DOWN SYNDROME UK

England & Wales · Charity number 1184564

Details

Other names	DSUK, PADS, Positive About Down Syndrome
Status	Registered
Legal form	CIO
Registered	2019-07-24
Register	View on the Charity Commission register

Contact

Address	Down Syndrome UK 483 Green Lanes London N13 4BS
Phone	03301112121
Email	info@downsyndromeuk.co.uk
Website	www.downsyndromeuk.co.uk

Activities

Objects: TO RELIEF OF THOSE IN NEED BY REASON OF PARENTS AND FAMILIES OF CHILDREN AND YOUNG PEOPLE WITH DOWN SYNDROME IN THE UK THROUGH THE PROVISION OF A FORUM THAT PROVIDES ACCURATE UP TO DATE INFORMATION ON THE REALITIES OF LIVING WITH DOWN SYNDROME AND IS A CENTRAL HUB OF INFORMATION AND RESOURCES FOR THE CONDITION

Activities: Down Syndrome UK works to improve the lives of people with Down syndrome, and their families. We primarily work in maternity care and early years, providing resources, training and support to parents and professionals to empower those with Down syndrome to thrive and flourish.

Classification

- **How:** Provides Advocacy/advice/information
- **What:** Education/training, Disability, Human Rights/religious Or Racial Harmony/equality Or Diversity
- **Who:** Children/young People, People With Disabilities

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Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-08-31	£378,974	£361,055	-	-
2023-08-31	£317,265	£321,049	-	-
2022-08-31	£245,685	£253,097	-	-
2021-08-31	£191,972	£93,079	-	-
2020-08-31	£25,270	£5,104	-	-

Trustees

Name	Role	Appointed
Casimir Stephen Bower Knight	Chair	2022-01-12
CAROLINE WARREN		2019-07-24
Dr Ayesha Mahmud		2023-11-01
James Fox		2024-10-15
Richard Francis Baker		2023-02-15

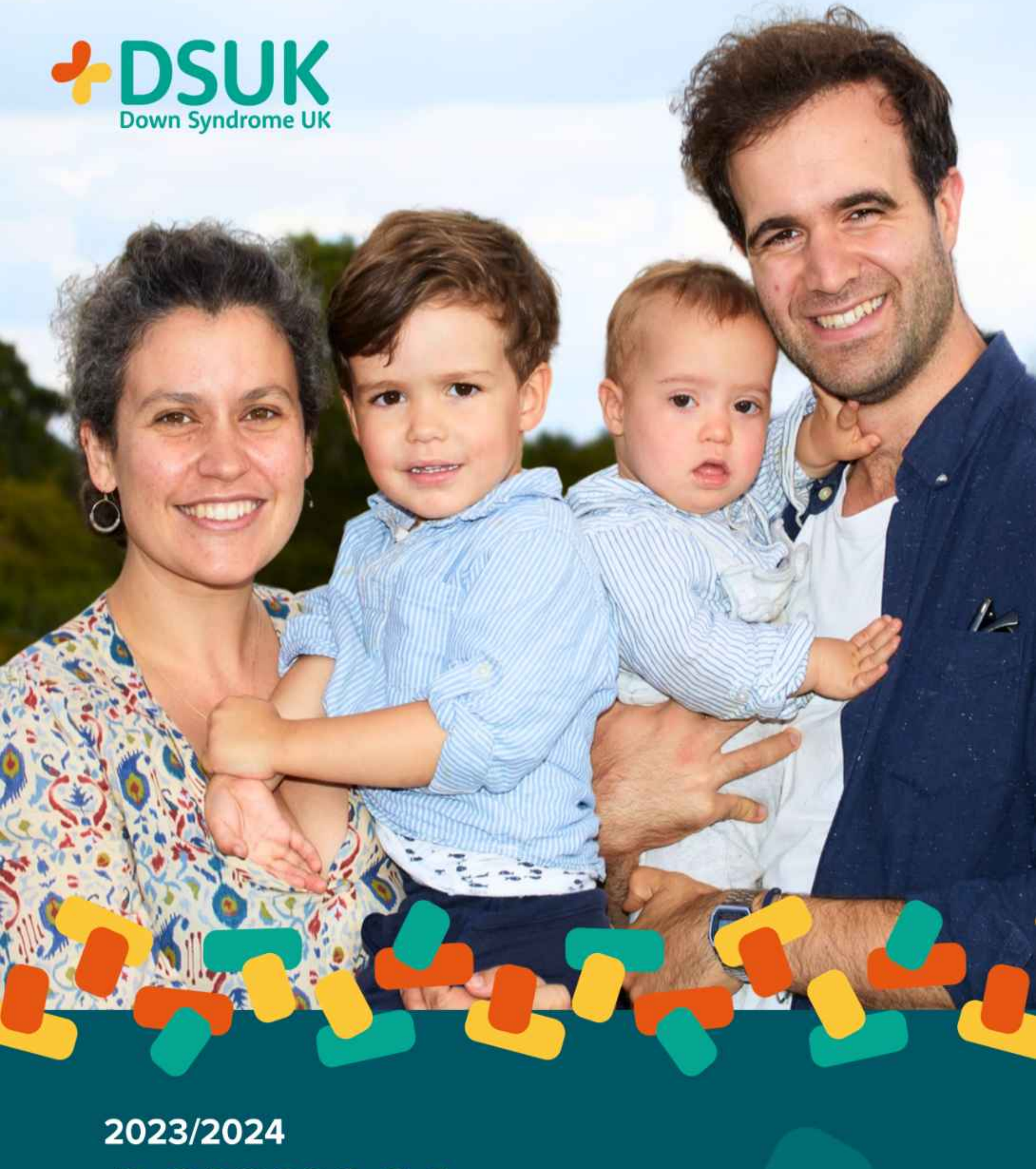
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DOWN SYNDROME UK

England & Wales - Charity number 1184564

Accounts

DSUK
Down Syndrome UK



2023/2024

ANNUAL REPORT

Annual report and accounts for the year ended 31 August 2024

Registered charity number: 1184564

Improving the lives of those with Down syndrome and their families.

Contents

	Page
Introduction	4
Our vision and mission	5
Our beliefs	6
Our values	7
Meet the team	8
Timeline of events	9
Achievements and performances for 2023-2024	10-16
Our year in numbers	18
Feedback from parents and professionals	19-20
Fundraising highlights	21-23
Funding and financials	24-25
Structure, governance and management	26-27
Statement of the trustees	28
Statement of financial activities	29-30
Balance sheet at 31 August 2024	31
Notes to the financial statements	32-38
Independent examiner's report	39

Introduction

Down Syndrome UK works to improve the lives of people with Down syndrome, and their families. Initially we concentrated on working in maternity care and the early years, providing resources, training and support to parents and professionals to empower those with Down syndrome to thrive and flourish. During the past year we have extended our offering and support to parents of children of primary school age.







Our vision

A world where everyone with Down syndrome lives their best life

Our mission

To empower parents & caregivers; to educate professionals; to enlighten the public; to lobby policy makers



At DSUK we believe...

We believe every expectant and new parent should receive the best possible care and support.

We believe the arrival of every baby with Down syndrome should be celebrated.

We believe every child with Down syndrome should be given every opportunity to flourish and thrive.

We believe every family should be cared about and empowered.

We believe every professional working with our members should be educated and supported.

We believe every student deserves the best education.

We believe every adult should have the opportunities and respect they deserve.

We believe everybody with Down syndrome should be included, valued and celebrated.

To enact these beliefs, we champion the lived experience by...

Empowering parents and caregivers with knowledge and support, by belonging to a strong community.

Educating professionals with evidence based insight and ongoing support.

Effecting change by lobbying policymakers with more informed policy guidance and knowledge-based solutions.

Enlightening the public with a contemporary and authentic view on everyday live with Down syndrome.



Our values

Real

We honestly and authentically reflect the experience of having a child or young person with Down syndrome, because we have the lived experience.

Collaborative

We create a nuturing environment for those we work with to enable relationships to flourish and for all involved to contribute positively towards our mission.

Practical

We provide meaningful support, training and information to empower families and professionals.

Challenging

We work hard to change & challenge outdated perceptions/attitudes.

'We are not afraid to address the elephant in the room.'

Impactful

Everything we do is with the intention to positively impact our families.

Meet the team

Trustees



Casimir Knight
Chair



Richard Baker
Treasurer



Caroline Warren



Jude Simpson



Dr Ayesha Mahmud

Staff



Nicola Enoch
CEO



Tracy Osborne-Foulkes
Operations Manager



Farah Cutter
Design Lead



Holli Sheahan
Marketing & Social Media Manager



Rachel Hristov
Community Fundraising Coordinator



Vicky Price-John
Administrator



Jennifer McGeeney
Training Coordinator



Kelly Field
Community Fundraising Coordinator



Jo Willcox
Executive Assistant to the CEO and Community Social Media and Marketing Coordinator



Dr Becky Baxter
Director of Education and Speech and Language Therapy

Freelancers



Lucience Cooper
Training Manager



Caroline Turner
Regional Maternity Manager



Sarah Ojar
Breastfeeding Supporter



Amy-Louise Roche
Parent Supporter



June Rogers MBE
Retired Children's Specialist Continence Nurse



Sue Aucutt
Counsellor



Sandra Redman
Early Years Trainer



Donna Murphy
Paediatric Physiotherapist



Maggie Hart
Primary School Trainer

Patrons



Lloyd Martin



Leon Harrop



Noah Matthews Matofsky



Heidi & James Carter



Christopher Eccleston

Timeline

2018
'New Parent' group launched

2019
'pants4school' toilet training advice launched

2019
'Great Expectations' for pregnant mums launched

2017
Positive about Down syndrome's (PADS) website launched



2019
Toilet training support aged 5+ launched

2020
Launched antenatal care pathway with St George's hospital

2020
'Preschool parents' group launched

2020
'PADS Cares' support group launched

2021
Toileting for c&yp ARM's / Hirschprung's & Down syndrome group launched

2020
Breastfeeding peer support group launched

2020
'PADS Dads' support group launched



2021
Secondary school age support launched

2021
PADS Party in the Park

2022
'16+ parents of young people/adults with Down syndrome' group launched

2022
'PADS Primary Parents' support group launched

2022
The Down Syndrome Act enacted

2022
Exhibited at Royal College of Midwives Conference





2022
Launched a national campaign, exhibited at Houses of Parliament 'You Can't Put Me Down-Syndrome'

2023
DLA support launched

2023
PADS Care parcels launched

2023
'PADS cares for grieving grandparents' group launched

2023
British Journal of Midwifery Conference

2023
DSUK's inaugural Celebratory Ball



2024
Twinkl monthly webinars launched

2024
DSUK's Early Years Development Programme launched

2024
DSUK's Primary Education Programme launched

2024
Royal College of Midwives collaboration of l-learning modules



Achievements and performances

We are immensely proud of all that we have achieved in this, our fifth year as a registered charity. Having initially focused on improving information and support in maternity care for expectant and new parents - and developing exceptional peer support and expert advice for parents of preschool-age children - we have, over the past year, built on our strong foundations by extending our services to support primary schools with children Down syndrome.

In January 2024, we were delighted to welcome Dr Becky Baxter to the team as Director of Education and Speech & Language. Becky is widely recognised as one of the UK's most experienced speech and language therapists. She has supported children from infancy through to adulthood, worked directly in education settings, and run early development and communication groups with local parent-led networks. Becky has been a tremendous asset to DSUK and our community, with her appointment already benefitting hundreds of families across the UK.

Early Years Development Programme

Becky had worked with DSUK on a consultancy basis since 2020 and had already begun developing our Early Years Development Programme, which we formally launched in summer 2024.

We were honoured to be invited by the online education provider Twinkl to deliver monthly webinars. Becky has led these since February 2024, and the feedback has been extremely positive - a fantastic opportunity for thousands of schools to access Down syndrome-specific expertise.

In May, we hosted a preschool education conference for families, which was well attended and received excellent feedback.

> ***From information events, physio advice, early development groups and really practical EHCP advice, we feel so lucky to have had access to such a broad range of information and support as well as the brilliant online community of parents.***
>
> **Parent, Rozie, September 2024**

Achievements and performances

In preparation for the new academic year in 2024, Becky developed our Primary Education Programme (PEP), an extensive resource available to primary schools across the UK through an annual subscription. PEP includes regular expert-led online support, a CPD-accredited training course for classroom staff, a training video for all school staff, and access to practical guidance on learning, health, and behaviour. Schools also receive resources to support curriculum access and to track individual pupil progress.

As a parent-led charity, we understand first-hand the challenges many families face in securing an Education, Health and Care Plan (EHCP) in England. In September, we launched a new service to support parents of children starting school and navigating the EHCP process.

To date, we have supported over 400 families through our closed Facebook groups, and our expert Justine is available to undertake individual EHCP draft reviews.

Primary Education Programme



Achievements and performances



Meeting families is always a highlight of our year. Our Celebratory Ball in October 2023 gave us the opportunity to connect and party with many families, and our regular PADS Party in the Park events in Buckinghamshire and Cheshire in September were also well attended.



As the charity has grown rapidly, we recognised the importance of pausing to reflect and plan ahead. We were pleased to be selected by the CAF Foundation for a Resilience Grant, which funded the part-time appointment of Jo Willcox as Executive Assistant to our CEO, a role she began in June 2024. At our summer team meeting, we began work on our Theory of Change and have continued to co-develop our strategic plans.

Another exciting development was the opportunity to work pro bono with leading creative agency Havas London to develop and refine our branding.



Achievements and performances

We continue to value the opportunity to share our work at exhibitions and conferences. This year, we were invited to exhibit and speak at the Institute of Health Visiting's SEND conference, where CEO Nicola and our toilet training expert June Rogers MBE presented a session on our award-nominated #pants4school programme. We were immensely proud when June received an award at the RCN Awards in recognition of her outstanding contribution to our work.



Our Annual Conference for DSUK's network of local support groups was well attended, featuring a diverse range of speakers including students from Star College, Prof Simon Gaisford from UCL, Claire Cookson of DFN Project Search, professionals from The Feeding Trust and members from groups sharing best practice on holiday clubs and group family time away.

Support Group Network





World Down Syndrome Day is always a highlight in our calendar. This year, Trustee Caroline and CEO Nicola - both founding members of the National Down Syndrome Policy Group - attended a reception at 10 Downing Street hosted by Dr Liam Fox.



Achievements and performances

Once again, we were blown away by the phenomenal support of our community, with families across the UK marking the day and raising over £60,000 to support DSUK's work. Our Sunflower Challenge continues to grow in popularity in early years settings, while families baked, ran, swam, rattled tins and raised both funds and awareness in wonderful ways. We are immensely grateful.



Research remains a key part of our work. We continued our collaboration with Professor Simon Gaisford of UCL on the use of probiotics to improve or eliminate symptoms of constipation. We also worked with the University of Warwick to publish findings from our study on maternity experiences, *Down syndrome in maternity care: Mothers' experiences of mental health support*. A key finding reinforced the need for specific training and support for maternity professionals: In the CQC's 2022 national Maternity Survey, 85% of women felt they had received adequate mental health support during pregnancy. Among mothers of a baby with Down syndrome in our survey, just 38.1% said the same.

This stark contrast underlines the urgency of our continued efforts in this area.

Since our inception, we've provided free resources to maternity units to signpost families to PADS. This year alone, we posted over 400 maternity packs to nearly 200 settings. We are proud to now supply every maternity unit in Wales and nearly two-thirds of the 231 in England. These resources are only possible thanks to our Regional Maternity Coordinators and our brilliant fundraisers.

We exhibited at the RCM Conference in Liverpool and presented at Midwifery Festivals in London, Birmingham, Manchester and Bristol. Following a conversation at the RCM Conference, we began collaborating with the RCM to co-produce a series of i-learning 'coffee modules' - the first of which launched in March 2024.



Achievements and performances

In March 2024, we also exhibited at the RCPCH Conference in Birmingham, where we received a warm welcome from paediatricians interested in the breadth of support we provide to families.

Training remains a priority, for both families and professionals. During the year, we continued to educate and empower parents through a range of sessions and resources. Our evening information-sharing sessions have grown in popularity - 37 sessions were delivered to nearly **1,500** parents, covering topics such as dysphagia and will writing. We also began working with two specialist charities: The Feeding Trust and Glue Ear Together, both offering highly valued support to our families.

We deliver training both in person and online to professionals across education and healthcare. Our lunchtime maternity webinars continue to grow, with Training Manager Lu hosting 9 sessions attended live by **675** professionals - with many more accessing recordings. In total, we delivered over 89 training sessions to almost **2,000** professionals.

Collaboration is central to our approach. We were proud to join the Maternal Mental Health Alliance, with CEO Nicola presenting at a members' meeting, and an MMHA representative delivering an insightful session at one of our maternity webinars.

We continue to work hard to fill gaps in information and services. During the year, we published several new resources, including Choosing a Primary School, The Royal College of Paediatrics and Child Health booklet for health visitors, A guide to breastfeeding a baby with Down syndrome, and the Breastfeeding Professionals Report 2024.

A known pressure point for families is the Disability Living Allowance application process. In response, we launched a new support service. Parent Lisa - a former DWP employee - now delivers regular online sessions guiding families through DLA applications and renewals.

Our Heart Buddies programme, coordinated by Rozie Haines, supported nearly 50 families this year whose child underwent heart surgery. We remain deeply thankful to Rozie for her care, compassion and tireless work.

Heart Buddies Support



Thank you

DSUK has created a thriving parent community through our PADS groups. We are grateful to the many families who give their time to support others - whether through being a member of our social media team or knitting bonding squares and hats for newborns. We are also deeply grateful to our Board of Trustees for generously giving their time and sharing their expertise to ensure we continue to work hard to ensure everyone with Down syndrome can live their best life.



"Thanks to PADS for everything you do to support us parents and children. From getting all the support and giving us access to resources to advice on how to navigate our journey including educating us on knowing our rights! Championing our children is easy. The hard bit is to convince the rest of the world and policy makers that our kids deserve the same basic rights and more!"

Parent, Anoushka



Thank you to PADS for the amazing support this year I joined the great expectations group at the start of the year and will forever be grateful. It's crazy to think this time last year I'd never heard of PADS and then the impact had this year, the feeling of not being alone, the education and the party in the park have really made this year so different. Thank you!

Parent, Samantha

December 2024

Our year in numbers

Positive About Down Syndrome Community

Welcomed:

69 babies through our pregnancy group

Number of parents supported:

104 Expectant

877 New

2,106 Preschool

1,157 Primary

41 Families through heart surgery

49 babies awaiting surgery

19 New Heart Buddies volunteers

Heart Buddies Support

5,165 Families and professionals accessing Pants4School toilet training programme

579 Preschool

657 Primary schools

704 Healthcare

Pants 4 School Programme

Number of professional members:

1,911 healthcare professionals trained through 89 events

Over the course of 9 webinars, we reached **675** healthcare professionals

Early Years Development Programme

EYDP pilot, 23 settings

35 members

Primary Education Programme

PEP pilot, 14 settings

25 members

Number of resources distributed:

199 maternity units with resources

434 maternity packs sent out

Information sharing session (ISS) topics: 37

1,545 people across all ISS's



Parents' views surveyed in 2024

97%

parents said that PADS was supportive

93%

parents said that PADS was non-judgemental

90%

parents said that PADS was inspiring

92%

agreed that PADS is their go to place for general support, the opportunity to ask questions and seek advice and support around Down syndrome.

Feedback from parents and professionals

"DSUK/PADS is aspirational, unapologetic, professional, fast-paced, productive, responsive, attractive, easy to access, well networked - Huge respect and gratitude for those at the helm".

Parent, PADS survey 2024

"You guys are great! Without PADS there are genuinely times where my son would have had poorer health outcomes, wouldn't have the EHCP he has, etc. The way the charity connects parents across the country is second to none".

Parent, PADS survey 2024

"Thank you - it's hard to comprehend how much PADS offers, with such a small team. You have made our journey since pregnancy, through heart surgery, to where we are now so much smoother and more well-informed than it might have been. When we found out the likely Down syndrome diagnosis early in pregnancy, I was frantically googling and searching to try and find something like PADS. And then I found you, and you are everything we need."

Parent, PADS survey 2024

"I attended this Information Sharing Session by DSUK/PADS last night and it was fantastic! Super informative, especially for a student like me who has not necessarily had much teaching around this topic. Loved how it focused on not just difficulties but the strengths of those with Down syndrome too."

Jodie, Final Year SaLT, 2024

"We, at Owls Nursery, have been delighted to receive all the lovely resources from DSUK in relation to the very informative training provided regarding Down Syndrome. The feelings and emotions cards, behaviour poster, sound cards and matching activities are all incorporated into daily nursery routines alongside other teaching resources to further support and develop strengths in all areas of the EYFS curriculum."

Owls Nursery, December 2024

Fundraising

We are incredibly grateful to everyone who has fundraised for Down Syndrome UK this year. From intrepid challenge participants to dedicated school communities and generous corporate partners, your phenomenal support has helped us provide vital resources and make a positive difference to families across the UK.

Community fundraising highlights

Our community of fundraisers never ceases to amaze and inspire. Highlights from this year include:



A team of five took on the **London Landmarks Half Marathon**, including parent supporter Amy-Louise and her husband Sean.



Ten thrill-seekers, including Aisha pictured here with her neice Mia, braved a skydive for **World Down Syndrome Day**.



The **Yorkshire Three Peaks Challenge** saw fundraisers tackle rugged terrain in support of DSUK.



Ava Batty, our youngest challenge event participant, raised over £1,800 – a remarkable achievement.



Toad Hall Nursery hosted a charity fun day, raising over £2,000



A team completed the **London Marathon** for DSUK.



Supporters also took part in the **Sunflower Challenge, Allstate's 5K fun run**, and other events across the year.



Rosemead Prep selected DSUK as their charity of the year, raising over £1,500 through events such as a fun run, Christmas raffle, and non-uniform days.

Charity Partners

We are fortunate to have been supported by several organisations this year:

Morgan Lewis, our charity partner of the year, raised £3,534 through various fundraising activities, with an additional £2,276 from a team member who took on the Hampton Court Half Marathon.

Delta Balustrades, Rosemead Prep and Toukon Academy selected DSUK as their charity of the year, with Toukon raising £1,000 in one event alone.

Cash 4 Clothes, collection company based in Essex, supported us in 2024 with monthly donations from clothing collections – with a minimum of £50 expected each month.

We continue to benefit from creative and heartfelt fundraising ideas. From **Colour-In Christmas Cards** to sponsored reads, every initiative plays a part in helping us support families and raise awareness.

To all who took part, donated, or cheered on from the sidelines – thank you. Your efforts bring us closer to our vision: ***a world where everyone with Down syndrome lives their best life.***

AVIVA

We were delighted to be nominated by Antony Adler of Adler Fairways and to win £2,000 at AVIVA's event in London in October.

We invested in approaching Trusts and Foundations, and were very grateful to the Souter Foundation, Albert Gubay, CAF Foundation and Compton Scorfen who each kindly supported our work.

Legacy

We were very grateful to Kathleen Aucutt, proud grandmother to actor Bethany Asher, who kindly left a generous donation to DSUK in her will.



Events and Campaigns



The **DSUK Celebratory Ball** in October was a fantastic evening, with over 80 people coming together to celebrate. We were joined by our Patrons Noah, James and Heidi. Highlights included a lively auction and a memorable group conga.



In March, a heartfelt **memorial football match** in honour of Ollie Baillie raised over £1,000, bringing people together in memory and support.

Our **Christmas Campaign** invited donations to support our PADS Care Parcels – a thoughtful initiative providing comfort and care for families during challenging times.



Funding and financials

Funding

The main risk to Down Syndrome UK would be a loss of funds due to our donors no longer being able to commit further funding.

Future Plans

DSUK is a dynamic and proactive Charity, led and managed by parents of children and young people with Down syndrome. Immersed in the community, we identify and respond to issues and challenges that our families face by providing information, resources, and support. We regularly connect with our families and undertake surveys to monitor our performance as well as to establish any needs we are not meeting. We also look to influence and impact national policy and practice by collaborating with relevant policymakers and providers.

During 2024/2025 we will continue to work hard to improve the maternity experiences of our parents and to ensure every baby with Down syndrome is welcomed into the world with the care and support they deserve. We will increase our reach to universities and maternity units to deliver training to future and current practitioners in maternity care and are looking to extend this to other medical professionals.

We aim to provide more services and support to the education professionals who work with our children in pre and primary school settings, as well as to our families of older children and young people.

DSUK continues to actively listen and respond to people with Down syndrome, their families and the professionals who work with them to work towards a more inclusive society.

Financial Review

The majority of our income is generated by the generosity of parents, friends and families undertaking a range of challenges and activities to support our work. Our income for the year was £378,974 (2023: £317,265) and we spent £361,055 (2023: £321,049) as set out in these accounts. We ended the year with cash at bank of £206,147 (2023: £158,272).

Reserves Policy

Reserves are required to cover an unexpected loss of income and to allow ongoing commitments to be met in these circumstances. Since the majority of our income is by gift from private donors, a sudden loss of this income would likely result in a need to close the Charity. To mitigate this risk, we aim to have at least six months of staff costs plus three months of variable service costs, at any one time.

Investment Policy

As a young Charity, we have not yet built substantial investments and, in these early years, the aim is to protect our funds. We will consider a more formal policy as we grow.

Risk management

The Trustees have conducted a review of the major risks to which the Charity is exposed. Where appropriate, systems or procedures have been established to mitigate the risks the Charity faces.

Structure, governance and management

Governing Document

Down Syndrome UK is registered with the Charity Commission of England and Wales, Registration Number 1184564. It is governed by a Trust Deed, dated 23 July 2019. The Charity was registered from 24 July 2019.

Approach to Governance

The Trustees appointed under the Trust Deed are entitled to hold office for a period of 2-4 years initially, with option to extend. Further Trustees may be appointed by invitation and resolution of the current Trustees.

The Trustees meet at least quarterly, to review existing projects and discuss new ones.

The Trustees provide governance to the Charity and assist the CEO and management to both develop the strategy and deliver it. The Trustees have a legal obligation to supervise and shepherd the Charity and have ultimate responsibility for the Charity and its activities. The Trustees aim to develop the Trustee board in order to increase its impact and diversity while supporting staff and the community.

The Trustees consider the Board of Trustees as comprising the key management personnel of the Charity in charge of directing and controlling the Charity and running and operating the Charity on a day to day basis.

Trustees are required to disclose all relevant interests to the board meetings and, in accordance with the Trust's policy, withdraw from decisions where a conflict of interest arises.

Structure, governance and management

Reference and administrative information

Trustees

The following served as Trustees during the year and up to the date of this report: -

C S B Knight (Chair)
J F Simpson
R F Baker (Treasurer)
C L Warren
Dr A Mahmood (appointed November 2023)

Trustee Recruitment and Training

The Trustees review and undertake recruitment and training as required.

Administrative information

Address	5 Hill Close Leamington Spa CV32 7RQ
Bankers	CAF Bank Limited 25 Kings Hill Avenue West Malling Kent ME19 4JQ
Independent Examiner	Khizer Kayani ACA 2 Coldharbour Lane Bushey London WD23 4NS

Statement of the Trustee's responsibilities for the financial statements

The Trustees are responsible for preparing the Trustees' Report and the financial statements in accordance with applicable law and regulations.
Charity law requires the trustees to prepare financial statements for each financial year in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards) and applicable law.
Under charity law, the Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charity and of its net outgoing resources for that period. In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgments and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material 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 to operate.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charity's transactions and disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by the Board of Trustees on 16 June 2025 and signed on their behalf by



Casimir Knight
Chair

Statement of financial activities

	Notes	Unrestricted Funds £	Restricted Funds £	Total 2024 £	*Total 2023 £*
INCOME AND ENDOWMENTS FROM:					
Donations		**230,874**	**-**	**230,874**	*198,519*
Gift aid		**30,343**	**-**	**30,343**	*17,044*
Grants		**13,000**	**32,963**	**45,963**	*40,280*
Interest		**316**	**-**	**316**	*275*
Charitable activities: Support Groups		**71,478**	**-**	**71,478**	*61,147*
Total income		**346,011**	**32,963**	**378,974**	***317,265***
EXPENDITURE ON:					
Costs of generating funds		**41,975**	**-**	**41,975**	*24,051*
Charitable activities	2	**298,513**	**20,567**	**319,080**	*296,998*
Total resources expended		**340,488**	**20,567**	**361,055**	*321,049*
NET INCOME/(EXPENDITURE)		**5,523**	**12,396**	**17,919**	*(3,784)*
Transfer between funds		**-**	**-**	**-**	**-**
NET MOVEMENT IN FUNDS		**5,523**	**12,396**	**17,919**	*(3,784)*
FUNDS AT 1 SEPTEMBER 2023 (2022)		**139,971**	7,000	**146,971**	*150,755*
FUNDS AT 31 AUGUST 2024 (2023)		**145,494**	**19,396**	**164,890**	*146,971*

The notes on pages 29 to 38 form part of the financial statements

Statement of financial activities

				COMPARATIVE YEAR
INCOME AND ENDOWMENTS FROM:				
Donations		*198,519*	*-*	*198,519*
Gift aid		*17,044*	*-*	*17,044*
Grants		*28,100*	*12,180*	*40,280*
Interest		*275*		*275*
Charitable activities: Support Groups		*61,147*	*-*	*61,147*
Total income		*305,085*	*12,180*	*317,265*
EXPENDITURE ON:				
Costs of generating funds		*24,051*	*-*	*24,051*
Charitable activities	2	*291,818*	*5,180*	*296,998*
Total resources expended		*315,869*	*5,180*	*321,049*
NET (EXPENDITURE)		*(10,784)*	*7,000*	*(3,784)*
Transfer between funds		*-*	*-*	*-*
NET MOVEMENT IN FUNDS		*(10,784)*	*7,000*	*(3,784)*
FUNDS AT 1 SEPTEMBER 2022		*150,755*	*-*	*150,755*
FUNDS AT 31 AUGUST 2023		*139,971*	*7,000*	*146,971*

The notes on pages 29 to 38 form part of the financial statements

Balance sheet at 31 August 2024

	Notes	2024		*2023*
		£	£	*£*
CURRENT ASSETS				
Stock		**1,675**		-
Debtors	4	**12,843**		*7,502*
Cash at bank		**206,147**		*158,272*
		220,665		*165,774*
CREDITORS: Due within one year		**(55,775)**		*(18,803)*
NET CURRENT ASSETS			**164,890**	*146,971*
NET ASSETS			**164,890**	*146,971*
REPRESENTED BY:				
Unrestricted funds			**145,494**	*139,971*
Restricted funds	5		**19,396**	*7,000*
			164,890	*146,971*

Approved by the Trustees on 16 June 2025 and signed on their behalf by:



C Knight
Chair

Notes to the financial statements for the year ended 31 August 2024

1. ACCOUNTING POLICIES

a) Basis of Preparation

The financial statements have been prepared in accordance with the Charities SORP (FRS102) applicable to charities preparing their financial statements in accordance with the Financial Reporting Standards applicable in the UK and Republic of Ireland and the Charities Act 2011 and UK Generally Accepted Practice as it applies from 1 January 2015.

The financial statements have been prepared to give a 'true and fair' view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a 'true and fair view'. This departure has involved following Accounting and Reporting by Charities preparing their financial statements in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) issued 16 July 2014 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 which has since been withdrawn.

Down Syndrome UK meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note.

Going Concern

In their assessment of going concern the Trustees have considered the significant cash balance and impact on the Charity of the current economic conditions.

Having regard to the above, the directors believe it appropriate to adopt the going concern basis of accounting in preparing the financial statements.

Notes to the financial statements (continued) for the year ended 31 August 2024

b) Critical accounting judgements and key sources of estimation uncertainty.

In the application of the Charity's accounting policies, which are described in note 1, Trustees are required to make judgements, estimates and assumptions about the carrying value of assets and liabilities that are not readily apparent from other sources. The estimation and underlying assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an on-going basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised if the revision affects only that period, or in the period of revision and future periods if the revision affects the current and future periods.

In the view of the Trustees, no assumptions concerning the future or estimation uncertainty affecting the assets and liabilities at the balance sheet date are likely to result in a material adjustment to their carrying amounts in the next financial year.

c) Financial Instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

Notes to the financial statements (continued) for the year ended 31 August 2024

1. ACCOUNTING POLICIES (continued)

d) Income

All incoming resources are included in the statement of financial activities when the charity is entitled to the income, the amount can be quantified with reasonable accuracy and receipt is probable.

The following specific policies are applied to particular categories of income:

- Voluntary income is received by way of grants, donations and gifts and is included in full in the Statement of Financial Activities when receivable. Grants, where entitlement is not conditional on the delivery of a specific performance by the charity, are recognised when the charity becomes unconditionally entitled to the grant.

- Investment income is included when receivable.

e) Expenditure

Expenditure is recognised on an accrual basis as each liability is incurred.

Costs of generating funds comprise the costs associated with fundraising activities.

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

f) Grants and Donations Payable

Grants are recognised in the accounts when a commitment has been made and there are no conditions to be met relating to the grant which remain in the control of the Charity.

Notes to the financial statements (continued) for the year ended 31 August 2024

g) Fund Accounting

Unrestricted funds held by the charity are those which can be used in accordance with the charitable objectives at the discretion of the Trustees.

Restricted funds are where specific conditions are imposed by the donor which restricts the use of unspent funds. The income is taken directly to the relevant restricted funds.

h) Taxation

The Trust is exempt from income tax on its charitable activities.

i) Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid after taking account of any trade discounts due.

j) Creditors and provisions

Creditors and provisions are recognised when the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably.

1. ACCOUNTING POLICIES (continued)

k) Cash

Cash is represented by cash in hand and deposits with financial institutions repayable without penalty on notice of not more than 24 hours.

2. CHARITABLE ACTIVITIES

	Unrestricted Funds £	Restricted Funds £	2024 Total £	*2023 Total £*
Administration and support costs:	**177,134**	**2,389**	**179,523**	*148,636*
Salary costs	-	-	-	-
Systems development and implementation	**22,650**	-	**22,650**	*28,995*
General operating costs	-	-	-	*8,627*
Advocacy and campaigning costs				
Charitable activities:	**98,729**		**116,907**	
Provision of services and resources including support groups, counselling, information sharing sessions, early development groups and physiotherapy		**18,178**		*110,740*
	298,513	**20,567**	**319,080**	*296,998*

2023 Comparatives

Administration and support costs:	*148,636*	-	*148,636*
Salary costs	-	-	-
Systems development and implementation	*28,995*	-	*28,995*
General operating costs	*8,627*	-	*8,627*
Advocacy and campaigning costs	*105,560*	-	*110,740*
Charitable activities:		*5,180*	

Notes to the financial statements (continued) for the year ended 31 August 2024

3. STAFF COSTS

	2024 Total £	*2023 Total £*
Wages and salaries Number of staff during the	179,523	*148,636*
year:		
Administration	9	*7*

No employee earned over £60,000 in either year.

4. DEBTORS

	2024 £	*2023 £*
Gift aid reclaim and prepayments	12,843	*7,502*

5. RESTRICTED FUNDS

		Movement in Funds			
	1 September 2023 £	Incoming Resources £	Resources Expended £	Transfers £	31 August 2024 £
Restricted Funds					
Awards for All	*4,500*	-	4,500	-	-
Albert Gubay	-	7,014	4,121	-	2,893
CAF resilience	-	19,445	5,189	-	14,256
RTR	-	6,504	4,257		2,247
Dorothy Paula Smith	*2,500*	-	2,500	-	-
	7,000	32,963	20,567	-	19,396

Notes to the financial statements (continued) for the year ended 31 August 2024

6. ANALYSIS OF NET ASSETS

	Cash at bank £	Current Assets £	Current Liabilities £	Liabilities after one year £	Total £
Restricted Funds					
Albert Gubay	46,379	-	(43,486)	-	2,893
CAF resilience	14,256	-	-	-	14,256
RTR	2,247	-	-	-	2,247
	62,882	-	(43,486)	-	19,396
Unrestricted Funds	143,265	14,518	(12,289)	-	145,494
	206,147	14,518	(55,775)	-	164,890

7. TRUSTEE EXPENSES

No Trustees claimed any expenses.

8. RELATED PARTY TRANSACTIONS

No related party transactions.

Independent examiner's report to the Trustees of Down Syndrome UK

I report on the financial statements of the Trust for the year ended 31 August 2024, which are set out on pages 30-36.

This report is made solely to the charity's trustees, as a body, in accordance with section 154 of the Charities Act 2011. My independent examiner's work has been undertaken so that I might state to the charity's trustees those matters I am required to state to them in an independent examiner's report and for no other purpose. To the fullest extent permitted by law, I do not accept or assume responsibility to anyone other than the charity, the charity's members as a body and the charity's trustees as a body for my independent examiner's work, for this report, or for the opinions I have formed.

Responsibilities and basis of report

As the charity trustees of the Trust you are responsible for the preparation of the financial statements in accordance with the requirements of the Charities Act 2011 ('the Act').
I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the 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 in respect of the Trust as required by section 130 of the Act; or
2. the financial statements do not accord with those records; or
3. the financial statements do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the financial statements give a 'true and fair view which is not a matter considered as part of an independent examination.

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.

Khizer Kayani ACA
2 Coldharbour Lane, Bushey, London, WD23 4NS

Date: 1 June 2025

DSUK
Down Syndrome UK

www.downsyndromeuk.co.uk

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Down Syndrome UK Registered Charity No. 1184564



DOWN SYNDROME UK

England & Wales - Charity number 1184564

Accounts

dsuk
down syndrome uk

Positive about Down syndrome



2022/2023

ANNUAL REPORT

Annual report and accounts for the year ended 31 August 2023

Registered charity number: 1184564


Improving the lives
of those with
Down syndrome
and their families.
dsuk
down syndrome uk

Contents

	Page
Our vision and mission	4
Introduction	5
Our beliefs	6
Our values	7
Meet the team	8
Timeline of events	9
Achievements and performances for 2023	10-18
Our year in numbers	19
Fundraising highlights	20-21
Feedback from parents and professionals	22-23
Funding	24
Financial review	25
Structure, governance and management	26
Reference and administrative information	27
Statement of the trustees	28
Statement of financial activities	29
Balance sheet at 31 August 2023	30
Notes to the financial statements	31-37
Independent examiner's report	38



Our vision

A world where everyone with Down Syndrome lives their best life

Our mission

To empower parents & caregivers; to educate professionals; to enlighten the public; to lobby policy makers

Introduction

The Board of Trustees present their Annual Report for the year ended 31 August 2023 under the Charities Act 2011, together with the financial statements for the year. The Board confirms that the latter comply with the requirements of the Charities Act 2011, the trust deed and the Charities SORP FRS 102 (2019).

Objects of the Charity

Relief of those in need by reason of parents and families of children and young people with Down syndrome in the UK through the provision of a forum that provides accurate up to date information on the realities of living with Down syndrome and is a central hub of information and resources for the condition.

The objects are exclusively for the public benefit to promote the effectiveness or efficiency of charities and to advance any other charitable purpose within the meaning of English Law.

The Trustees have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the Charity's purposes and aims, and when planning future activities. In particular, we consider how planned activities will contribute to the achievement of the objectives and aims.

Beliefs and aims for 2022

Down Syndrome UK works to improve the lives of people with Down syndrome, and their families. We primarily work in maternity care and the early years providing resources, training and support to parents and professionals to empower those with Down syndrome to thrive and flourish.

We believe every parent should receive the best possible care and support.

We believe the arrival of every baby with Down syndrome should be celebrated.

We believe every child with Down syndrome should be given every opportunity to flourish and thrive.

To enact these beliefs, we have 4 core aims which underpin our work:

1. Raising awareness of the modern reality of living with Down syndrome in the UK today.

2. Connecting parents of children with Down syndrome to experts, best practice, and each other.

3. Ensuring all children with Down syndrome have the best start in life, and access to the support to enable them to live their lives to the full.

4. Helping parents, the public, professionals, policy makers, and politicians to celebrate and support people with Down syndrome as valued and important members of society.

At DSUK we believe in...

Equality

The discrimination around Down syndrome must be challenged and addressed, so that people with Down syndrome and their families, should be treated with the same respect and care as anybody else.

Inclusion

Every child with Down syndrome should have the opportunity to be fully included in mainstream settings – both in and outside of education.

Research

To improve the lives of people with Down syndrome.





Our values

Real

We honestly and authentically reflect the experience of having a child or young person with Down Syndrome, because we have the lived experience.

Collaborative

We create a nuturing environment for those we work with to enable relationships to flourish and for all involved to contribute positively towards our mission.

Practical

We provide meaningful support, training and information to empower families and professionals.

Challenging

We work hard to change & challenge outdated perceptions/attitudes.

'We are not afraid to address the elephant in the room.'

Impactful

Everything we do is with the intention to positively impact our families.

Meet the team

Trustees



Casimir Knight
Chair



Richard Baker
Treasurer



Caroline Warren



Jude Simpson

Staff



Nicola Enoch
CEO



Tracy Osbourne-Foulkes
Operations Manager



Farah Cutter
Design Lead



Holli Sheahan
Marketing & Social Media Manager



Rachel Hristov
Community Fundraising Coordinator



Vicky Price-John
Administrator



Jennifer McGeeney
Training Coordinator

Freelancers



Lucience Cooper
Training Manager



Caroline Turner
Regional Maternity Manager



Sarah Ojar
Breastfeeding Supporter



Amy-Louise Roche
Parent Supporter



June Rogers MBE
Children's Specialist Continence Nurse



Sue Aucutt
Counsellor



Sandra Redman
Early Years Trainer



Dr Becky Baxter
Speech and Language Therapist



Donna Murphy
Paediatric Physiotherapist



Maggie Hart
Primary School Trainer

Patrons



Leon Harrop



Noah Matthews Matofsky



Heidi & James Carter



Christopher Eccleston





Timeline

2019
January
'pants4school' toilet training advice launched

2018
December
'New Parent' group launched

2019
December
'Great Expectations' for pregnant mums launched





2017
September
PADS Website Launched



2019
October
Toilet training support aged 5+ launched



2020
April
'Preschool parents' group launched



2020
August
'PADS Dads' support group launched

2020
May
'PADS Cares' support group launched

2020
December
Breastfeeding peer support group launched



2022
July
'16+ parents of young people/adults with Down syndrome' group launched

2022
April
The Down Syndrome Act enacted

2020
December
Launch antenatal care pathway with St George's hospital

2022
September
'PADS Primary Parents' support group launched



2021
September
PADS Party in the Park



2021
January
Toileting for c&yp ARM's / Hirschprung's & Down syndrome group launched

2021
February
Secondary school age support launched

2022
October
Exhibited at Royal College of Midwives Conference

2023
March
British Journal of Midwifery Conference

2022
October
Launched a national campaign, exhibited at Houses of Parliament 'You Can't Put Me Down-Syndrome'

2024
March
Royal College of Midwives collaboration to launch e-learning modules

2023
August
PADS Care parcels launched

2023
May
'PADS cares for grieving grandparents' group launched





Achievements and performances for 2023

In our fourth year as a registered charity, DSUK has grown significantly in income and activities, expanding our resources, support, outreach, and engagement.

Since inception, we've provided lived experiences to expectant and new parents via our website, distributing contemporary literature to maternity staff. We've enhanced our website and published #NobodyToldMe: the truth about Down syndrome, sent to expectant and new parents. We have welcomed more than 300 babies through our Great Expectations group and supported over 1,500 new parents.

DSUK is immensely proud of the wide range of resources and services that we offer. Initially focused on expectant and new parents, in response to demand, we extended our support to families with children in primary schools. Experienced volunteers and experts moderate our extensive range of closed Facebook groups, providing peer support and helping to identify issues needing attention.

We appointed Tracy Osborne-Foulkes as Operations Manager to support our CEO. Tracy had worked with us as a Regional Maternity Coordinator and demonstrated her excellent organisational skills. We further strengthened the team by appointing Jennifer McGeeney to provide admin support to our Training Manager. Amy Roche joined as our Parent Supporter, providing invaluable support to expectant and new parents. We were delighted to welcome Noah Matthews Matofsky, an inspiring actor, as a Patron.



Achievements and performances for 2023

Our online Early Development Groups and Physiotherapy Support provide essential information and support. These initiatives, developed and led by experienced experts, empower families with knowledge and practical advice, promoting early development and the opportunity for our children to flourish and thrive.

In September, we were excited to host more family get-togethers at our fabulous PADS Parties in the Park, with sessions in Cheshire and Buckinghamshire. Once again, Patrons Heidi and James joined us and enjoyed meeting over 120 families! Our new merchandise was a hit, and provided wonderful photo opportunities.

We were delighted to be finalists at the Nursing Times Awards for our highly impactful #Pants4School initiative, with over 4,500 parents and professionals accessing our free support. Our toilet training boot camps remain very popular, with many families from across the UK attending sessions.

We continue our pioneering work around educating and empowering parents and professionals about constipation, a condition that affects many of our preschool children.

In August 2023, we launched PADS Care Parcels for children with extended hospital stays, containing carefully curated gifts, treats and practical items as recommended by our parents.

DSUK values the importance of supporting mental health and wellbeing. Our weekly online yoga TomFit sessions promote holistic family wellbeing. Since 2020, we've provided independent professional counselling to individuals and groups, including bereaved parents.

Our Grandparents group remains active, with new support offered for bereaved grandparents, kindly funded by Freddie's Wishes. To better support dads, we launched a WhatsApp group and commissioned podcasts featuring their experiences.



Finalists at the Nursing Times Awards.



PADS Care Parcels for children with extended hospital stays.

Achievements and performances for 2023

We are committed to supporting our mothers who wish to breastfeed with peer support information and guidance. Our Breastfeeding Supporter, Sarah Ojar, has developed a breastfeeding training module for professionals and regularly delivers online sessions to expectant and new parents.

On World Down Syndrome Day, our CEO Nicola Enoch published an article with the OECD, spoke at the British Journal of Midwifery's Annual Conference, attended a celebratory event at the Houses of Parliament with our friends from the National Down Syndrome Policy Group, and the Charity Film Awards at Leicester Square as a finalist.

In June, DSUK exhibited at UKIO's Congress in Liverpool, where Nicola and patron Heidi were guest speakers. We also presented at the Virtual International Midwifery Conference – extending our reach beyond the UK!



Achievements and performances for 2023



Our advocacy and campaigning work included a photography exhibition at the Houses of Parliament. The campaign – You Can't Put Me Down Syndrome – was produced in collaboration with VMLY&R and attracted significant media attention and support from over 60 Parliamentarians.





Achievements and performances for 2023



Training Manager Lucienne Cooper delivered training to over 2,200 medical professionals and students. Our powerful training module, based on our research 'Sharing the News – the Maternity Experience' of 1,410 women, highlights best practices, the importance and impact of language and attitudes, how to share the news that a baby has/may have Down syndrome and having a contemporary understanding of Down syndrome.



We actively support and promote research, with ongoing projects with the University of Hertfordshire on tube feeding, the maternity experience with the University of Warwick and probiotics to alleviate constipation with UCL. We presented again at the Down Syndrome Research Forum and exhibited at the Royal College of Midwives Research Forum in Birmingham.

We expanded our training for education professionals, publishing resources for parents and educators. Our collaboration with Twinkl extends our reach to 14 million users.

We delivered training sessions on over 20 topics, including will writing, guardianship, sleep apnoea, dysphagia, EHCPs, early toileting skills, audiology, weaning, positive behaviour and early communication skills.

We continue to invest time, money and resources in collaborating with maternity units across the UK. Our Regional Maternity Coordinators doubled our reach from 70 to 150 maternity units, ensuring a supply of PADS resources is available to expectant and new parents.



Achievements and performances for 2023

We attended maternity festivals and events, including exhibiting at the Royal College of Midwives conference in Cardiff, where maternity professionals were delighted to learn about PADS's services and resources. Wanting to extend our reach, we once again exhibited at the Primary Care Event at the NEC, where we engaged with GPs, health visitors, continence and school nurses.



At DSUK, we have always valued and appreciated the fantastic work local regional groups undertake nationwide, and we work hard to dovetail and complement their work. Aware that many groups do not have the capacity or resources to undertake the breadth of services our families benefit from, we identify where knowledge, support and information are lacking and develop resources and ongoing support accordingly.

Since 2015, Nicola has been organising and hosting an annual networking event to which the 100+ local groups are invited. In October 2022, the network conference was once again well attended, with both external speakers and those from within the community speaking on a range of topics.

We enjoyed another successful fundraising year, with fantastic support from our community with various initiatives, including the PADS Sunflower Challenge aimed at nurseries and early years settings and an online draw for signed copies of George Webster's book This is me. Dragon's Den favourites, Stand Out Socks collaborated with us to create a PADS sock that stood out and sold out! We are grateful to the National Lottery for a grant from their Reaching Communities grant, to The Scorfen Trust and Dorothy Pamela Smith CIO for their generous support.



Achievements and performances for 2023



DSUK has created an amazing community through our PADS parent facing groups, and we are always thrilled at how many families give of their time to support others. We appreciate the fantastic work of our volunteers, from social media support to knitting hats and bonding squares for new babies.

PADS Heart Buddies supported more than 60 families whose child underwent heart surgery and we have more than 40 awaiting surgery—special thanks to Rozie Haines, who, since March 2021, has kindly coordinated PADS Heart Buddies.

We are immensely grateful for the community's phenomenal support, which enables DSUK to remain a thriving, proactive and practical charity, working hard to ensure people with Down syndrome can live their best lives.









They made contact with us straight away and added us into the New Parent group. It was the first time since Down Syndrome was first mentioned to us immediately after birth that we didn't feel petrified. We received the loveliest pack in the post with lots of resources to help us on this journey and they have been supporting us as a family ever since.

We have been welcomed into an online community that is just so supportive and have also been lucky enough to meet a lot of other families in person at the yearly family days both in the North and South of the country. I honestly don't know where we would be without them!

The MacDonald Family



Massive thanks to Nicola and everyone at PADS - I honestly don't know where I'd be without PEGS and POPS helping me to support Sam, this is a lovely safe place to ask all the questions (or search for them) and the endless support whenever required. The work you all do is amazing!

Laura, mum to Sam

9,129
parents and professionals were supported by Down Syndrome UK in 2022-2023

Our year in numbers

We supported:

97 Expectant women

887 New parents

1,699 Preschool parents

Positive about Down syndrome

62 Families through heart surgery

42 babies awaiting surgery

101 Heart Buddies Volunteer's

Heart Buddies

4,626 Families and professionals accessing Pants4School

pants4school

830 Preschool

648 Primary schools

137 Secondary schools & 16+

st&r support, training & resources

Number of professional members:

dsuk down syndrome uk

445 Professionals in preschool settings

543 Professionals in primary schools

Number of professionals trained:

567 Maternity professionals

2,227 Health care professionals and students accessed training through 69 events

the DSUK network

110 Regional support groups

174 Superstar volunteers

Fundraising highlights from the past 12 months



Teddy's Trundle

Charli, a PADS parent, organised Teddy's Trundle. A walk from Peel to Douglas on a 21km adventure ending at Douglas Prom. They raised an incredible £4,921.



Sky Dive

We had seven thrill-seeking supporters take to the skies for a sky dive and collectively raised an incredible £17,361.



Cardiff Half Marathon

A team of 5 from UKLS took on the Cardiff Half Marathon, raising £1,762 in support of PADS.



Appalachian Trail

Paul Hills, one of our grandparents, hiked the Appalachian trail. He had to cut his adventure short but returned a second time to see how much further he could get. His fundraiser raised £500.



1,000,000 Steps

Gilly Wynne set a challenge of 1,000,000 steps in 3 months and raised £1,551. She said, "I wanted to support a charity that has been an absolute lifesaver for a friend of mine."



English Channel Swim

Nicole Murray is a wonderful Speech and Language Therapist who has worked with DSUK for 3 years. Nicole was part of a 4-person relay team, swimming the English Channel and she raised an incredible £2,380 for us.

Fundraising highlights from the past 12 months



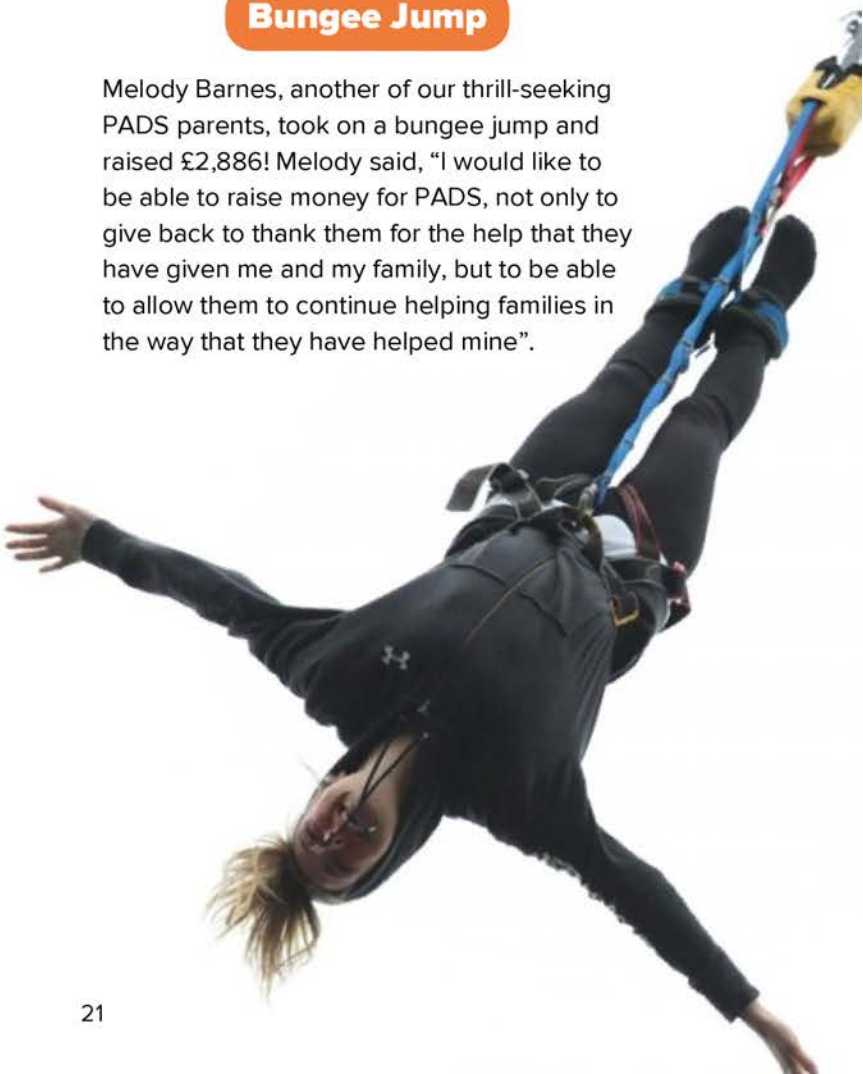
Tough Mudder

The operations team from Five Guys took on a Tough Mudder to support their training manager Ryan, wife Sarah and their son Conall who has Down syndrome. Ryan said, "Our son Conall was blessed with an extra chromosome, and he is such a special, inspirational boy. We will work tirelessly to raise positive awareness and make the world see that children born with Down syndrome deserve equality! Conall's smile lights up the room and he adores his big sister more than anyone! One of the captions for Down syndrome is 'theluckyfew' and we genuinely believe that we are the luckiest parents in the world to have Orlaith and Conall." They raised £2,184.



Bungee Jump

Melody Barnes, another of our thrill-seeking PADS parents, took on a bungee jump and raised £2,886! Melody said, "I would like to be able to raise money for PADS, not only to give back to thank them for the help that they have given me and my family, but to be able to allow them to continue helping families in the way that they have helped mine".



Feedback from parents and professionals

PADS has been an absolute lifeline. Without it, I don't know how we would have coped. From feeling so scared and alone, we can now see an exciting positive future for our son, and know that PADS is there to hold our hands all the way.
Sarah, mum to Charlie.

Nobody gets it unless you're actually in the same situation... so it's been amazing to be able to meet and chat with other mums who have the same concerns and worries, and to be able to see and hear from those further down the line to see that everything's going to be ok.
Beth, mum to Emily.

I enjoyed the new perspective given on Down syndrome and how little changes like language can have a big significance on families and how they view and feel about their babies. I feel more equipped to signpost parents to get information and support as well as supporting breastfeeding.
Midwifery student at University of Leicester.

Massive thanks to Nicola and everyone at PADS - I honestly don't know where I'd be without PEGS and POPS helping me to support Sam, this is a lovely safe place to ask all the questions (or search for them) and the endless support whenever required. The work you all do is amazing!
Laura, mum to Sam.

This evening I opened a package from the amazing team at Positive about Down syndrome. It made me cry! This is exactly what parents need in the first few hours after diagnosis, not 'we are sorry' and then nothing until you see your consultant. This information / education is so valuable.
Sarah, mum to Ayda.

Huge thanks to PADS for your eye screening session. I went into our opthamology appointment ready and armed. The optometrist listened to my concerns and was very impressed with my knowledge. I feel so relieved and grateful to this support group for all of the knowledge sharing.
Laura, mum to Lucy.



Parents' views

90%

of parents surveyed in 2023, advised DSUK is their go to place for support

95%

of parents trust the information they receive from DSUK

89%

of parents advised DSUK has helped them to feel empowered to support their child

Funding

The main risk to Down Syndrome UK would be a loss of funds due to our donors' inability to commit further funding.

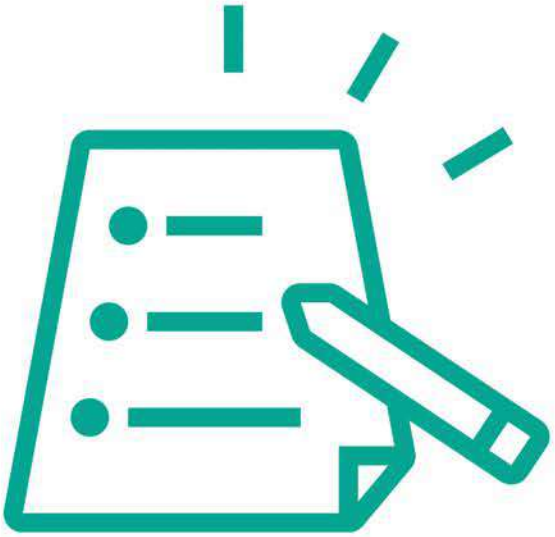
Future Plans

DSUK is a dynamic and proactive Charity led and managed by parents of children and young people with Down syndrome. Immersed in the community, we identify and respond to issues and challenges our families face by providing the necessary information, resources, and support. We regularly connect with our families and undertake surveys to monitor our performance as well as to establish any needs we are not meeting. We also look to influence and impact national policy and practice by collaborating with relevant policymakers and providers.

During 2023/2024 we will continue to work hard to improve the maternity experiences of our parents and to ensure every baby with Down syndrome is welcomed into the world with the care and support they deserve. We will increase our reach to universities and maternity units to deliver training to future and current practitioners in maternity care and are looking to extend this to other medical professionals.

We continue to aim to provide more services and support to the education professionals who work with our children in pre and primary school settings.

DSUK continues to actively listen and respond to people with Down syndrome, their families and the professionals who work with them to work towards a more inclusive society.



Financial review

The majority of our income is generated by the generosity of parents, friends and families undertaking a range of challenges and activities to support our work. Our income for the year was £317,265 (2022:£245,685) and we spent £321,049 (2022:£253,097) as set out in these accounts. We ended the year with cash at bank of £158,272 (2022: £151,678).

Reserves Policy

Reserves are required to cover an unexpected loss of income and allow ongoing commitments to be met in these circumstances. Since the majority of our income is from gifts from private donors, a sudden loss of this income would likely result in a need to close the Charity. To mitigate this risk, we aim to have at least six months of staff costs plus three months of variable service costs, at any one time.



Investment Policy

As a young Charity, we have not yet built substantial investments and, in these early years, the aim is to protect our funds. We will consider a more formal policy as we grow.

Risk Management

The Trustees have conducted a review of the major risks to which the Charity is exposed. Where appropriate, systems or procedures have been established to mitigate the risks the Charity faces.

Structure, governance and management

Governing Document

Down Syndrome UK is registered with the Charity Commission of England and Wales, Registration Number 1184564. It is governed by a Trust Deed, dated 23 July 2019. The Charity was registered from 24 July 2019.

Approach to Governance

The Trustees appointed under the Trust Deed are entitled to hold office for a period of 2-4 years initially, with option to extend. Further Trustees may be appointed by invitation and resolution of the current Trustees.

The Trustees meet at least quarterly, to review existing projects and discuss new ones.

The Trustees provide governance to the Charity and assist the CEO and management to both develop the strategy and deliver it. The Trustees have a legal obligation to supervise and shepherd the Charity and have ultimate responsibility for the Charity and its activities. The Trustees aim to develop the Trustee board in order to increase its impact and diversity while supporting staff and the community.

The Trustees consider themselves as the key personnel of the Charity in charge of directing and controlling the Charity.

Trustees are required to disclose all relevant interests to the board meetings and, in accordance with the Trust's policy, withdraw from decisions where a conflict of interest arises.



Reference and administrative information

Trustees

The following served as Trustees during the year: -

C S B Knight (Chair)
N Enoch (resigned April 2023)
J F Simpson
R F Baker (Treasurer)
C L Warren

Trustee Recruitment and Training

The Trustees review and undertake recruitment and training as required.

Administrative information

Address	5 Hill Close Leamington Spa CV32 7RQ
Bankers	CAF Bank Limited 25 Kings Hill Avenue West Malling Kent ME19 4JQ
Independent Examiner	Khizer Kayani ACA 2 Coldharbour Lane Bushey London WD23 4NS

Statement of the Trustee's responsibilities for the financial statements

The Trustees are responsible for preparing the Trustees' Report and the financial statements in accordance with applicable law and regulations.

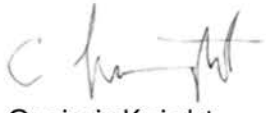
Charity law requires the trustees to prepare financial statements for each financial year in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards) and applicable law.

Under charity law the Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charity and of its net outgoing resources for that period. In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgments and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material 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 to operate.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charity's transactions and disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by the Board of Trustees on 21 June 2024 and signed on their behalf by



Casimir Knight
Chair

Statement of financial activities

	Notes	Unrestricted Funds £	Restricted Funds £	Total 2023 £	*Total 2022 £*
INCOME AND ENDOWMENTS FROM:					
Donations		**198,519**	**-**	**198,519**	*176,363*
Gift aid		**17,044**	**-**	**17,044**	*3,942*
Grants		**28,100**	**12,180**	**40,280**	*-*
Interest		**275**	**-**	**275**	*-*
Charitable activities: Support Groups		**61,147**	**-**	**61,147**	*65,380*
Total income		**305,085**	**12,180**	**317,265**	*245,685*
EXPENDITURE ON:					
Costs of generating funds		**24,051**	**-**	**24,051**	*8,244*
Charitable activities	2	**291,818**	**5,180**	**296,998**	*244,853*
Total resources expended		**315,869**	**5,180**	**321,049**	*253,097*
NET (EXPENDITURE)		**(10,784)**	**7,000**	**(3,784)**	*(7,412)*
Transfer between funds		**-**	**-**	**-**	*-*
NET MOVEMENT IN FUNDS		**(10,784)**	**7,000**	**(3,784)**	*(7,412)*
FUNDS AT 1 SEPTEMBER 2022 (2021)		**150,755**	**-**	**150,755**	*158,167*
FUNDS AT 31 AUGUST 2023 (2022)		**139,971**	**7,000**	**146,971**	*150,755*

COMPARATIVE YEAR

INCOME AND ENDOWMENTS FROM:				
Donations		*176,363*	*-*	*176,363*
Gift aid		*3,942*	*-*	*3,942*
Charitable activities: Support Groups		*65,380*	*-*	*65,380*
Total income		*245,685*	*-*	*245,685*
EXPENDITURE ON:				
Costs of generating funds		*8,244*	*-*	*662*
Charitable activities	2	*244,853*	*-*	*52,021*
Total resources expended		*253,097*	*-*	*52,683*
NET (EXPENDITURE)		*(7,412)*	*-*	*(55,696)*
Transfer between funds		*-*	*-*	*-*
NET MOVEMENT IN FUNDS		*(7,412)*	*-*	*(55,696)*
FUNDS AT 1 SEPTEMBER 2021		*158,167*	*-*	*337,315*
FUNDS AT 31 AUGUST 2022		*150,755*	*-*	*281,619*

The notes on pages 31 to 37 form part of the financial statements

Balance sheet at 31 August 2023

	Notes	2023 £	£	2022 £
CURRENT ASSETS				
Debtors	4	7,502		9,953
Cash at bank		158,272		151,678
		165,774		161,631
CREDITORS: Due within one year		(18,803)		(10,876)
NET CURRENT ASSETS			146,971	150,755
NET ASSETS			146,971	150,755
REPRESENTED BY:				
Unrestricted funds			139,971	150,755
Restricted funds	5		7,000	-
			146,971	150,755

Approved by the Trustees on 21 June 2024
and signed on their behalf by:



C Knight
Chair

The notes on pages 31 to 37 form part of the financial statements

Notes to the financial statements for the year ended 31 August 2023

1. ACCOUNTING POLICIES

a) Basis of Preparation

The financial statements have been prepared in accordance with the Charities SORP (FRS102) applicable to charities preparing their financial statements in accordance with the Financial Reporting Standards applicable in the UK and Republic of Ireland and the Charities Act 2011 and UK Generally Accepted Practice as it applies from 1 January 2015.

The financial statements have been prepared to give a 'true and fair' view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a 'true and fair view'. This departure has involved following Accounting and Reporting by Charities preparing their financial statements in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) issued 16 July 2014 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 which has since been withdrawn.

Down Syndrome UK meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accountin policy note.

Going Concern

In their assessment of going concern the Trustees have considered the significant cash balance and impact on the Charity of the current economic conditions.

Having regard to the above, the directors believe it appropriate to adopt the going concern basis of accounting in preparing the financial statements.

Notes to the financial statements (continued) for the year ended 31 August 2023

b) Critical accounting judgements and key sources of estimation uncertainty.

In the application of the Charity's accounting policies, which are described in note 1, Trustees are required to make judgements, estimates and assumptions about the carrying value of assets and liabilities that are not readily apparent from other sources. The estimation and underlying assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an on-going basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised if the revision affects only that period, or in the period of revision and future periods if the revision affects the current and future periods.

In the view of the Trustees, no assumptions concerning the future or estimation uncertainty affecting the assets and liabilities at the balance sheet date are likely to result in a material adjustment to their carrying amounts in the next financial year.

c) Financial Instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

Notes to the financial statements (continued) for the year ended 31 August 2023

1. ACCOUNTING POLICIES (continued)

d) Income

All incoming resources are included in the statement of financial activities when the charity is entitled to the income, the amount can be quantified with reasonable accuracy and receipt is probable.

The following specific policies are applied to particular categories of income:

- Voluntary income is received by way of grants, donations and gifts and is included in full in the Statement of Financial Activities when receivable. Grants, where entitlement is not conditional on the delivery of a specific performance by the charity, are recognised when the charity becomes unconditionally entitled to the grant.

- Investment income is included when receivable.

e) Expenditure

Expenditure is recognised on an accrual basis as each liability is incurred.

Costs of generating funds comprise the costs associated with fundraising activities.

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

f) Grants and Donations Payable

Grants are recognised in the accounts when a commitment has been made and there are no conditions to be met relating to the grant which remain in the control of the Charity.

Notes to the financial statements (continued) for the year ended 31 August 2023

g) Fund Accounting

Unrestricted funds held by the charity are those which can be used in accordance with the charitable objectives at the discretion of the Trustees.

Restricted funds are where specific conditions are imposed by the donor which restricts the use of unspent funds. The income is taken directly to the relevant restricted funds.

h) Taxation

The Trust is exempt from income tax on its charitable activities.

i) Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid after taking account of any trade discounts due.

j) Creditors and provisions

Creditors and provisions are recognised when the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably.

Notes to the financial statements (continued) for the year ended 31 August 2023

1. ACCOUNTING POLICIES (continued)

k) Cash

Cash is represented by cash in hand and deposits with financial institutions repayable without penalty on notice of not more than 24 hours.

2. CHARITABLE ACTIVITIES

	Unrestricted Funds £	Restricted Funds £	2023 Total £	*2022 Total £*
Administration and support costs:				
Salary costs	**148,636**	**-**	**148,636**	*95,324*
Systems development and implementation	**-**	**-**	**-**	*28,313*
General operating costs	**28,995**	**-**	**28,995**	*41,862*
Advocacy and campaigning costs	**8,627**	**-**	**8,627**	
Charitable activities:				
Provision of services and resources including support groups, counselling, information sharing sessions, early development groups and physiotherapy	**105,560**	**5,180**	**110,740**	*79,354*
	291,818	**5,180**	**296,998**	*244,853*
2022 Comparatives				
Administration and support costs:				
Salary costs	*95,324*	-	*95,324*	
Systems development and implementation	*28,313*	-	*28,313*	
General operating costs	*41,862*	-	*41,862*	
Charitable activities:				
Provision of services and resources including support groups, counselling, information sharing sessions, early development groups and physiotherapy	*79,354*		*79,354*	
	244,853	-	*244,853*	

Notes to the financial statements (continued) for the year ended 31 August 2023

3. STAFF COSTS

	2023 Total £	2022 Total £
Wages and salaries	148,636	95,324
Number of staff during the year: Administration	7	5

No employee earned over £60,000 in either year.

4. DEBTORS

	2023 £	2022 £
Gift aid reclaim and prepayments	7,502	9,953

5. RESTRICTED FUNDS

	1 September 2022 £	Movement in Funds: Incoming Resources £	Resources Expended £	Transfers £	31 August 2023 £
Restricted Funds					
Awards for All	-	9,440	4,940	-	4,500
Freddie's Wishes	-	240	240	-	-
Dorothy Pamela Smith	-	2,500	-	-	2,500
	-	12,180	5,180	-	7,000

Notes to the financial statements (continued) for the year ended 31 August 2023

6. ANALYSIS OF NET ASSETS

	Cash at bank £	Current Assets £	Current Liabilities £	Liabilities after one year £	Total £
Restricted Funds					
Awards for all	4,500	-	-	-	4,500
Freddie's Wishes	-	-	-	-	-
Dorothy Pamela Smith	2,500	-	-	-	2,500
	7,000	-	-	-	7,000
Unrestricted Funds	151,272	7,502	(18,803)	-	139,971
	158,272	7,502	(18,803)	-	146,971

7. TRUSTEE EXPENSES

One Trustee received remuneration during the year of £31,833 (2022: £36,000) for services as the Charity's CEO. This Trustee resigned on 24 April 2023 and continues as CEO. The disclosure here is for the entire year.

8. RELATED PARTY TRANSACTIONS FUNDS

A close family member of a Trustee was paid £1,632 (2022: £2,242) for their services during the year.

Independent examiner's report to the Trustees of Down Syndrome UK

I report on the financial statements of the Trust for the year ended 31 August 2023, which are set out on pages 29 to 37.

This report is made solely to the charity's trustees, as a body, in accordance with section 154 of the Charities Act 2011. My independent examiner's work has been undertaken so that I might state to the charity's trustees those matters I am required to state to them in an independent examiner's report and for no other purpose. To the fullest extent permitted by law, I do not accept or assume responsibility to anyone other than the charity, the charity's members as a body and the charity's trustees as a body for my independent examiner's work, for this report, or for the opinions I have formed.

Responsibilities and basis of report

As the charity trustees of the Trust you are responsible for the preparation of the financial statements in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the 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:

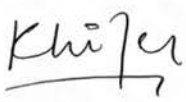
1. accounting records were not kept in respect of the Trust as required by section 130 of the Act; or

2. the financial statements do not accord with those records; or

3. the financial statements do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the financial statements give a 'true and fair view which is not a matter considered as part of an independent examination.

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.

Khizer Kayani ACA
2 Coldharbour Lane, Bushey, London, WD23 4NS



Date: 25 June 2024





dsuk
down syndrome uk

www.downsyndromeuk.co.uk

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E: info@downsyndromeuk.co.uk

Down Syndrome UK Registered Charity No. 1184564

DOWN SYNDROME UK

England & Wales - Charity number 1184564

Accounts

dsuk
down syndrome uk

Positive about Down syndrome

Annual Report

Report and accounts for the year ended 31 August 2022




Improving the lives
of those with
Down syndrome
and their families.

Contents

Introduction	4
Meet the team	5
Achievements and performance	6
Our year in numbers	12
Feedback	13
Funding	14
Financial review	15
Organisational structure	16
Statement of Trustees' responsibilities	17
Statement of financial activities	18
Notes to the accounts	20
Independent examiners report	24

Introduction

The Board of Trustees present their Annual Report for the year ended 31 August 2022 under the Charities Act 2011, together with the financial statements for the year. The Board confirms that the latter comply with the requirements of the Charities Act 2011, the trust deed and the Charities SORP FRS 102 (2015) (update bulletin 1).

Objects of the Charity

Relief of those in need by reason of parents and families of children and young people with Down syndrome in the UK through the provision of a forum that provides accurate up to date information on the realities of living with Down syndrome and is a central hub of information and resources for the condition.

The objects are exclusively for the public benefit to promote the effectiveness or efficiency of charities and to advance any other charitable purpose within the meaning of English Law.

The Trustees have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the Charity's purposes and aims, and when planning future activities. In particular, we consider how planned activities will contribute to the achievement of the objectives and aims.

Beliefs and aims for 2022

Down Syndrome UK works to improve the lives of people with Down syndrome, and their families. We primarily work in maternity care and the early years providing resources, training and support to parents and professionals to empower those with Down syndrome to thrive and flourish.

We believe every parent should receive the best possible care and support.

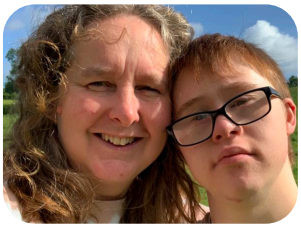
We believe the arrival of every baby with Down syndrome should be celebrated.

We believe every child with Down syndrome should be given every opportunity to flourish and thrive.

To enact these beliefs, we have 4 core aims which underpin our work:

1. Raising awareness of the modern reality of living with Down syndrome in the UK today.
2. Connecting parents of children with Down syndrome to experts, best practice, and each other.
3. Ensuring all children with Down syndrome have the best start in life, and access to the support to enable them to live their lives to the full.
4. Helping parents, the public, professionals, policy makers, and politicians to celebrate and support people with Down syndrome as valued and important members of society.

Meet the team



Caroline Warren
Trustee



Casimir Knight
Trustee



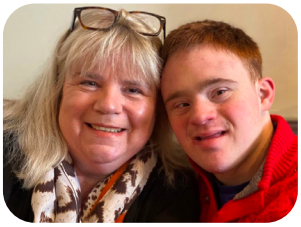
Jude Simpson
Trustee



Richard Baker
Trustee & Treasurer
(appointed April 2023)

Nicola Enoch (resigned April 2023)
Sarah Costerton (resigned February 2022)

Staff



Nicola Enoch
CEO



Farah Cutter
Design Lead



Holli Sheahan
Marketing & Social Media Manager



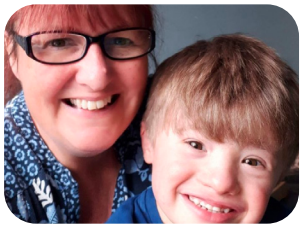
Rachel Hristov
Community Fundraising Coordinator



Vicky Price-John
Administrator



Lucienne Cooper
Training Manager



Caroline Turner
Regional Maternity Manager



Sarah Ojar
Breastfeeding Supporter



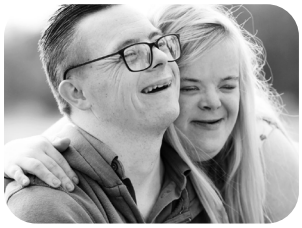
Lorraine McCabe
Parent Supporter



Rozie Haines
Heart Buddies Coordinator



June Rogers MBE
Children's Specialist Continence Nurse



Heidi & James Carter
Patrons



Leon Harrop
Patron

Achievements and performance

Review of Achievements and Performance for 2022

In this third year of charitable registration, DSUK has undergone a rapid expansion of activities, outreach, and engagement.

From our inception as a charity providing the lived experience to expectant and new parents via a website, and then distributing contemporary literature to maternity staff and units, we have built on this work, improving, and expanding our excellent website and producing an accompanying book #NobodyToldMe the truth about Down syndrome, that is sent to expectant and new parents of a baby with Down syndrome. Our aim is to reach all expectant and new parents of a baby with a high chance or confirmed result of Down syndrome.

In addition, we have strengthened our online communities, with dedicated closed Facebook pages for expectant women, for new parents, for grandparents, for bereaved parents and for preschool parents amongst many others. These groups are carefully moderated and monitored by an experienced group of DSUK volunteers along with experts in their field and whilst they are mostly used for hugely appreciated peer support, they have also been useful in identifying issues that parents have worried about but not been able to name and assisting in referral to the correct professionals.

In March 2021 we celebrated World Down Syndrome Day with a community fundraiser and were delighted to raise over £60,000.

Buoyed by this level of community engagement we have moved to increase our reach further by employing a small team of part-time staff. These staff provide administrative support, design services, social media presence and community fundraising support. With this step change in activities, we also employed Nicola Enoch as Chief Executive Officer, a role that until July 2021 she had been undertaking voluntarily. On behalf of the community, the Trustees thank her for all the voluntary work she has done over the years and all that she continues to do for the Down syndrome community.

Covid has, of course, provided a unique challenge, but the advent and widespread societal uptake of effective online communications platforms, such as Zoom and Teams, has meant that we can reach more families and our online offering has expanded to provide Early Development Groups for preschool early learning, POPS – PADS Online Physiotherapy Support and #Pants4Schools' toileting boot camps in collaboration with June Rogers MBE, formerly of Bladder & Bowel UK.

Nicola and Caroline became Founding Members of the **National Down Syndrome Policy Group** that, during this year, provided the secretariat to start an All-Party Parliamentary Group on Down Syndrome and were chosen by Dr Liam Fox MP to support his Private Member's Bill; the Down Syndrome Bill, which in June 2022 became enacted into law in England.



DSUK is immensely proud of the range of resources and services that we provide. Whilst our primary focus has been ensuring expectant and new parents receive the information and support that they deserve, we have continued to evolve and expand, in response to demand.

In September we were delighted to host our first family get together – PADS Party in the Park. We met at Thomley Activity Centre in Buckinghamshire, where over 150 people travelled from the four corners of the UK. With so many lock down babies it was a wonderful experience for families to meet in person and enjoy being members of such a proactive dynamic community.



Founder and CEO Nicola Enoch's commitment to the Charity and wider community, was acknowledged when she was voted Star Mum at Hello magazine's Inspiration Awards.



We were also delighted to be finalists at the Nursing Times Awards for our highly successful #Pants4School initiative, a tremendous achievement for such a small Charity.





Throughout the year Training Manager Lucienne Cooper delivered training to medical professionals and students across the UK. We have developed a very powerful training module that includes data from our published research **Sharing the News** – the maternity experience of 1,410 women in the UK who have had a baby with Down syndrome, together with focusing around sharing best practice, considering language and attitudes, how to share the news baby has/may have Down syndrome and having a contemporary understanding of the condition. Lucienne and Nicola delivered training to more than 1,000 professionals including franchisees from Window to the Womb, and health visitors at the annual iHV conference.

Research continues to be an area we support and promote – with Nicola presenting the findings from our **breastfeeding report** at the Down Syndrome Research Forum, and the **Nystagmus report** in which we collaborated with Dr Maggie Woodhouse. We also launched our collaboration with University of Warwick repeating our maternity research. Articles written by DSUK personnel were published by the International Journal of Birth and Parent Education, Nursery World, and the British Journal of Midwifery.





Educating and empowering professionals who work with our children and young people is an area we are continuing to expand, and we extended our offer to deliver training to professionals working in early years. Extensive training opportunities were provided throughout the year to our families, including around will writing, guardianship, constipation, positive behaviour and early communication skills.

During the year we have expanded our work, reaching more maternity units across the UK. We have achieved this by the introduction of Regional Maternity Coordinators. We also developed a training offer to deliver training sessions online to maternity staff around the country.

We continue to invest time, money and resources collaborating with maternity units across the UK to ensure expectant and new parents receive the care, information and support that they deserve. We now work with more than 70 maternity units via our team of Regional Maternity Coordinators, who each liaise with their local maternity units to act as a central point of contact, ensuring a supply of PADS resources are available to expectant and new parents.

We also invested in attending Midwifery festivals in London, Birmingham, Cardiff and Manchester where maternity professionals were delighted to learn about the services and resources PADS provides. Wanting to extend our reach beyond maternity professionals, we exhibited at the Primary Care Event at the NEC, where we engaged with GPs, health visitors, continence and school nurses.



Our very popular Early Development Groups – **PEGS** continue to attract families who are unable to access local specialist support, and we were delighted to introduce POPS – PADS **online physiotherapy sessions**. We encourage families to introduce gentle physiotherapy activities from birth and working with a highly experienced paediatric physiotherapist, families benefit from her extensive knowledge and practical advice.

At DSUK, we value and appreciate the amazing work **local regional groups** undertake across the country, and work hard to dovetail and compliment their work. Aware that many groups do not have the capacity or resources to undertake the breadth of services our families benefit from, we identify where knowledge, support and information are lacking and develop resources and ongoing support accordingly.

Since 2015 Nicola has been organising and hosting an annual networking event to which the 100+ local groups are invited. In October 2021 the network conference was very well attended, with both external speakers and those from within the community speaking on a range of topics including Prof Simon Gaisford of UCL feeding back about a trial we have undertaken around constipation, and research with charity Parkinson's Disease re a potential correlation between constipation and dementia. We also had excellent presentations from Dr Hana D'Souza of University of Cambridge, Dr Liz Corcoran of the DSRF, Emma Austin of Central England Law Centre, Laura Baxter of Special Olympics, and representatives from Downright Special, 21&Co, Down Syndrome Training and Support Services Ltd, Oxford DSSG, Cheshire DSSG and from the National Down Syndrome Policy Group.

We enjoyed another successful fundraising year, with amazing support from our community. The annual Big PADS Push was well attended in August, and an online draw for an iPad donated by a parent raised £1,047. The lead up to World Down Syndrome Day on 21st March generated over £60k which was an amazing effort by many families and individuals, and we are immensely grateful to all those who choose to support DSUK.



In June we encouraged families to celebrate the Queen's Jubilee by participating in PADS PositiviTea event, which raised wonderful awareness as well as funds.



The creation and sale of calendars enabled us to raise sufficient funds to provide calendars to every maternity unit in the UK, raising positive awareness and signposting to our services.

Volunteers continue to play a significant part in supporting our social media activities, as well as providing an amazing resource to our PADS Heart Buddies scheme. During the year we supported more than 60 families whose child underwent heart surgery and have more than 92 parent volunteers registered as PADS Heart Buddies.



We can see significant impact of our award nominated #Pants4School initiative. During the year we ran 5 bootcamps, working directly with more than 125 families.
Our online support groups continue to flourish, with more than 3,144 parents and professionals in our under 5's group and 1,163 accessing information and support for those over 5.



At DSUK we are committed to supporting our mothers who wish to breastfeed, by providing peer support, and in March we appointed Sarah Ojar as our Breastfeeding Supporter. Sarah has been working to develop a breastfeeding training module, expanding our resources and providing ongoing support to our families.



> ***DSUK has helped our family massively!! From potty training tips to speech and language sessions, their advice and knowledge covering all areas of raising a child with Down Syndrome is invaluable to us. We will forever support and be grateful for everything they do.***
> **Tracy, Mum to Izabella**

Being immersed in the community and regularly seeking feedback and asking for views, we are able to identify and respond to need. Over the year we introduced online bootcamps to work with families to support and promote positive behaviour. We introduced more resources including information around infantile spasms, as well as ongoing support to the professionals who work with our children in preschool settings.

We take a very holistic approach providing support to the whole family and promoting mental wellbeing. Our weekly online yoga sessions continue to be well attended, as do our weekly Sunday morning TomFit sessions.

We are very proud to have provided independent professional counselling on both an individual and group basis since 2020 and we know many families highly value and appreciate this support. We endeavour to provide support to all families. We have a closed group for those parents who sadly are bereaved and have provided counselling and ongoing support to these families too.

As the Charity grows, Trustees identified the need to develop a database to ensure we deliver effective and impactful resources and communications with all those we engage with. Working with a consultancy, we have now implemented a bespoke Sales Force database which we continue to extend and develop in line with our operations.

We were delighted to be selected by Help Films who developed a fabulous **video** for us to share with expectant and new parents. And our collaboration with LTS Global Solutions continued with further branding of more of their fleet, providing a unique opportunity to spread awareness across the highways of the UK!

Huge thanks to all those who continue to ensure DSUK is a thriving, proactive and effective Charity, ensuring that the future for people with Down syndrome looks bright.



Our year in numbers

Positive about Down syndrome

133 Expectant women being supported

250+ Babies welcomed

903 New parents

248 Breastfeeding parents supported

1,147 Preschool parents

1,101 Grandparents

pants4school

3,144 Families and professionals accessing Pants4School

The number of children supported by st&r support, training & resources

1,467 Preschool

504 Primary schools

878 Secondary schools

314 16+

The number of professional members dsuk down syndrome uk

1,387 Medical practitioners trained

271 Preschool teachers

183 Primary teachers

the DSUK network

108 Regional support groups

150 Volunteers

Feedback from parents and professionals

PADS has been an absolute lifeline. Without it, I don't know how we would have coped. From feeling so scared and alone, we can now see an exciting positive future for our son, and know that PADS is there to hold our hands all the way. **Sarah, mum to Charlie.**

Nobody gets it unless you're actually in the same situation... so it's been amazing to be able to meet and chat with other mums who have the same concerns and worries, and to be able to see and hear from those further down the line to see that everything's going to be ok. **Beth, mum to Emily.**

I enjoyed the new perspective given on Down syndrome and how little changes like language can have a big significance on families and how they view and feel about their babies. I feel more equipped to signpost parents to get information and support as well as supporting breast feeding. **Midwifery student at University of Leicester.**

Massive thanks to Nicola and everyone at PADS - I honestly don't know where I'd be without PEGS and POPS helping me to support Sam, this is a lovely safe place to ask all the questions (or search for them) and the endless support whenever required. The work you all do is amazing! **Laura, mum to Sam.**

This evening I opened a package from the amazing team at Positive about Down syndrome. It made me cry! This is exactly what parents need in the firs few hours after diagnosis, not 'we are sorry' and then nothing until you see your consultant. This information / eduction is so valuable. **Sarah, mum to Ayda.**

Huge thanks to PADS for your eye screening session. I went into our opthamology appointment ready and armed. The optometrist listened to my concerns and was very impressed with my knowledge. I feel so relived and grateful to this support group for all of the knowledge sharing. **Laura, mum to Lucy.**

Funding

The main risk to Down Syndrome UK, apart from the pandemic and subsequent economic impact, would be a loss of funds due to our donors no longer being able to commit further funding.

Future Plans

DSUK is a dynamic and proactive Charity, led and managed by parents of children and young people with Down syndrome. Immersed in the community we identify and respond to issues and challenges that our families face, by providing information, resources, and support as necessary. We also look to influence and impact national policy and practice by collaborating with relevant policy makers and providers.

During 2022/2023 we will continue to work hard to improve the maternity experiences of our parents and to ensure every baby with Down syndrome is welcomed into the world with the care and support they deserve. We will increase our reach to universities and maternity units to deliver training to future and current practitioners in maternity care and are looking to extend this to other medical professionals.

We aim to provide more services and support to the education professionals who work with our children in pre and primary school settings.

DSUK will continue to listen to people with Down syndrome, their families and the professionals who work with them to work towards a more inclusive society.



Financial review

The majority of our income is generated by the generosity of parents, friends and families undertaking a range of challenges and activities to support our work.

Our income for the year was £245,685 (2021 (restated): £231,080) and we spent £253,097 (2021: £93,079) as set out in these accounts. We ended the year with cash at bank of £151,678 (2021: £119,059).

Reserves Policy

Reserves are required to cover an unexpected loss of income and to allow ongoing commitments to be met in these circumstances. Since the majority of our income is by gift from private donors, a sudden loss of this income would likely result in a need to close the Charity. To mitigate this risk, we aim to have at least 6 months' trading reserve at any one time.

Investment Policy

As a young Charity, we have not yet built substantial investments and, in these early years, the aim is to protect our funds. We will consider a more formal policy as we grow.

Risk Management

The Trustees have conducted a review of the major risks to which the Charity is exposed. Where appropriate, systems or procedures have been established to mitigate the risks the Charity faces.

Structure, governance and management

Governing Document

Down Syndrome UK is registered with the Charity Commission of England and Wales, Registration Number 1184564. It is governed by a Trust Deed, dated 23 July 2019. The Charity was registered from 24 July 2019.

Organisational structure

The Trustees appointed under the Trust Deed are entitled to hold office for a period of 2-4 years initially, with option to extend. Further Trustees may be appointed by invitation and resolution of the current Trustees.

The Trustees meet at least quarterly, to review existing projects and discuss new ones.

The Trustees provide corporate governance the Charity, and assist the CEO and management to both develop the strategy and deliver it. The Trustees have a legal obligation to supervise and shepherd the Charity and have ultimate responsibility for the Charity and its activities.

The Trustees aim to develop the Trustee board in order increase its impact and diversity while supporting staff and the community.

Key Management Personnel Remuneration

The Trustees consider the Board of Trustees as comprising the key management personnel of the Charity in charge of directing and controlling the Charity and running and operating the Charity on a day to day basis.

Trustees are required to disclose all relevant interests to the board meetings and, in accordance with the Trust's policy, withdraw from decisions where a conflict of interest arises.

Reference and Administrative Information

Charity registration number: 1184564

Principal Office:
5 Hill Close
Leamington Spa
CV32 7RQ

Trustees

The Trustees during the year and up to the date of this report were:

S Costerton (resigned 12 January 2022)
N Enoch (resigned April 2023)
C S B Knight (appointed 12 January 2022)
J F Simpson (appointed 12 January 2022)
C L Warren
R F Baker (appointed April 2023)

Independent Examiner

Khizer Kayani ACA, 2 Coldharbour Lane, Bushey, London, WD23 4NS

Bankers

CAF Bank Limited
25 Kings Hill Avenue
West Malling
Kent, ME19 4JQ

Approved by the Trustees on
28th June 2023

and signed on their behalf by:



Caroline Warren
Chair

Statement of Trustees' responsibilities

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

The law applicable to charities in England and 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 of the Charity for that period. In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgments and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material 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 business.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the Charity's transactions, disclose with reasonable accuracy at any time the financial position of the Charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charities (Accounts and Reports) Regulations 2008 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.

Statement of financial activities

For the year ended 31 August 2022

	Note	2022 £	2022 £	2021 (restated) £	2021 (restated) £
Income and endowments from:					
Donations			**176,363**		192,037
Gift Aid			**3,942**		6,011
Charitable Activities: Support Groups			**65,380**		33,032
Total income			**245,685**		231,080
Expediture on:					
Fundraising: Events		**8,244**		1,276	
Charitable activities	2	**244,853**		91,803	
Total resources expended			**253,097**		93,079
Net (Deficit)/Income and Movement in Funds			**(7,412)**		138,001
Fund balances brought forward			**158,167**		20,166
Fund balances carried forward			**150,755**		158,167

All funds were unrestricted in the current and preceding year. The notes on pages 20 to 23 form part of these accounts.

Balance sheet as at 31 August 2022

		2022		2021 (restated)
	Note	£	£	£
Current assests:				
Debtors	3	**9,953**		39,108
Bank balances		**151,678**		119,059
		161,631		158,167
Liabilities:				
Creditors: Amounts falling due within one year				
Accruals		**(10,876)**		-
NET current assets			**150,755**	158,167
Total NET assets			**150,755**	158,167
Total funds: Unrestricted funds			**150,755**	158,167

Approved by the Trustees and signed on their behalf by:



Caroline Warren
Trustee

Date: 28th June 2023

The notes on pages 20 to 23 form part of these accounts.

Notes to the accounts for the year ended 31 August 2022

1. Accounting Policies

a) Basis of Accounts Preparation

The accounts have previously been prepared on a cash basis. Due to the Charity's size, the accounts have now been prepared on an accruals basis. The impact of the transition is set out in note 6 to these accounts.

The accounts have been prepared in accordance with the Charities SORP (FRS102) applicable to charities preparing their accounts in accordance with the Financial Reporting Standards applicable in the UK and Republic of Ireland and the Charities Act 2011 and UK Generally. Accepted Practice as it applies from 1 January 2015.

The accounts have been prepared to give a 'true and fair' view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a 'true and fair view'. This departure has involved following Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) issued 16 July 2014 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 which has since been withdrawn.

Down Syndrome UK meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note.

In their assessment of going concern the trustees have considered the impact on the Charity of the COVID-19 virus and current economic conditions.

Having regard to the above, the Trustees believe it appropriate to adopt the going concern basis of accounting in preparing the financial statements.

b) Critical Accounting Judgements and Key Sources of Estimation Uncertainty.

In the application of the Charity's accounting policies, which are described in note 1, Trustees are required to make judgements, estimates and assumptions about the carrying value of assets and liabilities that are not readily apparent from other sources. The estimation and underlying assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an on-going basis. Revisions to accounting

estimates are recognised in the period in which the estimate is revised if the revision affects only that period, or in the period of revision and future periods if the revision affects the current and future periods. In the view of the Trustees, no assumptions concerning the future or estimation uncertainty affecting the assets and liabilities at the balance sheet date are likely to result in a material adjustment to their carrying amounts in the next financial year.

c) Financial Instruments

The Charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

d) Income

All incoming resources are included in the statement of financial activities when the Charity is entitled to the income, the amount can be quantified with reasonable accuracy and receipt is probable.

The following specific policies are applied to particular categories of income:

- Voluntary income is received by way of grants, donations and gifts and is included in full in the Statement of Financial Activities when receivable. Grants, where entitlement is not conditional on the delivery of a specific performance by the Charity, are recognised when the Charity becomes unconditionally entitled to the grant.
- Investment income is included when receivable.

e) Expenditure

Expenditure is recognised on an accrual basis as each liability is incurred.

Costs of generating funds comprise the costs associated with fundraising activities.

Charitable expenditure comprises those costs incurred by the Charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

f) Grants and Donations Payable

Grants are recognised in the accounts when a commitment has been made and there are no conditions to be met relating to the grant which remain in the control of the Charity.

g) Taxation

The Trust is exempt from income tax on its charitable activities.

h) Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid after taking account of any trade discounts due.

i) Creditors and provisions

Creditors and provisions are recognised when the Charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

j) Cash

Cash is represented by cash in hand and deposits with financial institutions repayable without penalty on notice of not more than 24 hours.

2. Charitable Activities

	2022	2021
	£	£
Administration and support costs:		
Salary costs	**95,324**	14,001
System development and implementation	**28,313**	-
General operating costs	**41,862**	28,129
Charitable activities:		
Provision of services and resources including support groups, counselling, information sharing sessions, early development groups and physiotherapy	**79,354**	49,673
	244,853	91,803

3. Debtors

	2022	2021
	£	£
Amounts due from donation platforms	-	33,097
Gift aid reclaim	**9,953**	6,011
	9,953	39,108

4. Trustee Expenses

One Trustee received remuneration during the year of £36,000 (2021: £6,000) for services as the Charity's CEO. This Trustee resigned on 24 April 2023 and continues as CEO.

5. Related Party Transactions

A close family member of a Trustee was paid £2,242 (2021: £1,593) for their services during the year.

6. Change of Accounting Basis

The accounts have previously been prepared on a cash basis and this year they have been prepared on an accruals basis.

Two adjustments were required to the prior year ended 31 August 2021:

1. Accounting for a donation of £33,097 which was due in that year but received during the year ended 31 August 2022.
2. Accounting for gift aid of £6,011 to be reclaimed, which was not received in the year ended 31 August 2021.

Impact on reported result for year ended 31 August 2021: £98,893 as previously reported is now £138,001.

Impact on reported reserves as at 31 August 2021: £119,059 as previously reported is now £158,167.

Independent examiner's report to the Trustees of Down Syndrome UK

I report to the trustees on my examination of the accounts of Down Syndrome UK (the Trust) for the year ended 31 August 2022, which are set out on pages 18 to 23.

This report is made solely to the Charity's trustees, as a body, in accordance with section 154 of the Charities Act 2011. My independent examiner's work has been undertaken so that I might state to the Charity's trustees those matters I am required to state to them in an independent examiner's report and for no other purpose. To the fullest extent permitted by law, I do not accept or assume responsibility to anyone other than the Charity, the Charity's members as a body and the Charity's trustees as a body for my independent examiner's work, for this report, or for the opinions I have formed.

Responsibilities and basis of report

As the Charity trustees of the Trust you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the 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 in respect of the Trust as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair view which is not a matter considered as part of an independent examination.

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 accounts to be reached.

Khizer Kayani ACA
2 Coldharbour Lane, Bushey, London, WD23 4NS

Signed: 

Date: 28th June 2023

DOWN SYNDROME UK

England & Wales - Charity number 1184564

Accounts

Trustees' Annual Report for the period

	Period start date				Period end date		
	Day	Month	Year		Day	Month	Year
From	01	09	2020	**To**	31	08	2021

Section A Reference and administration details

Charity name	Down Syndrome UK
Other names charity is known by	Positive about Down syndrome
Registered charity number (if any)	1184564
Charity's principal address	5 Hill Close
	Leamington Spa
	Warwickshire
	Postcode **CV32 7RQ**

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Nicola Enoch	CEO		
2	Caroline Warren			
3	Sarah Costerton			
4				
5				
6				
7				
8				
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				

Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

Section B Structure, governance and management

Description of the charity's trusts

Type of governing document (eg. trust deed, constitution)	Constitution
How the charity is constituted (eg. trust, association, company)	CIO
Trustee selection methods (eg. appointed by, elected by)	Appointed by existing Trustees

Additional governance issues (Optional information)

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity's organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees' consideration of major risks and the system and procedures to manage them.

Nicola Enoch and Caroline Warren are both Trustees of the Ups of Downs.
Sarah Costerton is a Trustee of Down's Syndrome Research Foundation.
Caroline Warren is a Trustee of the Scorfen Charitable Trust.
All three Trustees also became Founding Officers of the National Down Syndrome Policy Group during the year.

Section C Objectives and activities

Summary of the objects of the charity set out in its governing document

RELIEF OF THOSE IN NEED BY REASON OF PARENTS AND FAMILIES OF CHILDREN AND YOUNG PEOPLE WITH DOWN SYNDROME IN THE UK THROUGH THE PROVISION OF A FORUM THAT PROVIDES ACCURATE UP TO DATE INFORMATION ON THE REALITIES OF LIVING WITH DOWN SYNDROME AND IS A CENTRAL HUB OF INFORMATION AND RESOURCES FOR THE CONDITION

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

Down Syndrome UK works to improve the lives of people with Down syndrome, and their families. We primarily work in maternity care and the early years providing resources, training and support to parents and professionals to empower those with Down syndrome to thrive and flourish.

Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.

Section D Achievements and performance

Summary of the main achievements of the charity during the year

In this second year of charitable registration, DSUK has undergone a rapid expansion of activities, outreach, and engagement.

From our inception as a charity providing the lived experience to expectant and new parents via a website, and then distributing contemporary literature to maternity staff and units, we have built on this work, improving, and expanding our excellent website and producing an accompanying book #NobodyToldMe the truth about Down syndrome, that is sent to all expectant and new parents of a baby with Down syndrome (DS). We aim to reach all expectant and new parents of a baby with a high chance or confirmed result of DS.

During the year we have expanded our work, reaching more maternity units across the UK. We have achieved this by the introduction of Regional Maternity CoOrdinators, who each liaise with their local maternity units to act as a central point of contact, ensuring a supply of PADS resources are available to expectant and new parents. We also developed a training offer to deliver training sessions online to maternity staff around the country, focusing around sharing best practise, considering language and attitudes, how to share the news baby has/may have DS and having a contemporary understanding of DS.

In addition, we have strengthened our on-line communities, with dedicated, closed, Facebook pages for expectant women, new parents, grandparents, bereaved parents, and pre-school parents amongst others. These groups are carefully moderated and monitored by an experienced group of DSUK volunteers along with experts in their field and whilst they are mostly used for hugely appreciated peer support, they have also been useful in identifying issues that parents have worried about but not been able to name and assisting in referral to the correct professionals.

In March 2021 we celebrated World Down Syndrome Day with a community fundraiser and were delighted to raise £60,000.

Buoyed by this level of community engagement we have moved to increase our reach further by employing a small team of part-time staff. These staff provide administrative support, design services, social media presence, community fundraising support, project management, regional maternity co-ordination and expert leadership for Early Development Groups. With this step-up in activities, we also employed Nicola Enoch as Chief Executive Officer, a role that until July 2021 she had been doing voluntarily, and on behalf of the community her fellow Trustees thank her for all the voluntary work she has done and continues to do for the Down syndrome community.

Covid has, of course, provided a unique challenge, but the advent and widespread societal uptake of effective on-line communications platforms, such as Zoom and Teams, has meant that we can reach more families and our on-line offering has expanded to provide Early Development Groups for pre-school early learning and ‘Pants for Schools’ toileting boot camps in collaboration with June Rogers MBE, formerly of Bladder & Bowel UK.

Nicola and Caroline became Founding Members of the National Down Syndrome Policy Group that, during this year, started an All Party Parliamentary Group for DS and were chosen by Dr Liam Fox MP to support his Private Member’s Bill; the Down Syndrome Bill, which in June 2022 became enacted into law in England.

Section E Financial review

Brief statement of the charity's policy on reserves	We aim to have at least 6 months trading reserve at any one time.
Details of any funds materially in deficit	n/a

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about: • the charity's principal sources of funds (including any fundraising); • how expenditure has supported the key objectives of the charity; • investment policy and objectives including any ethical investment policy adopted.	The majority of our income is generated by the generosity of parents, friends and families undertaking a range of challenges and activities to support our work.

Section F Other optional information

Section G Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	Nicola Enoch	Caroline Warren
Position (eg Secretary, Chair, etc)	CEO	
Date	16th June 2022	

Section E Financial review

Brief statement of the charity's policy on reserves	We aim to have at least 6 months trading reserve at any one time.
Details of any funds materially in deficit	n/a

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about: • the charity's principal sources of funds (including any fundraising); • how expenditure has supported the key objectives of the charity; • investment policy and objectives including any ethical investment policy adopted.	The majority of our income is generated by the generosity of parents, friends and families undertaking a range of challenges and activities to support our work.

Section F Other optional information

Section G Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	Nicola Enoch	Caroline Warren
Position (eg Secretary, Chair, etc)	CEO	

Date	16th June 2022

CHARITY COMMISSION FOR ENGLAND AND WALES

Down Syndrome UK	1184564

Receipts and payments accounts

CC16a

For the period from	01-Sep-20	To	31-Aug-21

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Charitable Activities	33,032	-	-	33,032	-
Voluntary Receipts	158,940	-	-	158,940	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
***Sub total** (Gross income for AR)*	191,972	-	-	191,972	-
A2 Asset and investment sales, (see table).					
	-	-	-	-	
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	191,972	-	-	191,972	-
A3 Payments					
Salary Costs	14,001	-	-	14,001	-
General Office costs	28,129	-	-	28,129	-
Cost of Fundraising Events	1,276	-	-	1,276	-
Costs of Charitable Activities	49,673	-	-	49,673	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	93,079	-	-	93,079	-
A4 Asset and investment purchases, (see table)					
	-	-	-	-	
	-	-	-	-	
Sub total	-	-	-	-	-
Total payments	93,079	-	-	93,079	-
Net of receipts/(payments)	98,892	-	-	98,892	-
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	-	-	-	-	-
Cash funds this year end	98,892	-	-	98,892	-

Section B Statement of assets and liabilities at the end of the period

B1 Cash funds

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
	Bank Account	119,059	-	-
		-	-	-
		-	-	-
	Total cash funds (agree balances with receipts and payments account(s))	119,059	-	-

B2 Other monetary assets

Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
	-	-	-
	-	-	-
	-	-	-
	-	-	-
	-	-	-
	-	-	-

B3 Investment assets

Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
		-	-
		-	-
		-	-
		-	-
		-	-

B4 Assets retained for the charity's own use

Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
		-	-
		-	-
		-	-
		-	-
		-	-
		-	-
		-	-
		-	-
		-	-

B5 Liabilities

Details	Fund to which liability relates	Amount due (optional)	When due (optional)
		-	
		-	
		-	
		-	
		-	

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name	Date of approval
Caroline Warren	CAROLINE WARREN	20-6-22

CHARITY COMMISSION FOR ENGLAND AND WALES

Independent examiner's report on the accounts

Section A Independent Examiner's Report

Report to the trustees/ members of	Charity Name Down Syndrome UK		
On accounts for the year ended	23 July 2019 to 31 August 2020	**Charity no (if any)**	1184564
Set out on pages	1 - 2 (remember to include the page numbers of additional sheets)		

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the period ended 31 / 08 / 2020.

Responsibilities and basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the 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 which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

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 accounts to be reached.

** Please delete the words in the brackets if they do not apply.*

Signed:		**Date:**	25 May 2022
Name:	Khizer Kayani		
Relevant professional qualification(s) or body (if any):	ACA (Institute of Chartered Accountants England and Wales)		
Address:	2 Coldharbour Lane, Bushey London, WD23 4NS		

Section B	Disclosure
	Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).
Give here brief details of any items that the examiner wishes to disclose.	No material matters of concern

DOWN SYNDROME UK

England & Wales - Charity number 1184564

Accounts

Trustees' Annual Report for the period

	Period start date				Period end date		
From	23	July	2019	To	31	August	2020

Section A Reference and administration details

Charity name	Down Syndrome UK
Other names charity is known by	Positive About Down Syndrome
Registered charity number (if any)	1184564
Charity's principal address	5 Hill Close, Leamington Spa,
Postcode	CV32 7RQ

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Nicola Enoch	Chair		
2	Caroline Louise Warren			
3	Sarah Costerton			
4				
5				
6				
7				
8				
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				

Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

Section B Structure, governance and management

Description of the charity's trusts

Type of governing document (eg. trust deed, constitution)	Constitution
How the charity is constituted (eg. trust, association, company)	CIO
Trustee selection methods (eg. appointed by, elected by)	Appointed by existing Trustees

Additional governance issues (Optional information)

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity's organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees' consideration of major risks and the system and procedures to manage them.

Nicola Enoch & Caroline Warren are both Trustees of The Ups of Downs. Sarah Costerton is a Trustee of Down's syndrome research foundation. Caroline Warren is Trustee of Scorfen Charitable Trust

Section C Objectives and activities

Summary of the objects of the charity set out in its governing document

RELIEF OF THOSE IN NEED BY REASON OF PARENTS AND FAMILIES OF CHILDREN AND YOUNG PEOPLE WITH DOWN SYNDROME IN THE UK THROUGH THE PROVISION OF A FORUM THAT PROVIDES ACCURATE UP TO DATE INFORMATION ON THE REALITIES OF LIVING WITH DOWN SYNDROME AND IS A CENTRAL HUB OF INFORMATION AND RESOURCES FOR THE CONDITION

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

Down syndrome UK works to improve the lives of people with Down syndrome, and their families. We primarily work in maternity care and the early years providing resources, training and support to parents and professionals to empower those with Down syndrome to thrive and flourish.

Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.

Section D Achievements and performance

Summary of the main achievements of the charity during the year

Our first registered year was exciting and eventful. Following the success of PADS website and sending out resources to maternity units across the country, we launched a closed Facebook group exclusively for expectant women in the UK, who have received a high chance/confirmed result of baby having Down syndrome. Together with a closed group for new parents up to the age of 18 months. These support groups have provided amazing peer support to new and expectant parents and the feedback has been overwhelmingly positive. We have teams of experts on hand in each group to offer specialist input as and when required.

In September Founder & Trustee Nicola Enoch was invited to speak at the Professional Midwifery Advocate's conference and at Down syndrome education international's research forum.

In October 2019 we published Sharing the News – the maternity experience of having a baby with Down syndrome. We organised a photography exhibition at Westminster over 4 days at which we shared the findings of the report and met with over 40 Parliamentarians across the parties. The overall response to the report was concern at the lack of support and information provided to parents as well as shock at the expectation to screen and to terminate. Several influential Parliamentarians asked us to follow up the discussions.

In November 2019 Nicola had an article published in the British Journal of Midwifery and in December 2019 by the Royal College of Midwives.
D
In March 2020 we returned to Parliament and spoke again about the findings of the report but unfortunately follow up was side lined due to Covid. In March 2020 we were invited to attend and promote PADS at the Better Births conference in Manchester and at the CNO's annual conference in Birmingham.

In June 2020 we published #NobodyToldMe the truth about Down syndrome – a collection of experiences written by young people with Down syndrome, friends and family members to share the reality of our everyday lives.

Our initiative #Pants4School – to empower parents and professionals to ensure children with Down syndrome are toilet trained before they commence school was launched in March 2020 at Bladder & Bowel UK's annual conference. The closed Facebook groups continue to grow from strength to strength and as we entered lockdown we developed an online boot camp to work with groups of c25-30 families to focus on getting their child toilet trained.

The national support group network was unable to hold a conference in 2020 but the closed support group continued to grow, with over 100 groups representing several thousand families across the UK sharing best practise.

Section E Financial review

Brief statement of the charity's policy on reserves	A reserves policy will be introduced in our second financial year.
Details of any funds materially in deficit	n/a

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about: • the charity's principal sources of funds (including any fundraising); • how expenditure has supported the key objectives of the charity; • investment policy and objectives including any ethical investment policy adopted.	

Section F Other optional information

Section G Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	Nicola Enoch	Caroline Warren
Position (eg Secretary, Chair, etc)	Chair of the Trustees	Trustee
Date	21 June 2021	

CHARITY COMMISSION FOR ENGLAND AND WALES

Down Syndrome UK	1184564

Receipts and payments accounts

CC16a

For the period from	23-Jul-19	To	31-Aug-20

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Income from Charitable Activities	9,051	-	-	9,051	-
Voluntary Receipts	16,219	-	-	16,219	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
***Sub total** (Gross income for AR)*	25,270	-	-	25,270	-
A2 Asset and investment sales, (see table).					
	-	-	-	-	
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	25,270	-	-	25,270	-
A3 Payments					
General Office costs	144	-	-	144	-
Costs of Fundrasing Events	336	-	-	336	-
Costs of Charitable Activities	4,624	-	-	4,624	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	5,104	-	-	5,104	-
A4 Asset and investment purchases, (see table)					
	-	-	-	-	
	-	-	-	-	
Sub total	-	-	-	-	-
Total payments	5,104	-	-	5,104	-
Net of receipts/(payments)	20,166	-	-	20,166	-
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	-	-	-	-	-
Cash funds this year end	20,166	-	-	20,166	-

B2 Other monetary assets

	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £

B3 Investment assets

	Fund to which asset belongs	Cost (optional)	Current value (optional)

B4 Assets retained for the charity's own use

	Fund to which asset belongs	Cost (optional)	Current value (optional)

B5 Liabilities

	Fund to which liability relates	Amount due (optional)	When due (optional)

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name	Date of approval
	Nicola Enoch	21-Jun-21
	Caroline Warren	21-Jun-21

CHARITY COMMISSION FOR ENGLAND AND WALES

Independent examiner's report on the accounts

Section A Independent Examiner's Report

Report to the trustees/ members of

Charity Name
Down Syndrome UK

On accounts for the year ended

23 July 2019 to 31 August 2020

Charity no (if any) 1184564

Set out on pages

1 - 2

(remember to include the page numbers of additional sheets)

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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 accounts to be reached.

** Please delete the words in the brackets if they do not apply.*

Signed: Nicola Law **Date:** 08/06/2021

Name: Nicola Law

Relevant professional qualification(s) or body (if any): ACA (Institute of Chartered Accountants England and Wales)

Address: 34 Inveraray Avenue, Blackrod, Bolton, BL6 5UQ