only ones going through it, and it's so nice to speak to people who understand!***
>
> ***Being part of the parent hangouts helped me feel less alone during an incredibly isolating time. It was comforting to speak openly and to hear others share similar experiences — it reminded me that I wasn't the only one feeling that way.***

MEETINGS

We are pleased to welcome Bex, our newest trustee, who is dedicating time to organize small, informal face-to-face gatherings across the UK. While larger meetings coordinated with healthcare teams provide valuable 'DSD learning spaces,' our priority is to create 'fun spaces' where families and their children can forge informal connections and create joyful memories. Bex has developed a schedule of regular events set to commence in summer 2025.

PEER-TO-PEER TRAINING

To minimize barriers to referrals from healthcare teams, we began planning a peer-to-peer training programme toward the end of this financial year. This initiative builds upon existing training in areas such as listening skills, confidentiality, and boundaries, while incorporating DSD-specific topics. These topics include navigating the uncertainty of initial diagnoses, decisions about surgery, discussing DSD with children, and understanding the diagnostic process. Our goal is to conduct two training programmes during the upcoming financial year.

Other than our youth-led Instagram account, Your.Pace, we are not currently active on any Social Media channel. Our Twitter/X account has helped raise awareness about differences in 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 online supporters. However, as Social Media has become increasingly politicised and as tackling misrepresentation of these conditions can easily become a full-time job, we decided, as per last year, to halt posting on Twitter/X and concentrate on more effective ways to share information about Living with DSD.

Moving Forward:

- **Raising Awareness:** We will continue to engage healthcare professionals and multidisciplinary teams across the UK and Ireland, emphasizing the value families place on opportunities to connect and raising awareness of our support groups.
- **Expanding Engagement:** We will maintain a regular programme of online Hangouts for parents and carers, complemented by a new series of smaller, informal face-to-face meetings for families, fostering community and support.

- **Implementing Peer-to-Peer Training:** We are working towards the introduction of peer-to-peer training and will launch such courses in the next financial year.

3. Provision of educational services, equipment, and facilities

a. Since its inception, dsdfamilies has been actively engaged in the realm of educational services. Through our websites and various publications—one of which has been translated into over 14 languages—we have established a significant body of work.
Over the past four financial years, we have developed several key resources:

- A **School Resource on DSD**, designed for educators to understand DSD and support students affected by these conditions.
- A **Nursery Leaflet** for parents of boys with penoscrotal hypospadias, assisting them in finding appropriate nursery placements while addressing concerns about care and privacy.
- The **Story of Sex Development**, a tool to help families comprehend their child's sex development and the diagnostic process.
- **The Notepad Project**, aimed at facilitating communication between young patients and healthcare professionals about issues that matter most to them.

In the current financial year, our focus has been on disseminating and embedding these resources.

The challenge with resources is that they require regular reviews and potential updates. As we approach the 2025–26 financial year, we are committed to this process. Additionally, we recognize the existing "puberty gap" in our educational resources and have initiated efforts this financial year to explore options for extending the *Story of Sex Development* to encompass the complexities and experiences of puberty.

b. Our Thriving Mind grant has enabled **us to initiate a comprehensive review of the content and design of the dsdteens website**. This includes enhancing its integration with podcasts created by and featuring young people, addressing issues that matter most to them. Additionally, we've expanded our outreach to UK healthcare teams, ensuring that young patients are effectively signposted to these valuable resources. These efforts aim to foster a deeper understanding of the needs, concerns, and aspirations of young individuals living with differences in sex development.

4. Promote understanding and positive attitudes by being a leading advocate

a. Sports and DSD

Before this financial year, dsdfamilies have not been engaged in discussions on the inclusion of women athletes with specific DSD in elite female sports. Occasionally, since 2012, we have reached out to UK journalists to highlight the fact that sports doesn't happen in isolation and that there is a wider population of girls and women with 46XY, DSD and their families who are greatly impacted by media coverage.

That all changed following the Summer Olympics of 2024. Since September 2024, dsdfamilies has been working on a small-scale project aimed at exploring how and whether the organisation should take a more proactive role in DSD and sports.
We observed that, alongside the significant financial and political stakes involved in elite sport, there are conflicting perspectives regarding who is eligible to participate in the female sporting category. DSD often gets sidelined or misrepresented in these discussions. The language used to describe female athletes with DSD can be unhelpful, often reducing the diversity of the DSD population to overly simplistic terms. Indeed, the language used in discussions around sports prefigures who our girls and women are, and that is not fair.

Many healthcare professionals have expressed feeling ill-equipped to discuss sports, but all want to see women with 46, XY DSD treated with dignity and respect. They are keen to be able to signpost clear guidance, advice, and support.

In February 2025, World Athletics, i.e., the organisation led by Sebastian Coe and which coordinates all policies for global track and field athletics competitions, invited dsdfamilies to become a key stakeholder in the very short three-week consultation on 'Recommendations for the Eligibility Conditions for the Female Category.' We have no prior record of working on sports-related issues, and we hope this engagement signals an increasing awareness that the decisions made by World Athletics (and possibly other sporting bodies) have real-life consequences for young girls and women living with 46, XY DSD.

The Submission to WA is available from our dsdfamilies website. We have also started work on new dedicated pages around Sport and DSD to ensure your families, young women, and adults are as well informed as can be and have a voice in these discussions.

b.NHS England: In discussions with NHSE and healthcare professionals, dsdfamilies continue to advocate for a child-centered approach that addresses the genuine needs of families and young people while taking a long-term perspective: both the family and child require psychological support simultaneously—if not before—endocrine support is provided. They need peer support for the developing child and family, along with accessible, science-based, and practical information geared toward living well with these conditions.

c. Working with professionals in the UK and internationally
As we have been working with a reduced number of trustees, we haven't been as pro-active this year in engaging with professionals nationally and internationally. Clearly, personal connections help build trust and help identify needs and resources. We are committed to revisiting this important strand of work next financial year, including through the recruitment of additional professional trustees.

Other activities

- Trustee Ieuan Hughes continues to be a member of the DSD Special Interest Group of the British Society for Paediatric Endocrinology and Diabetes and has ongoing discussions to work symbiotically for the benefit of dsdfamilies.
- We are also grateful to all professional supporters who included information about dsdfamilies in their conference presentations or published work.

Beneficiaries

Our Direct Beneficiaries

- **Children and Families in the UK**: We support families across the UK who reach out to us via our website, Facebook, or email for guidance and assistance.
- **Youth Engagement**: Through our youth project and the Instagram account 'YourPace.dsd', we engage directly with young people, providing them with a platform to connect and share experiences.
- **Healthcare Professionals**: Attendees at events where we speak or participate - including doctors, consultants, and specialist nurses - benefit from our insights. These interactions often lead to discussions on how to approach sensitive topics with empathy and understanding, reinforcing the importance of considering the lived experiences of young people and families affected by DSD.
- **Global Reach**: Our resources, such as e-booklets, are freely available in multiple languages—including Arabic, Bulgarian, Dutch, English, French, German, Polish,

Portuguese, Russian, Swedish, Turkish, Urdu, and Japanese - making them
- accessible to families worldwide. dsdfamilies.org
- **International Initiatives**: The Notepad project, designed to facilitate communication between young people and healthcare professionals, is being adapted in other countries. A French translation is underway, and a new 'cards' version is being produced in Belgium and the Netherlands.
- **Clinical Integration**: In the UK, clinicians incorporate our materials into routine care. For instance, in Bristol, the specialist DSD Nursing team provides new families with our 'When Your Baby Is Born with Genitals That Look Different - The First Days' booklet. At the first multidisciplinary meeting, the psychologist discusses the importance of open dialogue with children and maintaining parental self-care, introducing our 'Top Tips for Talking' booklet. As families progress, clinicians use the 'Story of Sex Development' to explain individual cases, and girls preparing for dilation clinics receive our 'Top Tips for Dilation' booklet. Our new 'Notepad' is also utilized in adolescent and young adult clinics. In another example, The psychology team at Great Ormond Street Hospital (GOSH) has utilized 'Top Tips for Talking' and the 'Notepad' to facilitate workshops with the families and young people in their care.

Public Awareness and Advocacy

Our efforts to raise public awareness and understanding serve both direct and indirect beneficiaries. To foster confident, healthy young people who are engaged with the world around them, society must embrace and understand variations in sex development. Therefore, we will continue to engage with policymakers, academics, media, and other stakeholders to ensure an accurate understanding of DSD, as this directly contributes to positive outcomes for individuals living with these conditions in the UK and Ireland, and beyond.

Future Plans

We are confident that dsdfamilies continues to punch well above its weight. Our plans for the next financial year include:

- Keep a tight focus on charity development, sustainability, and good governance.
- While carefully growing our peer-to-peer support services through the introduction of small meetings, we need to ensure we focus on the support and training of our peer supporters. This will be a key aim for the next financial year.
- Continue the development of dsdteens as a vehicle to bring together various media and resources.
- Work with clinics across the UK to encourage the use of our resources as well as get input from professionals and the young people in their care.
- Have a presence in policy debates involving our population

Financial Information

The financial position is as shown in the attached financial statements which comply with statutory requirements. The deficit for the period amounted to £18,842 with income totalled £4779.

Structure, governance and management

Constitution

dsdfamilies is 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 due to 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 or more than twelve. Appointment and removal are in accordance with the CIO document, which requires that appointment be by way of a resolution passed by a majority vote at a meeting of the Trustees.

The charity considers its key management personnel, to comprise of its Trustees. The Board meets three times a year and considers monitoring the charity's progress in achieving its performance and quality objectives in detail.

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 organisation's history, structure, activities and objectives, roles and expectations of Trustees, and other supporting information. A new Trustee would be provided with information on the charity's activities, financing, and management structure, 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 a 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 to prevent and detect fraud and other irregularities.

The Trustees declare that they have approved the Trustees' Report above.
Signed on behalf of the charity's Trustees on 1/12/2025
Jo Williams, Trustee

DSDFAMILIES

(A company limited by guarantee)

STATEMENT OF FINANCIAL ACTIVITIES

(INCLUDING SUMMARY INCOME & EXPENDITURE ACCOUNT)

For the year ended 5th April 2025 5th April 2025

	Notes	Unrestricted Funds	Restricted Funds	**Total 2025**	Total 2024
		£	**£**	**£**	**£**
Income from:					
Donations and legacies	0	1,116	-	**1,116**	2,003
Charitable activities	0	3,663		**3,663**	
Grants and contracts	0	-	-	**-**	15,000
Other trading activities	0	-	-	**-**	-
Investments	8	-	-	**-**	-
Total income		4,779	-	**4,779**	17,003
Expenditure on:					
Charitable activities	0	-		**-**	10,018
Operation of the charity	0	-	18,842	**18,842**	-
Total expenditure		**-**	18,842	**18,842**	10,018
Net income/(expenditure) before investment gains/(losses)		4,779	(18,842)	**(14,063)**	6,985
Reconciliation of funds					
Total funds brought forward		25,907	-	**25,907**	-
Total funds carried forward		30,686	(18,842)	**11,844**	6,985

The Statement of Financial Activities includes all gains and losses recognised in the year. All income and expenditure derive from continuing activities.

DSDFAMILIES
(A company limited by guarantee)
BALANCE SHEET
As at 5th April 2025 5th April 2025

	Notes	£	Total 2025 £	£	Total 2024 £
Current assets					
Debtors	15	-		-	
Cash at bank and in hand	16	11,824		25,907	
Total current assets		**11,824**		**25,907**	
Creditors: amounts falling due within one year	17	-		-	
Total net assets or liabilities			**11,824**		**25,907**
Funds of the charity					
Unrestricted income funds			30,686		6,985
Restricted income funds			(18,842)		-
Total funds			**11,844**		**6,985**

The company was entitled to an exemption from audit under s477 of the Companies Act 2006 relating to small companies.
The members have not required the company to obtain an audit in accordance with section 476 of the Companies Act 2006.
The directors acknowledge their responsibilities for complying with the requirements of the Companies Act with the respect to accounting records and the preparation of accounts.
These accounts have been prepared in accordance with the provisions applicable to small companies subject to the small companies regime and in accordance with FRS102 SORP.

These financial statements were approved by the Board on 1/12/2025

and are signed on its behalf by: **Jo Williams, Chair**

Jo Williams

DSDFAMILIES

England & Wales - Charity number 1169896

Accounts

CCEW Charity No. 1169896

Company No. CE008386
OSCR Charity No. SC048672

DSDFAMILIES

REPORT AND FINANCIAL STATEMENTS

For the year ended 4 April 2024

DSDFAMILIES

REPORT AND FINANCIAL STATEMENTS

For the year ended 4 April 2024

Contents	**Pages**

DSDFAMILIES

TRUSTEES' REPORT

For the year ended 4 April 2024

Introduction

The Trustees present their annual report with the financial statements of the charity for the year ended 4 April 2024.

Charity Information

TRUSTEES
Ieuan Hughes
Gareth Hopkins (resigned 1 March 2024)
Jo Williams
Caroline Sanders
Dilyana Tosheva
Jennifer Sanderson (resigned 1 April 2024)

PRINCIPAL ADDRESS
dsdfamilies
61 Dublin Street
Edinburgh
EH3 6NL

REGISTERED CHARITY NUMBER
1169896
SC048672

REGISTERED COMPANY NUMBER
CE008386

INDEPENDENT EXAMINER
Steven Smillie Esq
Chiene + Tait LLP (trading as CT)
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 third report and the financial statements as a charitable incorporated organisation (CIO) for the year ended 4 April 2024.

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:

- Incorporate the experiences and voices of families, children, and young people affected by Differences of Sex Development (DSD) into the development and delivery of best practices 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 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

Following a transition year in '22- '23 when the co-founder of dsdfamilies stepped down as a trustee, we experienced another challenging year as two trustees had to temporarily step back because of health reasons and maternity leave.

Although we had a slower-paced year, 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 charity's key objectives and aims.

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

Our young ambassadors have continued to develop a social media presence on the Instagram account YourPace.dsd. They decide entirely independently on content and produce an average of 10 posts per month. They liaise with other young people (and sometimes parents), reaching out to them and providing peer support.

We know that we will likely support a wider 'incognito' audience because young people (and their families) will keep dsd private and not 'follow' the account. Our young ambassadors continue to help disseminate our school brochure and the Notepad Resource. Together, we also reached out to DSD teams in the UK and Europe to grow the number of your people who are aware of our service, normalise youth work in dsd, and widen their impact.

1. Provision of opportunities for greater engagement for young people living with DSD Social Media (cont'd)

Thriving Mind supported Youth centred work

Part 1: Understanding the landscape

Background
Our collaboration with the Centre for Appearance Research (CAR), initiated in July 2021, has been a key aspect of our work this year. Together, we have been exploring ways to address the mental health and well-being needs of young people with DSD, as advocated by our young ambassadors.

This work was informed by the work in Germany, Empower-DSD, which aimed to draw together a group of young people with XX/XY DSD. Often, the group of 'girls' or 'females' with XY is missing from the support groups. The Empower-DSD is a two-day program delivered in groups of 6-8 persons of the same age group (e.g. young adults aged 18-24 years). Such "workshops" are for children aged 8-13 years and youth and young adults 14-24 years and for their parents. Within Empower-DSD the team have developed these programs for different diagnoses: CAH, Turner-syndrome, Klinefelter-Syndrome and XX-/XY-DSD.

Report '23- '24
Our collaboration with the Centre for Appearance Research included the following:

- Scoping review of the youth centred literature
- PPI work with young ambassadors
- Connections with global organisations.

The outcome from this work is very useful in the following ways, and we will be taking this forward in the next years:

- Peer-to-peer engagement is a crucial aspect of psychosocial support for UK DSD youth, yet it is currently lacking. To meet the goals of being person-centred, support needs must be accessible and valuable, supported by providers in ways that enrich connection to peers and are equitable and inclusive. There is a need for greater representation of ethnicity and race.

    - To address this, we propose working with clinically positioned partners to advocate youth-centred work. We recognise that despite a reach out to the community, the CAR work drew in a limited number of youth and young adults as experienced in UK, European and International research with young people. Ensuring young people between 16-22 especially feel comfortable to take part remains a big priority.

    - Education settings present a high-risk space that can result in recurrent trauma for the young person. There are currently no psychosocial approaches that connect providers, educators in schools, and peer-to-peer networks for young people with DSD and their families. We need to build a connection with secondary education champions to explore how to situate work in Relationships, Sex, and Health Education (RSHE), especially in light of the 2020 Guidance.

    - Peer-to-peer online work is an option for some young people, but it needs to be part of an approach rather than the only offering. A hybrid approach is required to support face-to-face and online needs; we are unaware of any such DSD psychosocial approach in the UK or abroad.

    - Parents need support systems and networks to navigate the challenges they encounter in supporting their children and young people work towards wellness and well-being.

- Advocating for peer support must happen in the clinical space as well as outside of this space.

    - There needs to be dialogue with DSD teams in the UK about the role they see peer-to-peer support have and how they can uplift and support this work for it to succeed.

    - To explore this opportunity follow-up meetings have been scheduled during next financial year.

1. Provision of opportunities for greater engagement for young people living with DSD Social Media (cont'd)

- Updating the website is a helpful approach to sharing information and ongoing KT activities.
    - This has commenced, but funding will continue to be needed to support translating the information from the CAR work to a KT tool.
    - The website dsdteens needs a fulsome review, and we have connected with a clinical lead at GOSH to explore whether this work could be completed or is within their scope to inform.
    - We would like to complete and have youth add to the genetics leaflet and have this published on dsdfamilies site and translated.
- Podcasting will reach an audience but must be inclusive and apply principles of trauma-informed care.
    - This work has been ongoing with the development of several Podcasts (see below). We want to apply for further funding to explore building new material that draws on the outputs from CAR i.e., videos for example https://cahcanada.ca/ video as an example, built by a dsd trustee and is cited as an example.

Part 2: Getting practical support out there: podcasts

In addition to the research project, our Thriving Mind funding allowed us to produce those urgent and important first tangible practical outputs. Our youth ambassadors felt that a series of freely accessible podcasts could reach most of their peers and be most useful. Following consultations with peers and a lot of rescheduling due to other activities and the availability of an experienced and sensitive podcaster, recordings began in January 2023.

The 2 young adults, series producer/recorder and a trustee had an initial meeting about the plan, topics, style, content and communication, and from this a process was agreed. The initial 5-part series was confirmed with a detailed plan for each session outlining specific themes and content to be explored within that conversation, as well as considering the different audiences who may access the series. The series order was agreed on as:

1. Diagnosis/Your Journey with a dsd
2. Mental health
3. School and education experiences
4. Relationships/Intimacy
5. Your body/acceptance

The producer then met online with the 2 young adults over a series of meetings, to both discuss and record the content as previously planned.

Each session started with a check-in, to ascertain where each individual was at, share a bit of news and check in about how they were feeling about the session and topic, with a chance to share anything, clarify details of the session and revisit the episode plan. Once both young adults were ready, the session was then recorded, with minimal input from the producer, simply an occasional prompt or request for clarification. The sole aim was to capture an open direct conversation between two young adults with a dsd.

At the end of each session, post-recording, there was again a little check-in, debrief about the conversation and a discussion about what would happen next.

Each online session took approximately 2 hours, with the final edited episodes ranging from 35-55 minutes. The episode lengths are also overall longer than our initial expectation, due to the open nature of the conversations. This made it hard to plan ahead with certainty, and was more editing and revision than initially anticipated, but this open free style of conversation gives a very personalised and honest result which is what the 2 young adults participating wanted to go for.

1. Provision of opportunities for greater engagement for young people living with DSD Social Media (cont'd)

During the course of this process the group between them experienced several personal, technical, commitment and timing issues which meant the original schedule became stretched out. Many of the planned sessions had to be changed at short notice to accommodate a change in circumstance, but these changes were managed swiftly and all via a whatsapp group.

There was also a plan in place to review and revisit the whole series once everything had been recorded and edited to ensure the content tallied up with the aims, made sense for the listener as a cohesive journey, and most importantly that the participants were happy with what they had shared.

Once the 5th episode of the series had been recorded, the producer felt it was important to revisit the first conversation again, to revisit this main overarching theme once the other areas had been discussed, and the process of speaking at length had occurred. A second recording of this conversation was then recorded which is now ready for release once signed off by the Trustees and participants (with release last summer 2024).

Revisiting and re-doing the first episode has delayed the release of the series, as it being the first, needed to be completed to go out first. However the time that elapsed across the process has also given the benefit of more reflection on the material and making a stronger first episode. The 2 young adults said they felt more confident about sharing their personal experiences and revisiting by the 2nd time around and that the conversation had a more natural flow.

The aims of the podcast series identified with the young adults were:

- To give some insight into some of the challenges, difficulties and positives of living with a dsd
- To talk openly about difficult things
- To put people's minds at ease
- To help prepare for talking with others/ loved ones/ partners
- To become better informed (some members of the general public might not have even heard of a DSD -It is common for people not to have heard about this umbrella set of conditions without directly knowing someone affected).
- To answer questions, explain the medical information, understand some of the experiences of young people living with a dsd, hear different points of view.
- To communicate shared experiences with other young people, even though the individual circumstances are different. - eg, navigating relationships, relationships to ones bodies, and mental health are all very relatable topics across many young people.

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

Our Facebook groups continue to grow and provide opportunities for families to 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. Some 140 families are now connected in this way.

The groups are administered by a family trustee who lives with a DSD, is a mum, and is an NHS healthcare professional. She is the first person families contact 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.

Often, Facebook members from the UK and Ireland, when they find out they live near each other, connect privately and form support bubbles.

The groups continue to receive a large number of international requests to join but to date we remain confident that the closer geographical and cultural connections outweigh having a larger sized Facebook group. Trustees will continue to evaluate this.

Of course, we know other families who are uncomfortable joining a Facebook group; we still provide peer support on a smaller scale often via email or phone. We also know from feedback that our youth-led Instagram account attracts parents, too, who find the positive and can-do approach of our youth ambassadors really inspiring.

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

Our Twitter/X account has been helpful in raising awareness about differences in 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. However, we don't have the resources to address the misrepresentation of these conditions, so as per last financial year we decided to halt posting on Twitter/X.

Moving forward:

- 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
- Whilst we are committed to hosting larger family events again, the practicalities and volunteer time needed have prevented us from running such events this financial year. We know that families who have made connections via Facebook are meeting up, and indeed, we encourage this.

3. Provision of educational services, equipment and facilities

a. Since its inception, dsdfamilies has been very active in this space of education services. From our websites to our various booklets – one translated into 14 plus languages – we know that we have built an important body of work.

In the last 3 financial years, we produced a School Resource on DSD (aimed at schools and teachers and explaining what DSD is and how they can best support children and young people living with these conditions), a Nursery leaflet (for parents of boys with penoscrotal hypospadias who are looking for nursery places and are concerned about issues around care and maintaining privacy). We also finalised 'the Story of Sex Development' and last year finalised 'The Notepad Project' which seeks to aid communication in clinics between a young person and a healthcare professional about the issues that matter most to young people.

This financial year, we wanted to focus on disseminating these resources, ensuring professionals and families know how to use them, and generally embedding them, e.g. the Story of Sex Development is an excellent tool to help families understand their child's sex development as well as map and understand the diagnostic process.
As technology moves on we also wanted to take time to evaluate how and when to update these resources we will make up an important part of our next three years of work.

b. Our Thriving Mind grant also gave us the opportunity to start creating podcasts with young people about issues that are important to them; these will be important tools to help the wider understanding of the needs, concerns and hopes of young people living with different sex development.

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

a. Display in The Science Museum
We received excellent feedback on the work we did last year with the Science Museum in the Who Am I? gallery. The new display includes stories and objects that explore themes of sex development and gender identities and how science and medicine shape and intersect with these aspects of us in different ways.

As part of this new display, dsdfamilies trustees and one youth ambassador shared stories on their/their child's experiences and perspectives on their/their child's sex development at universal moments across a lifetime – conception, birth, puberty and adulthood.

b. 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.

4. Promotion of understanding and positive attitudes through being a lead advocate (cont'd)

In discussions with NHSE and healthcare professionals, dsdfamilies continue 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.

As per last year, the review of the surgical policy has come to a standstill this financial year, and we continue to push for clarity from NHSE on this. We have been assured that the Service Specification work is slowly progressing and are hoping for implementation no later than Easter 2025.

c. Working with professionals in the UK and internationally
As we have been working with a reduced number of trustees we haven't been as pro-active this year in engaging with professionals nationally and internationally. Clearly, personal connections help build trust and help identify needs and resources. We are committed to revisiting this important strand of work next financial year, including through the recruitment of additional professional trustees.

Other activities

- Trustee Ieuan Hughes continues to be a member of the DSD Special Interest Group of the British Society for Paediatric Endocrinology and Diabetes and has ongoing discussions to work symbiotically for the benefit of dsdfamilies.
- We are also grateful to all professional supporters who included information about dsdfamilies in their conference presentations or published work.

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 and our Instagram account 'YourPace.dsd'.

Other direct beneficiaries are attendees of events we speak at and attend: 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. It also gives us a chance to remind healthcare professionals of the lived experience of young people and families living with DSD and how they can be more supportive of our realities.

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 addition, the Notepoad project is already being repurposed in other countries – with a French translation under way and a new 'cards' version being produced in Belgium and the Netherlands.

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'. Our new 'Notepad' can be used at every consultation in adolescent/young adult clinics.

Beneficiaries (*cont'd*)

Our investment in public awareness and understanding sits in between direct and indirect benefit – and we hope our work with the British Science Museum (see trustees report 22/23) will continue to make a major contribution to this. 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.

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 £6,985 (2023: £9,866) with income totalled £17,003 (2023: £19,807).

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 £25,907 (2023: 18,922). Unrestricted reserves are in surplus by £8,680 (2023: £6,833) as at the period end.

Plans for the future

Even though 2 trustees had to step back temporarily during the '23-'24 financial year because of health reasons and maternity leave during the course of the financial year, we continued to punch well above our weight.
Our plans for the next financial year include:

- Recruitment of new trustees bringing new perspectives and fresh energy will be a crucial part of next year's activity (and as part of a natural replacement of trustees). We will be looking to recruit trustees with a special interest or experience in: peer support, charity governance and fundraising. We will also be looking at healthcare professionals to join our board of trustees.
- In addition, in 2019, following the largest consultation of families and young people living with dsd ever done in the UK (the report of this, Listen to Us, is available from our Resources pages) we developed a '20-'24 strategy. We will evaluate our work -taking into account how Covid impacted on these plans-but crucially will prepare our '25-'28 strategy.
- In the last 5 years much energy has been spent on some of the big issues and debates around DSD: 'nomenclature', LGBTI and Politics, Surgery in DSD, and Public Understanding of DSD. Whilst all these issues are relevant when working towards 'living well with DSD', in the next financial year we want to focus especially on peer support -online and face to face- for families,children, teens and young people.

Our Thriving Mind grant has allowed us some flexibility however and allows us to be focused on the following activities

- Centre the learning experience of our young ambassadors so they can take up leadership positions overtime.
- Maintain the Podcast work and complete in-progress activities.
- Continue to develop the Instagram account YourPace and encourage more young people to take an active part.
- Having consulted widely on access to educational and medical info and peer support we will prioritise the development of dsdteens as a vehicle to bring together various media and resources.
- Work with clinics across the UK to encourage use of our resources as well as get input from professionals and the young people in their care.

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 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 due to 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 or more than twelve. Appointment and removal are in accordance with the CIO document, which requires that appointment be by way of a resolution passed by a 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 considers monitoring the charity's progress in achieving its performance and quality objectives in detail.

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 organisation's history, structure, activities and objectives, roles and expectations of Trustees, and other supporting information.

A new Trustee would be provided with information on the charity's activities, financing, and management structure, 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 a 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 to prevent and detect fraud and other irregularities.

Signed on behalf of the charity's Trustees on 28 October 2024

Jo Williams

Jo Williams
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 2024 which are set out on pages 12 to 16.

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.

Steven Smillie

Steven Smillie CA
CT
Chartered Accountants and Independent Examiners
61 Dublin Street
Edinburgh
EH3 6NL

DSDFAMILIES

RECEIPTS AND PAYMENTS ACCOUNT

For the year ended 4 April 2024

	Note	Unrestricted	Restricted	Total Funds Year ended 4 April 2024	Total Funds Year ended 4 April 2023
		£	£	£	£
Receipts					
Grants received	3	-	15,000	15,000	18,400
Donations		2,003	-	2,003	1,407
Total receipts		2,003	15,000	17,003	19,807
Payments					
Charitable activities	4	156	9,862	10,018	9,941
Total payments		156	9,862	10,018	9,941
Net (payments)/receipts		1,847	5,138	6,985	9,866
Transfers to/(from) funds		-	-	-	-
Surplus for the year		1,847	5,138	6,985	9,866

All income and expenditure derive from continuing activities.

The notes on pages 14 to 16 form part of these financial statements

DSDFAMILIES

STATEMENT OF BALANCES

At 4 April 2024

	Unrestricted	Restricted	Total 2024	Total 2023
	£	£	£	£
Bank and cash in hand				
Opening balances	6,833	12,089	18,922	9,056
Surplus for the period	1,847	5,138	6,985	9,866
Closing balances	8,680	17,227	25,907	18,922
Creditors: Amounts falling due within one period				
Accruals			3,060	1,500

Approved by the Trustees on 28 October 2024 and signed on their behalf by the following: -

Jo Williams

Jo Williams
Trustee

The notes on pages 14 to 16 form part of these financial statements

DSDFAMILIES

NOTES to the FINANCIAL STATEMENTS

For the year ended 4 April 2024

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, one trustee was reimbursed for travel and other expenses incurred on behalf of the charity during the period, totalling £nil (2023: £394).

3. Grant income

	Year ended 4 April 2024	Year ended 4 April 2023
	£	£
UK Youth	15,000	16,500
Society of Endocrinology	-	1,900
	15,000	18,400

£15,000 (2023: £18,400) of the income relates to restricted funds.

4. Expenditure

	Year ended 4 April 2024	Year ended 4 April 2023
	£	£
Charitable activities:		
Legal & professional fees	9,142	6,259
Printing & postage	-	420
Travel & subsistence	-	658
Internet & website	720	738
Support costs:		
Insurance	96	96
Bank charges	60	60
Governance costs:		
Independent examination	-	1,710
	10,018	9,941

£9,862 (2023: £7,232) of the expenditure relates to restricted funds.

5. Statement of funds

Unrestricted funds	At 5 April 2023 £	Income £	Expenditure £	Transfers £	**At 4 April 2024** £
General funds	6,833	2,003	(156)	-	8,680
	6,833	2,003	(156)	-	8,680

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 2023 £	Income £	Expenditure £	Transfers £	**At 4 April 2024** £
Society of Endocrinology	1,400	-	-	-	1,400
UK Youth	10,689	15,000	(9,862)	-	15,827
	12,089	15,000	(9,862)	-	17,227

Youth Focused Activities for youth focused activities.

Society for Endocrinology for development of information and support materials for families and dissemination ("Families").

DSDFAMILIES

England & Wales - Charity number 1169896

Accounts

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

DSDFAMILIES

REPORT AND FINANCIAL STATEMENTS

For the year ended 4 April 2023

DSDFAMILIES

REPORT AND FINANCIAL STATEMENTS

For the year ended 4 April 2023

Contents	**Pages**

DSDFAMILIES

TRUSTEES' REPORT

For the year ended 4 April 2023

Introduction

The Trustees present their annual report with the financial statements of the charity for the year ended 4 April 2023.

Charity Information

TRUSTEES
Ieuan Hughes
Gareth Hopkins
Susan Chynoweth (resigned 1 October 2022)
Jo Williams
Caroline Sanders
Dilyana Tosheva
Jennifer Sanderson

PRINCIPAL ADDRESS
dsdfamilies
61 Dublin Street
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EH3 6NL

REGISTERED CHARITY NUMBER
1169896
SC048672

REGISTERED COMPANY NUMBER
CE008386

INDEPENDENT EXAMINER
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EH3 6NL

BANKERS
HSBC
118 Princes Street
Edinburgh
EH1 4AA

The Trustees of dsdfamilies present their fifth report and the financial statements as a charitable incorporated organisation (CIO) for the year ended 4 April 2023.

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

This year was an important transition year for dsdfamilies as one of the most active drivers behind dsdfamilies, a parent trustee using the alias Ellie Magritte, stepped down as a trustee. Ellie set up dsdfamilies as patient group in 2011 and became one of the four founding trustees in 2016. Ellie stepped down to concentrate on new initiatives. Further, Ellie recognised that this is a time for change to allow a new membership to champion the next journey for dsdfamilies.

As trustees, either as stakeholders caring for children and young people or as professionals or families, we expressed our deepest gratitude to Ellie for her initiative and drive and wished her all the best in her future.

Whilst trustees have been sharing Ellie's workload, her absence has been felt this year, especially in terms of the speed with which we have been able to progress certain projects, not in the least the fantastic Thriving Minds grant we received from Youth UK.

Nevertheless, although we had a slower-paced start to the financial year, 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 charity's key objectives and aims. We will share the key objectives and outputs from activity over the last 12 months.

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

Our young ambassadors have continued to develop a social media presence on the Instagram account YourPace.dsd, where they quickly built up a following of 300+ followers. They decide entirely independently on content and produce an average of 10 posts per month. They liaise with other young people (and sometimes parents), reaching out to them and providing peer support.

We know that we will likely support a wider incognito audience because young people (and their families) will keep DSD private and not 'follow' the account. Our young ambassadors continue to help disseminate our school brochure and are finalising work on the Notepad Resource. Together, we also reached out to DSD teams in the UK and Europe to grow the number of your people who are aware of our service, normalise youth work in DSD, and widen their impact.

We ensured our youth ambassadors received wellbeing support and recruited a specialist psychologist to work alongside them as needed.

Thriving Minds/ UK Youth Grant
Early in this financial year, we received the fantastic news that families had been awarded a 3-year grant from Thriving Minds/UK Youth to focus on youth work and support by and for young people. This opened long-awaited opportunities for significant investments in work dedicated to young people.

The need to review the current evidence & explore the current psychosocial landscape – research undertaken by The Centre of Appearance Research

To kickstart the three-year project and to address the gap in evidence-based psychosocial support for young people with DSD, we commissioned the Centre for Appearance Research at the University of the West of England to produce a report that would 1) provide an up-to-date scoping review of the evidence-based psychosocial support interventions currently available to young people with a DSD, 2) gain lived experience perspectives of young people and their families on current support provision and future support development through Patient and Public Involvement.

Because researchers with the necessary experience and knowledge of DSD were unavailable, this project's start date was delayed until early 2023. We will report on this in the next financial year.

Getting practical support out there: podcasts

In addition to the research projects, we wanted to produce tangible practical outputs. Our youth ambassadors felt that a series of freely accessible podcasts could reach most of their peers and be most useful. Following consultations with peers and a lot of rescheduling due to other activities and the availability of an experienced and sensitive podcaster, recordings began in January 2023.
The topics for the initial five podcasts were identified as:

1. Mental health.
2. Relationships/Intimacy.
3. School and education experiences.
4. Diagnosis/Your DSD journey.
5. Your body/acceptance.

Discussing what we wanted to achieve and get out of this, young people said:

- To give some insight into some of the challenges, difficulties and positives of living with a DSD.
- To talk openly about difficult things.
- To put people's minds at ease.
- Preparation for talking with others/ loved ones/ partners.
- To become better informed—some members of the general public might not have even heard of a DS. (It is common for people not to have heard about this umbrella set of conditions without knowing someone affected).
- To answer questions, explain the medical information, understand some of the experiences of young people living with a DSD, hear different points of view.
- Understand where there are shared experiences with other young people, even though the individual circumstances are different.

Recording for the podcasts started in February 2023, and we will report further in the next annual report.

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

Our Facebook groups continue to grow and provide opportunities for families to 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. Some 130 families are now connected in this way.

The groups are administrated by a family trustee who lives with a DSD, is a mum, and is an NHS healthcare professional. She is the first person families contact 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.

Often, Facebook members from the UK and Ireland, when they find out they live near each other, connect privately and form support bubbles. In addition to the informal connections via Facebook, we continued to run our Circles for Parents - online events. The Circles are like a book club, where the same people (up to 6 per session) come together to discuss a specific topic, but with plenty of opportunities to broaden the discussion. The Circles were hosted by another parent of a child with DSD who is a trained facilitator. So far, the feedback has been 100% positive.

Of course, we know other families who are uncomfortable joining a Facebook group; we still provide peer support on a smaller scale often via email or phone. We also know from feedback that our youth-led Instagram account attracts parents, too, who find the positive and can-do approach of our youth ambassadors really inspiring.

Our Twitter/X account has been helpful in raising awareness about differences in 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. However, we don't have the resources to address the misrepresentation of these conditions, so we decided this year to halt posting on Twitter/X.

Moving forward:

- 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
- Whilst we are committed to hosting larger family events again, the practicalities and volunteer time needed have prevented us from running such events this financial year. We know that families who have made connections via Facebook are meeting up, and indeed, we encourage this.

3. Provision of educational services, equipment and facilities

a. Since its inception, dsdfamilies has been very active in this space of education services. From our websites to our various booklets – one translated into 14 plus languages – we know that we have built an important body of work.

In the last financial year, we produced a School Resource on DSD (aimed at schools and teachers and explaining what DSD is and how they can best support children and young people living with these conditions), a nursery leaflet (for parents of boys with penoscrotal hypospadias who are looking for nursery places and are concerned about issues around care and maintaining privacy). We had only just finalised 'the Story of Sex Development'. This year, we wanted to focus on disseminating these resources, ensuring professionals and families know how to use them, and generally embedding them.

b. We finalised the Notepad Project, funded by the British Society for Paediatric and Adolescent Gynaecology. The resource seeks to aid communication in clinic between a young person and a healthcare professional about the issues that matter most to young people. Research shows that these concerns are often overlooked; instead, medical issues are prioritised using medical language.

The Notepad resource comes with several supplements to maximise its impact. In addition to the Notepad/questions, we have developed supporting materials to challenge professionals in how they discuss sex and to encourage them to move on from 'sexual function' to 'pleasure'. Another supporting material directly addresses the differing and challenging experience of one of our young black youth ambassadors. Professionals do understand that for some BAME young people, the cultural context makes learning about and living with DSD a lot harder. We hope our work can inform new approaches to caring and communication for all young people. We also provided practical advice on how to use the resource.

c. In addition, we continued working on the websites, and our Thriving Mind award allowed us to draw up plans to invest in and redevelop dsdteens' website.

d. Our Thriving Mind grant also gave us the opportunity to start creating podcasts with young people about issues that are important to them. Getting everyone together caused some delays, but after the first recordings, we are well on the way. Our objective is to produce five podcasts as part of our Year 1 Thriving Minds grant (see above).

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

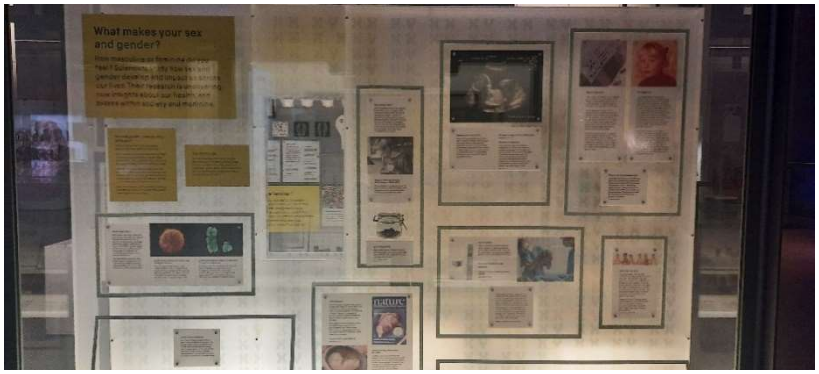
a. Display in The Science Museum

This year, we worked with the London-based Science Museum on their new display in the Who Am I? gallery. The new display includes stories and objects that explore themes of sex development and gender identities and how science and medicine shape and intersect with these aspects of us in different ways.

As part of this new display, dsdfamilies trustees and one youth ambassador shared stories on their/their child's experiences and perspectives on their/their child's sex development at universal moments across a lifetime – conception, birth, puberty and adulthood.

This new display is in 'Showcase 5', one of 15 showcases in the Who Am I? gallery. Who Am I? is a permanent gallery on the Science Museum's first floor. Its content explores how biomedical science can inform and challenge how we define and experience our identities.

Since its launch in June 2000, Who Am I? has become one of the most popular destinations for museum visitors, particularly for families with children aged 10+. Its attractive design, playful displays, and interesting subject matter, combined with its wide range of digital interactives, art pieces, and personal stories, have ensured its enduring popularity. The dsdfamilies display was installed in January 2023, and dsdfamilies trustees visited the museum in May 2023.



b. 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.

5. Promotion of understanding and positive attitudes through being a lead advocate (*cont'd*)

In discussions with NHSE and healthcare professionals, dsdfamilies continue 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.

As per last year, the review of the surgical policy has come to a standstill this financial year, and we continue to push for clarity from NHSE on this. We have been assured that the Service Specification work is slowly progressing.

c. Working with professionals in the UK and internationally
During the year, we continued to work with professionals in the UK and internationally on initiatives to improve support and best-practice care for children, young people and families. This included a co-written publication as a guest for three members of the families trustee Board.

Magritte, E., Williams, J., Amyot, E., Usipuik, M., & Sanders, C. (2022). Listening to individuals "not doing surgery doesn't mean doing nothing". *Horm Res Paediatr*
https://www.karger.com/Article/FullText/525452

Ellie Magritte and Jo Williams contributed to an international evaluation of care and research, identifying areas of agreement, especially areas where more work is needed (sometimes urgently, e.g., provision of psychology and peer support). Following reviewers' comments, a new round of consultation with co-authors is underway, and we are looking at resubmission early next financial year.

Other activities

- Trustees Dilyana Tosheva and Ieuan Hughes attended the Annual Scottish DSD Managed Clinical Network Conference as well as the iDSD conference in Switzerland, July 2022 where they promoted our resources, including the new Notepad.
- Trustees Caroline Sanders and Dilyana Tosheva attended the Society for Endocrinology Conference in Harrogate in November 2022 and circulated our materials and resources.
- Trustee Ieuan Hughes continues to be a member of the DSD Special Interest Group of the British Society for Paediatric Endocrinology and Diabetes and has ongoing discussions to work symbiotically for the benefit of dsdfamilies.
- We are also grateful to all professional supporters who included information about dsdfamilies in their conference presentations or published work.

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 and our Instagram account 'YourPace.dsd'.

Other direct beneficiaries are attendees of events we speak at and attend: 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. It also gives us a chance to remind healthcare professionals of the lived experience of young people and families living with DSD and how they can be more supportive of our realities.

Beneficiaries (*cont'd*)

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 addition, the Notepad project is already being repurposed in other countries – with a French translation under way and a new 'cards' version being produced in Belgium and the Netherlands.

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'. Our new 'Notepad' can be used at every consultation in adolescent/young adult clinics.

Our investment in public awareness and understanding sits in between direct and indirect benefit – and we hope our work with the British Science Museum will make a major contribution to this. 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.

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 £9,866 with income totalled £19,807.

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 £18,922. Unrestricted reserves are in surplus by £6,833 as at the period end.

Plans for the future

As a small charity, we continue to punch well above our weight, even if we have no full time funded positions and work mostly with Volunteers.

Plans for the future (*cont'd*)

Plans can be difficult to predict accurately with the small group and with changes in trustee membership. Our Thirving Mind grant allows us to be focused however on the following activities

- Maintain the Podcast work and complete in-progress activities.
- Continue to develop the Instagram account YourPace and encourage more young people to take an active part.
- Having consulted widely on access to educational and medical info and peer support we will prioritise the development of dsdteens as a vehicle to bring together various media and resources.
- Work with clinics across the UK to encourage use of our resources as well as get input from professionals and the young people in their care.
- Consider how to recruit to trustee vacancies and adjust to new leadership.
- Disseminate new resources to wider audiences.

Other emerging issues
During 22-23 we have experienced further turn over and unexpected changes to our Trustee group. This has left a gap that the Trustees need to address.

Taxation

The charity 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 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 due to 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 or more than twelve. Appointment and removal are in accordance with the CIO document, which requires that appointment be by way of a resolution passed by a 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 considers monitoring the charity's progress in achieving its performance and quality objectives in detail.

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 organisation's history, structure, activities and objectives, roles and expectations of Trustees, and other supporting information.

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

TRUSTEES' REPORT

For the year ended 4 April 2023 (*cont'd*)

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 a 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 to prevent and detect fraud and other irregularities.

Signed on behalf of the charity's Trustees on _____

Jo Williams
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 2023 which are set out on pages 12 to 16.

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.

Steven Smillie CA
CT
Chartered Accountants and Independent Examiners
61 Dublin Street
Edinburgh
EH3 6NL

DSDFAMILIES

RECEIPTS AND PAYMENTS ACCOUNT

For the year ended 4 April 2023

	Note	Unrestricted	Restricted	Total Funds Year ended 4 April 2023	Total Funds Year ended 4 April 2022
		£	£	£	£
Receipts					
Grants received	3	-	18,400	18,400	14,500
Donations		1,407	-	1,407	1,779
Total receipts		1,407	18,400	19,807	16,279
Payments					
Charitable activities	4	2,709	7,232	9,941	16,422
Total payments		2,709	7,232	9,941	16,422
Net (payments)/receipts		(1,302)	11,168	9,866	(143)
Transfers to/(from) funds		(21)	21	-	-
(Deficit)/surplus for the year		(1,323)	11,189	9,866	(143)

All income and expenditure derive from continuing activities.

The notes on pages 14 to 16 form part of these financial statements

DSDFAMILIES

STATEMENT OF BALANCES

At 4 April 2023

	Unrestricted	Restricted	Total 2023	Total 2022
	£	£	£	£
Bank and cash in hand				
Opening balances	8,156	900	9,056	9,199
(Deficit)/Surplus for the period	(1,323)	11,189	9,866	(143)
Closing balances	6,833	12,089	18,922	9,056
Creditors: Amounts falling due within one period				
Accruals			1,500	1,320

Approved by the Trustees on..... and signed on their behalf by the following: -

……

Jo Williams
Trustee

The notes on pages 14 to 16 form part of these financial statements

DSDFAMILIES

NOTES to the FINANCIAL STATEMENTS

For the year ended 4 April 2023

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, one trustee (2022; two trustees) was reimbursed for travel and other expenses incurred on behalf of the charity, totalling £394 (2022: £500).

3. Grant income

	Year ended 4 April 2023 £	Year ended 4 April 2022 £
UK Youth	16,500	-
Society of Endocrinology	1,900	500
Alder Hey Children's Charity	-	2,500
Leathersellers Co	-	1,000
Hugh Fraser Trust	-	2,000
The Sir Jules Thorn Charitable Trust	-	1,000
Albert Hunt SP	-	1,000
Brit Paediatric BritSpag	-	5,000
The Robertson Trust	-	1,000
Local Giving	-	500
	18,400	14,500

£18,400 (2022: £7,575) of the income relates to restricted funds.

4. Expenditure

	Year ended 4 April 2023 £	Year ended 4 April 2022 £
Charitable activities:		
Legal & professional fees	6,259	13,518
Printing & postage	420	104
Travel & subsistence	658	512
Internet & website	738	702
Telecoms	-	155
Support costs:		
Insurance	96	96
Bank charges	60	15
Governance costs:		
Independent examination	1,710	1,320
	9,941	16,422

£7,232 (2022: £7,380) of the expenditure relates to restricted funds.

For the year ended 4 April 2023

5. Statement of funds

Unrestricted funds	At 5 April 2022 £	Income £	Expenditure £	Transfers £	**At 4 April 2023** £
General funds	8,156	1,407	(2,709)	(21)	6,833
	8,156	1,407	(2,709)	(21)	6,833

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 2022 £	Income £	Expenditure £	Transfers £	**At 4 April 2023** £
Society of Endocrinology	-	1,900	(500)	-	1,400
UK Youth	-	16,500	(5,811)	-	10,689
Britspag	900	-	(921)	21	-
	900	18,400	(7,232)	21	12,089

Youth Focused Activities for youth focused activities.

British Society for Paediatric Adolescent Gynaecology (BritSpag) for production of a Notepad plus supporting materials to aid youth-oriented communication around DSD and sexual pleasure in the clinic. The transfer between funds represents an overspend on restricted funds.

Society for Endocrinology for development of information and support materials for families and dissemination ('Families').

DSDFAMILIES

England & Wales - Charity number 1169896

Accounts

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

DSDFAMILIES

REPORT AND FINANCIAL STATEMENTS

For the year ended 5 April 2022

DSDFAMILIES

REPORT AND FINANCIAL STATEMENTS

For the year ended 5 April 2022

Contents	**Pages**

DSDFAMILIES

TRUSTEES' REPORT

For the year ended 5 April 2022

Introduction

The Trustees present their annual report with the financial statements of the charity for the year ended 5 April 2022.

Charity Information

TRUSTEES
Kate Davies (Until 5 April 2022))
Ieuan Hughes
Gareth Hopkins
Susan Chynoweth
Jo Williams
Caroline Sanders
Dilyana Tosheva
Parent Representative with exemption permission from the charity commission not to be named (Until 5 April 2022)
Jennifer Sanderson (from 6 April 2022)

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 third report and the financial statements as a charitable incorporated organisation (CIO) for the year ended 5 April 2022.

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

Building on our 2020/2021 youth work we recruited two of our young ambassadors to develop a young person strategy and a social media presence. Having consulted with other young people living with DSD, and having reviewed existing materials our ambassadors decided to launch a stand-alone Instagram account called YourPace.dsd

Our youth ambassadors decide entirely independently on content, and each produces 10 posts per month. They will liaise with any other young person (and sometimes parent) reaching out to them providing peer support. In a short time, they developed a following of 200+.
We have been made aware that because young people (and their families) will keep having a DSD private and will not 'follow' the account, we are likely to support a wider 'incognito' audience as well.

Our Youth ambassadors coordinated a Youth review of our School brochure and Notepad Resource

Achievements and Performance *(cont'd)*

(See below).

Feedback received include the following:

> Thank you from all of us for being there to explain some key terms or just give general advice. We all appreciate it. (young person)
>
> Your work is amazing, thank you for all the great reminders! (young person)
>
> I just want to say that I love your page so much. (young person)
>
> I think it's great you do this for other kids. (a parent)
>
> Thanks for all your posts - I am a proud Mum of a 4 year old child and get so many tips from your page. (a parent)

The next stage of the project 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.
- training and management of peer supporters, to work directly with young people. We also consider it really important to ensure our youth ambassadors are themselves, supported at all times.
- developing a series of podcasts by and for young people and connect it with the redevelopment of the dsdteens website
- Thanks to a 3-year Thriving Minds grant we are now in a position to develop a longer-term strategy to ensure young people -and their needs- are at the centre of DSD care

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

Our Facebook groups continue to grow and provide opportunities for families to 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. Some 100 families are now connected in this way.

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.

Often Facebook members from the UK and Ireland, on finding out they live near each other have connected privately and form support 'bubbles.

We continue to receive a high number of requests from overseas families to join but are for now continuing to limit access to families living in the UK and Ireland. This remains a very difficult decision as dsdfamilies is recommended by professionals everywhere from Australia to Canada and everywhere in between, and of course we want to support our peers and their families. Scaling up that way, and the responsibility that comes with it (monitoring and support) needs more trained parent volunteers than we currently have. Trustees will however continue to monitor this.

Achievements and Performance *(cont'd)*

In addition to the informal connections via Facebook we have this year ran two different types of online events:

We hosted 2 **Circles for Parents.** The Circles are like a book club, where the same people (up to 6 per session) come together to chat together about a specific topic, but with plenty opportunity to broaden the discussion. The Circles were hosted by another parent of a child with DSD who is a trained facilitator. The Feedback has been 100% positive.

In addition, we ran **2 psychologists led Get Togethers** enabling up to 10 parents per session to talk about their challenges and how these can be addressed.

> I loved talking to other parents, it was a relief after months of not being able to talk to anyone else about my daughter following diagnosis. […} also had great advice and was brilliant steering our conversations gently and wisely.
>
> It has been so therapeutic to meet other parents who get it!
>
> I signed up so I could meet other parents and discuss some concerns. It was really helpful.
>
> I'd definitely recommend the sessions and think they have been really helpful and insightful. I think the best thing I have enjoyed is building a connection with other parents (which works best with regular attendance to the groups)
>
> I loved the sessions though found it difficult to have privacy at home. I would try to make it to all of them next time.

Of course, we know other families who are uncomfortable joining a Facebook group; we still provide peer support to them too on a smaller scale often via email or phone.

And we also know from feedback that our youth-led Instagram account attracts parents too who find the positive and can-do approach of our youth ambassadors really inspiring.

Finally, we had several very helpful discussions and exchanges with the healthcare professionals in Germany who are coordinating Empower DSD. Empower DSD is a government/health insurance collaboration between leading DSD clinics to provide psychology led information and peer support workshops to children, young people and their families. Workshops are fully funded and take place over a weekend. The initial feedback has been excellent, and we look forward to the in-depth analysis of processes, training and outcomes as it could be a model to work towards in the UK.

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
- As several smaller face-to-face get togethers have taken place we are looking forward to hosting again larger family events.

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 penoscrotal hypospadias who are looking for nursery places and are concerned

Achievements and Performance *(cont'd)*

about issues around care and maintaining privacy. We finalised the brochure in June 2021, and it has been very well received by professionals and parents alike.

b. School Resource on Differences of Sex Development
During the summer we developed a school-friendly resource on DSD. The booklet is aimed at schools and teachers and explains what DSD is and how they can best support children and young people living with these conditions. We know that it is rare for a child or young person to be open about their condition, so the Resource gives information about how to be DSD-inclusive, without singling out a child or young person. It also addresses some misconceptions around DSD. During the development of the brochure, we involved teachers and our youth consultants. Following the publication, we have been liaising with the Department for Education and organisations such as the Sex Education Forum.

c. Notepad Project
In August 2021 the British Society for Paediatric and Adolescent Gynaecology awarded us a grant to produce a Resource that would aid communication in clinic between a young person and the healthcare professional about the issues that matter most to young people. We know from research that these concerns are often overlooked; instead, medical issues are prioritised using a medical language. We have now developed a 'Notepad' that lists some 20 questions that young people and adults told us they really wanted to talk about with their healthcare team, but never had a chance to. In addition to the Notepad (a clinical tool) we have developed supporting materials to challenge professionals in how they discuss sex and to encourage them to move on from 'sexual function' to 'pleasure'. Another supporting material addresses directly the differing and challenging experience of one of our young black youth ambassadors. Professionals do understand that for some BAME young people the cultural context makes learning about and living with DSD a lot harder, and we hope that the work we have done can inform new approaches to caring and communication for all young people.

d. Diagnostic process/Genetics and Endocrine brochure
We have begun to research and consult on a new brochure to support families whose baby has a suspected DSD and must quickly acquire knowledge of endocrine and genetic testing. This brochure can be offered alongside the 'When your baby is born with genital difference – first days' brochure which focuses on emotional and practical needs of families.

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

f. We produced new infographics on dsdfamilies to be handed out at conferences and/or in clinic.

g. The collection of posts produced by our youth ambassadors is a hugely important new resources that we will look at disseminating in different ways.

h. Consultation and Review:
As well as produce our own resources, trustees and families are often asked to provide input and evaluate resources developed by others or provide a contribution as an end-user of healthcare E.g.: Our trustee Jo Williams contributed to a presentation at the European Conference of Endocrinology on the topic "Living with AIS, multidisciplinary care team and research".
Trustee Ellie Magritte, together with another volunteer parent, reviewed a new Parent Intervention tool, for parents of children with visible differences, produced by the Centre for Appearance Research at the University of West England and had discussions on how this could be repurposed.

Achievements and Performance *(cont'd)*

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.

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.
During this financial year the review of the surgical policy has come to a standstill, and we continue to push for clarity from NHSE on this. The Service Specification work is slowly progressing and dsdfamilies attended several meetings on this during the financial year.

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.

- Trustees Kate Davies and Ellie Magritte took part in the online conference and exhibition of the Association of Genetic Nursing and Counsellors Conference 26-27 April 2021.
- Trustees Jo Williams and Caroline Sanders - as well as former dsdfamilies Chair of Trustees Dr Julie Alderson - presented at the Conference of the European EPPC conference September 2021. The sessions they presented were '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, and the session 'Research Addressing the Challenges of Differences in Sex Development (DSD)'
- Trustee Dilyana Tosheva attended the Annual Scottish DSD Managed Clinical Network Conference
- Trustees Kate Davies and Dilyana Tosheva attended the Society for Endocrinology Conference in Edinburgh in November 2021; they also looked after the dsdfamilies exhibition stand.
- Trustee Dilyana Tosheva attended the online conference of the British Society for Paediatric Endocrinology and Diabetes in November 2021.
- Trustee leuan Hughes received the James M Tanner award in recognition of his outstanding, overall contribution to the field of paediatric endocrinology and diabetes, at the BSPED 2021 conference. Following the presentation of the award, leuan held a lecture for national and international paediatric endocrinologists highlighting our work in peer support and resource development and calling on healthcare professionals 'to work together with dsdfamilies for the benefit of children and families.
- Trustee Caroline Sanders made a presentation at the March 2022 conference of the British Society for Paediatric and Adolescent Gynaecology.
- We are also grateful to all professional supporters who included information about dsdfamilies in their conference presentations or indeed in their published work.

Achievements and Performance *(cont'd)*

c. Trustees also advocate for our families, children and young people by publishing in leading Journals. Ellie Magritte, Jo Williams and Caroline Sanders have worked on a paper around Informed Consent that has now been published in 'Hormone Research in Paediatrics'. It is a Free Access Commentary titled: Listening to Individuals with Differences in Sex Development or Intersex and Their Families: "Not Doing Surgery Does Not Mean Doing Nothing". Most of the work on this paper took place in the '21/'22 financial year. Ellie and Jo also contributed to an international evaluation of care and research, identifying areas of agreement and especially areas where more work is (sometimes urgently, e.g., provision of psychology and peer support) needed. A final draft was submitted towards the end of the financial year to an international science Journal, and we await details around publication.

d. We are often asked to give input on research projects (e.g., a UCL based project on 'intersex' and GP practices), proposals for media projects and documentaries (few which get beyond development stages because of the misunderstanding around DSD), or for general information from a wide range of people, from community mental health nurses to EDI staff from across the country. This year we also worked with a trainee psychologist at Liverpool Alderhey on an academic literature review on the current published evidence for children with health conditions and the efficacy of parenting classes/support groups aimed at parents.

e. We continue to have discussions with policymakers about the societal understanding of different sex development and the needs of people living with these conditions. Early in the financial year we had a meeting with NHS Scotland around this. Although the Scottish Government has been funding 'intersex initiatives' over the last 5 years, we were taking aback by the disconnect and absence of engagement between the Equalities and Health department. In May we had a lengthy meeting with Silvan Agius, Cabinet Expert of the European Commission, Cabinet of Commissioner for Equality Helena DALLI. We raised our concerns that EU policy and the research it is based on fails to address the real needs of children, families and young people with DSD and fails to reach them. Mr Agius took onboard our concerns. We have also been briefing members of the House of Lords and the Houses of Parliament.

f. 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 around £1500 this year. The Twitter feed can also be visited from our website homepage to maximise access. Current follower numbers are just under 2300, up from 1500 last year.

g. Towards the end of the financial year, we have moved our IT requirements to Pixelfish, a company providing web development services who we also worked with some 5 years ago, to prepare for redevelopment of our websites.

Finally, we are extremely grateful to Kate Davies as well as to our parent/patient representative, both founding trustees of dsdfamilies for their years of service. We look forward to working together in different ways 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.

Beneficiaries *(Cont'd)*

* Young people we are supporting through our youth project and our Instagram account 'YourPace.dsd'.

Other direct beneficiaries are attendees of events we speak at and attend: 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. It also gives us a chance to remind healthcare professionals of the lived experience of young people and families living with DSD and how they can be more supportive of our realities.

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'.

Finally, at the time of writing this report two globally important papers -including clinical practices guidelines- have just been published (respectively in European Journal of Endocrinology and Journal of the Endocrine Society) , both referencing dsdfamilies and our website for young people dsdteens as import support and information resources (Nordenström A e.a.. Pubertal induction and transition to adult sex hormone replacement in patients with congenital pituitary or gonadal reproductive hormone deficiency: an Endo-ERN clinical practice guideline. Eur J Endocrinol. 2022 Apr 21;186(6):G9-G49. Sinéad M McGlacken-Byrne, John C Achermann, Gerard S Conway, Management of a Girl With Delayed Puberty and Elevated Gonadotropins, Journal of the Endocrine Society, Volume 6, Issue 9, September 2022).

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

Last year we invested in strengthening our fundraising capabilities and this has successfully resulted in a diversification of our fundraising approaches. This year we built on this and prepared various Case for Support.

Financial Information

The financial position is as shown in the attached financial statements which comply with statutory requirements. The deficit for the period amounted to £(143) with income totalled £16,279.

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 £9,056.
Unrestricted reserves are in surplus by £8,156 as at the period end. We are all too aware of how the Cost-of-Living Crisis, and Covid before that, makes for a very challenging fundraising environment. The unrestricted funds over and above the reserves will enable us to commence confidently on the work to redevelop the youth focused dsdteens website whilst continuing to raise further funds for it.
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

We continue to punch well above our weight, achieving considerable impact in the UK and internationally.

This year's investment in fundraising capacity has led to the successful award of a 3-year grant with a total value of £45,000 to invest especially in our work with and for young people. This will lead initially to an evaluation of our work and resources (including the internationally renowned dsdteens.org website, our 20/21 youth work project and the BritSpag Notepad), followed by the creation of new peer support activities, and the (re)design and development of existing and new information resources.

Simultaneously our youth consultants will continue to develop the Instagram account YourPace.
We will be finalising the Notepad resource and the 'Diagnosis of a New Born' resources and disseminate with support from professionals organisations funding these resources (including BritSpag and Society for Endocrinology)

We will be finalising our sex development display with the British Science Museum as part of our awareness raising work. We will continue to take part in conferences and exhibitions, media and general debates.

We will continue to provide one-to-one and group peer support to families as well as explore how we can develop and deliver peer support training to expert parents (and young people).

We hope that in the next financial year the NHS will make progress on its planned Surgical Policy and its Service Specification Plans for DSD and we will continue to support this work. Indeed, ensuring peer support training is in place so local and regional medical teams have access to a trained pool of peer supporters is directly linked to this.

We remain 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. These 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 are 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.

TRUSTEES' REPORT

For the year ended 5 April 2022 (*cont'd*)

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 20 December 2022

Gareth Hopkins

Gareth Hopkins
Trustee

DSDFAMILIES

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 2022 which are set out on pages 15 to 19.

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

20 December 2022

DSDFAMILIES

RECEIPTS AND PAYMENTS ACCOUNT

For the year ended 4 April 2022

	Note	Unrestricted	Restricted	Total Funds Year ended 4 April 2022	Total Funds Year ended 4 April 2021
		£	£	£	£
Receipts					
Grants received	3	6,925	7,575	14,500	18,558
Donations		1,779	-	1,779	3,299
Total receipts		8,704	7,575	16,279	21,857
Payments					
Charitable activities	4	9,042	7,380	16,422	16,431
Total payments		9,042	7,380	16,422	16,431
Net (payments)/receipts		(338)	195	(143)	5,426
Transfers to/(from) funds		-	-	-	-
(Deficit)/surplus for the year		(338)	195	(143)	5,426

All income and expenditure derive from continuing activities.

The notes on pages 17 to 19 form part of these financial statements

DSDFAMILIES

STATEMENT OF BALANCES

At 4 April 2022

	Unrestricted	Restricted	Total 2022	Total 2021
	£	£	£	£
Bank and cash in hand				
Opening balances	8,494	705	9,199	3,773
(Deficit)/Surplus for the period	(338)	195	(143)	5,426
Closing balances	8,156	900	9,056	9,199
Creditors: Amounts falling due within one period				
Accruals			1,320	930

20 December 2022

Approved by the Trustees on..... and signed on their behalf by the following: -

Gareth Hopkins

.....

Gareth Hopkins

The notes on pages 17 to 19 form part of these financial statements

DSDFAMILIES

NOTES to the FINANCIAL STATEMENTS

For the year ended 4 April 2022

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 £500 (2021: £876).

3. Grant income

	Year ended 4 April 2022 £	Year ended 4 April 2021 £
Edinburgh Children's Hospital Charity	-	2,227
NSS	-	1,000
Society of Endocrinology	500	2,250
Comic Relief	-	9,995
Aviva	-	1,561
French Translations	-	1,065
Japanese Translations	-	500
Alder Hey Children's Charity	2,500	-
Leathersellers Co	1,000	-
Hugh Fraser Trust	2,000	-
The Sir Jules Thorn Charitable Trust	1,000	-
Albert Hunt SP	1,000	-
Brit Paediatric BritSpag	5,000	-
The Robertson Trust	1,000	-
Local Giving	500	-
	14,500	18,558

£7,575 (2021: £12,313) of the income relates to restricted funds.

4. Expenditure

	Year ended 4 April 2022 £	Year ended 4 April 2021 £
Charitable activities:		
Legal & professional fees	13,518	13,706
Printing & postage	104	-
Travel & subsistence	512	250
Internet & website	702	757
Telecoms	155	-
Support costs:		
Insurance	96	464
Bank charges	15	-
Governance costs:		
Independent examination	1,320	1,254
	16,422	16,431

£7,380 (2021: £11,608) of the expenditure relates to restricted funds.

5. Statement of funds

Unrestricted funds

	At 5 April 2021	Income	Expenditure	Transfers	**At 4 April 2022**
	£	£	£	£	£
Designated funds	4,000	-	(4,079)	79	-
General funds	4,494	8,704	(4,963)	(79)	8,156
	8,494	8,704	(9,042)	-	8,156

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 2021	Income	Expenditure	Transfers	**At 4 April 2022**
	£	£	£	£	£
Society of Endocrinology	-	500	(500)	-	-
Comic Relief	705	-	(705)	-	-
Robertson Trust	-	1,000	(1,000)	-	-
Local Giving	-	500	(500)	-	-
Leathersellers Company	-	1,000	(1,000)	-	-
Hugh Fraser Trust	-	2,000	(2,000)	-	-
Sir Jules Thorne Charitable Trust	-	1,000	(1,000)	-	-
Alder Hey Children's Hospital	-	175	(175)	-	-
Britspag	-	1,400	(500)	-	900
	705	7,575	(7,380)	-	900

Robertson Trust for work supporting young people with DSD (social media/ school brochure)
Local Giving for work supporting young people with DSD (social media/ school brochure)
Leathersellers Company for work supporting young people with DSD (social media/ school brochure)
Alder Hey Children's Hospital Charity grant to facilitate our work with families, including consultation and development of a brochure around nursery care for boys.
Hugh Fraser Trust for work supporting young people with DSD (social media/ school brochure)
Sir Jules Thorn Charitable Trust for work supporting young people with DSD (social media/ school brochure)
Youth Focused Activities for youth focused activities
British Society for Paediatric Adolescent Gynaecology (BritSpag) for production of a Notepad plus supporting materials to aid youth-oriented communication around DSD and sexual pleasure in the clinic.
Society for Endocrinology £500 Travel Grant
Comic Relief represents funding for the development a youth project for dsdfamilies.

DSDFAMILIES

England & Wales - Charity number 1169896

Accounts

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

DSDFAMILIES

REPORT AND FINANCIAL STATEMENTS

For the year ended 4 April 2021

DSDFAMILIES

REPORT AND FINANCIAL STATEMENTS

For the year ended 4 April 2021

Contents	**Pages**

DSDFAMILIES

TRUSTEES' REPORT

For the year ended 4 April 2021

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

TRUSTEES' REPORT

For the year ended 4 April 2021 (*cont'd*)

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 hyspospadias 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.

TRUSTEES' REPORT

For the year ended 4 April 2021 (*cont'd*)

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

7 June 2021

DSDFAMILIES

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

DSDFAMILIES

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:-

G Hopkins

.....

Gareth Hopkins

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

DSDFAMILIES

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."