dsdfamilies

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

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

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For the year ended 5 April 2025

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

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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)

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Shipston On Stour
Warwickshire
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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

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.

(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**