

DOWN'S SYNDROME RESEARCH FOUNDATION LIMITED

England & Wales · Charity number 1058548

Details

Other names D S R F, DOWN SYNDROME FOUNDATION

Status Registered

Legal form Charitable company

Company number [03228419](#)

Registered 1996-10-09

Register [View on the Charity Commission register](#)

Contact

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Bells Yew Green
Tunbridge Wells
TN3 9EA

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Website www.dsrf-uk.org

Activities

Objects: TO RELIEVE THE SICKNESS OF THOSE PERSONS SUFFERING FROM DOWN'S SYNDROME IN PARTICULAR THROUGH THE PROVISION OF GRANTS AND FUNDING FOR RESEARCH INTO DOWN'S SYNDROME FOR THE PURPOSE OF FINDING TREATMENTS AND CURES AND TO PUBLISH THE RESULTS OF SUCH RESEARCH WIDELY AND FOR THE PUBLIC BENEFIT.

Activities: The charity's objects are to relieve the sickness of persons living with Down's syndrome in particular through the provision of grants and funding for research into Down's syndrome for the purpose of finding treatments and cures and to publish the results of such research widely and for public benefit.

Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** General Charitable Purposes, Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, Elderly/old People, People With Disabilities, Other Charities Or Voluntary Bodies

Geography

- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£91,158	£70,519	-	-
2023-12-31	£83,131	£47,353	-	-
2022-12-31	£20,588	£233,586	-	-
2021-12-31	£10,444	£188,621	-	-
2020-12-31	£24,946	£49,026	-	-

Trustees

Name	Role	Appointed
Dr ELIZABETH JANE CORCORAN	Chair	
Alison Morley		2021-08-11
DR PETE ELLIOTT		
Lynn Murray		2017-05-20
MARIE KATO-KMIEC		2017-05-20
MRS SYLVIA ELLIOTT		
Sarah Costerton		2019-11-04

DOWNS SYNDROME RESEARCH FOUNDATION LIMITED

England & Wales - Charity number 1058548

Accounts

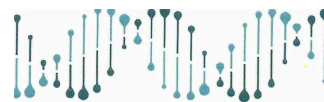
Charity registration number 1058548

Company registration number 3228419 (England and Wales)

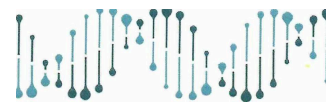


Downs Syndrome Research Foundation UK

**THE DOWN'S SYNDROME RESEARCH FOUNDATION LIMITED
ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2024**



Trustees	Dr E J Corcoran Mrs S M Elliott Dr P C Elliott Mrs L Murray Mrs M Kato-Kmiec Mrs S Costerton Mrs A Morley
Secretary	Mrs S M Elliott
Charity Number	1058548
Company Number	3228419
Registered Address	DSRF-UK P.O. Box 576 Tunbridge Wells Kent TN2 9WJ
Independent Examiner	Ashleigh Martin Simple Support Solutions 90 St Catherine's Road Southampton SO18 1LU
Bankers	CAF Bank Ltd 25 Kings Hill Avenue Kings Hill West Malling Kent ME19 4JQ



Trustees' Annual Report:

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The financial statements have been prepared in accordance with the accounting policies set out in the notes to the financial statements and comply with the charity's governing document, the Companies Act 2006 and 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)' effective 1 January 2019.

Governance

Legal Status

The charitable company was incorporated on 23 February 1996 and registered with the Charity Commission on 9 October 1996. The charitable company has no share capital but is limited by the guarantee of its members. The liability of the members is restricted to £10 each. The charitable company is governed by its revised Articles of Association which were adopted on 5th July 2010.

The Trustees, who are also the directors and the members for the purpose of the Companies Act, present this report and the un-audited financial statements of the charity for the year ended 31st December 2024.

Objects

The Charity's objects are to relieve the sickness of persons with Down's syndrome in particular through the provision of grants and funding for research into Down's syndrome for the purpose of finding treatments and cures, and to publish the results of such research widely and for the public benefit.

Organisation

The charity's activity is organised by the trustees, appointed by the members.

Financial Controls

The trustees have considered the key financial risks and have systems in place to mitigate those risks.

Registered address

PO Box 576, Tunbridge Wells, TN2 9WJ

Email: elizabeth.corcoran@dserf-uk.org

Website: www.dserf-uk.org



Trustees

The trustees, who served throughout the year ending 31 December 2024 and up to the date of the signing of this report, are:

Dr. E. J. Corcoran nee Elliott (Chair)
Mrs. S. M. Elliott (Secretary)
Mr. P. C. Elliott
Mrs. L. Murray
Mrs. M. Kato-Kmiec
Mrs. Sarah Costerton
Mrs. Alison Morely

As a charity our policy is to retain existing proven trustees in order to ensure continuity of the research aims and have within the charity those skills and experience essential for the work that we do.

When we seek a new trustee, it is always to improve the quality and efficiency of the work we do and to add to the skill set of the trustees. This includes the need to have additional trustees monitoring the day-to-day operations and finances of the charity. We can also use social media and email lists to advise interested people to apply.

Any person who is willing to act as a trustee, and is permitted by law to do so, may be appointed to be a trustee by a decision of the trustees. No person may be appointed as a trustee unless he or she has reached the age of 18 years. A trustee may not appoint an alternate director or anyone to act on his or her behalf at meetings of the trustees.

We may invite parents or individuals who show an interest in the aims of the charity and who do not have conflicts of interests in performing their duties as trustees. Every trustee is selected very carefully and must read the essential trustee guide from the Charity Commission, the governing document, the Articles of Association of the charity and agree to abide by these rules. Once elected as trustees they are trained on the job and can always resign or be asked to resign. In the year ahead we would like to invite a trustee who has Down's syndrome to join us.

The trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake.



Activities and Achievements

The DSRF UK is the only charity in the UK focused purely on medical research for the collection of biomedical difficulties caused by Trisomy 21, known as Down's syndrome (DS). The backbone of our work is the belief that people with DS also deserve the scientific innovations afforded to other conditions and illnesses over the last 50 years.

In all activities throughout 2024 due consideration towards the public benefit was made by the trustees, with reference to the Charity Commission's guidance on public benefit.

Our activities during 2024

Transcranial Photobiomodulation with Near-Infrared Light for Language in Individuals With Down Syndrome (TransPhoM-DS)

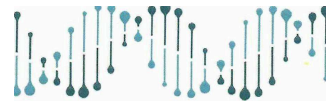
In early 2018 Dr. Corcoran began discussions with Dr Paolo Cassano, Assistant Professor of Psychiatry, (Harvard Medical School) and Director of Photobiomodulation (PMB) (Massachusetts General Hospital - Division of Neuropsychiatry) about the possibilities of a pilot study of PBM in DS. Throughout 2020 there have been multiple revisions and an external protocol review by PBM experts. In August 2020, the final protocol and budget was approved for DSRF UK funding by the board of trustees. In January 2021, the funding contract was signed to fund USD \$415,420 over 2 years (2021, 2022). Financial support was distributed in two payments. The first one, in the amount of \$211,000 (£151,323) has been sent. The second payment was made Sept. 30, 2022, in the amount of \$203,629 (£184,313). Dr. Corcoran hosted a Facebook Live webinar with Paolo covering the study which had close to 1,000 views adding to the increasing interest in this cutting-edge field. It was agreed that there would be a one year no cost extension to analyze and formalize the results which are expected to be released sometime in 2025.

Systematic review of treatment modalities for obstructive sleep apnoea (OSA) in children with Down's syndrome

This piece of work forms part of on-going research led by Dr. Cathy Hill and her team at the University Hospital Southampton. Our funding of the Systematic Review will allow Dr. Hill and her team to make further improvements. A Systematic Review of Research is a 'deep dive' into all published and unpublished research looking to answer a specific question. The scope of the search has been OSA treatments in children with Down syndrome, how best to diagnose it and what impact it has on children's sleep and developing brains. Dr Rina Cianfaglione, research fellow to Dr Hill, will scrutinise the papers and systematically review the research that we have to date on OSA treatments in children with DS.

The Foundation have given Dr. Hill's team two grants: £12,375 in 2019 to support the writing of the Systematic Review (including a professionals' workshop for potential research collaborators) and £10,465 in 2020 for a piece of work building evidence for a multi-centre treatment trial for obstructive sleep apnoea in children with Down's syndrome.

Our support strengthens the case for funding from a large body such as the NIHR as the next stage of research will be very costly and outside of the Foundations funding capabilities.



Additionally, The Foundation hosted a well-attended webinar on “Down’s Syndrome and Sleep” with expert guest speakers Prof. Cathy Hill, Dr. Rina Cianfaglione and Dr. Lizzie Hill.

The publishing of the Systemic Review has been delayed due to gathering all data from the researchers for the analysis. Southampton hosted a national online meeting with Sleep Researchers and the team in Dublin have put together an impressive protocol testing different sleep interventions for people with DS and they are looking to open more sleep study centers. Funding for a nurse may be looked into in the future. Talks continued and expanded into 2023-24 with Prof. Cathy Hill, Dr. Rina Cianfaglione and Dr. Lizzie Hill regarding the possibility of funding a refreshed sleep study. The study will be a multi city study with Southampton as the UK hub coordinating the data (180-200 subjects). The budget covers 4 years at around £133,417 (£33,354 a year). Further discussion is needed around possible co-funders that could be involved.

Down Syndrome and Sleep Research Network

In late 2023, following extensive discussions with leading experts in Down syndrome (DS) and sleep disorders, Dr. Elizabeth Corcoran identified a significant and long-standing need for a dedicated research network focused on sleep issues within this community. Recognizing the global gap in this area, Dr. Corcoran initiated plans to establish the world’s first Down Syndrome and Sleep Research Network.

This pioneering network will bring together researchers specializing in both adult and pediatric care, focusing on diagnosing and treating sleep disorders in individuals with Down syndrome across the UK. The early stages of planning and budgeting have been completed, and fundraising efforts are currently underway. The official launch of the Sleep Network is tentatively scheduled for May 2025.

Menstrual Health Research

Talks began with Dr Katie Greenland, Assistant Professor with the London School of Hygiene. Dr. Greenland was seeking funding for a project investigating the menstrual health-related experiences of 10-19yr olds with Down Syndrome in the UK. This study could be an extremely beneficial training tool around menstruation. In 2024 we approved a budget for the study of £16,588.

The research will generate important evidence on the unmet menstrual-related requirements and identify opportunities for interventions to improve the menstrual health of people with Down syndrome in the UK. Details of how to participate in this study will be forthcoming for carers and adolescents aged 10-19 years. Through comprehensive online surveys and in-depth interviews with adolescents with Down syndrome and their caregivers, the project seeks to uncover the unique challenges and needs of these young individuals.

“I am so glad this complex aspect of life is being researched. It is important for Health Care Professionals to understand the challenges people with Down’s syndrome and their families face regarding menstruation and its management” L (mum to daughter with DS and Autism)



People with learning disabilities experience a wide range of health inequities, and menstrual health is no exception. The well-being of adolescents during their menstrual cycle impacts not only their physical health but also their schooling, mental and social well-being. Despite its importance, there is a stark lack of evidence and guidance available to support individuals with Down syndrome and their caregivers or doctors in managing menstrual health well.

The team will include experts Sarah Polack, Associate Professor in Disability Research at the International Centre for Evidence in Disability (ICED) at LSHTM and Dr Jane Wilbur, Assistant Professor at the International Centre for Evidence in Disability (ICED) at the LSHTM, focusing on disability and water, sanitation and hygiene (WASH).

Sarah Pollock has a wealth of experience in discovering the health experiences and needs of those with disabilities, critically with those with living experience at the heart of her research methods. Dr Wilbur has research expertise in the area of menstrual health in those with learning disabilities developing the Bishesta campaign (in Nepal) and the Veivanua campaign for Vanuatu's humanitarian responses.

This partnership also marks a significant step forward in our commitment to supporting underserved communities and addressing health inequities faced by individuals with learning disabilities.

Going to Hospital

'Going to Hospital' is an accessible publication for patients with learning disability or autism and aims to help children & young people with additional needs to know what they might expect to see when visiting hospital for an appointment or when being admitted for a procedure. Trustees granted £1,000 towards its publication in 2023.

Advocacy and Campaign work





a. Don't Screen Us Out (DSUO) campaign activities

Since 2016, we have been dedicated to supporting the Don't Screen Us Out (DSUO) campaign, which addresses the ethical concerns surrounding current prenatal screening policies. The UK's obligations under the Convention on the Rights of Persons with Disabilities (CRPD) affirm that society must accommodate, include, and support disabled individuals and their families. Yet, there is significant evidence that parents of unborn children diagnosed with disabilities are not provided with the necessary information and resources to make an informed choice about continuing their pregnancy and raising a disabled child. This lack of support undermines the rights of both the child and their family, and we stand firmly against such practices.

b. Embracing Complexity Coalition (was the Neurodevelopmental Coalition Policy Group)

In March 2017 we became a part of a coalition of medical research charities representing various neurodevelopmental conditions/disabilities. Multi-morbidity is increasingly being recognised as the norm for people diagnosed with a neurodevelopmental condition.

We believe that priorities should be guided by the people we serve, with diagnosis being timely, accurate, and accessible. Clinical diagnosis should not be a prerequisite for receiving support or adjustments, which must be personalized, easily accessible, and rooted in the best available evidence. Research should shift away from predefined diagnostic categories and instead reflect the priorities of the neurodivergent community. Improving the lives of neurodivergent individuals is a responsibility shared by all public services and sectors of society. Ultimately, we achieve more when we collaborate and work together.

The current project is the Top 10 Priorities for Research on Neurodivergence.

c. NHS Fetal Anomaly Screening Programme (FASP) Information and Education Sub-Group

As a stakeholder in the antenatal screening programme, we are requested to provide our thoughts on any changes to the current antenatal screening pathways.

d. National Down Syndrome Policy Group (NDSPG)

In 2021 the National Down Syndrome Policy Group was formed comprising of people from a wide range of other charities and support groups: all with the common aim of ensuring that the voice of people with Down syndrome is heard in society and reflected in government policy. A third of the founding officers have Down's syndrome. Three of the DSRF UK trustees are Founding Officers; Lynn Murray, Elizabeth Corcoran and Sarah Costerton. The NDSPG is the Secretariat to the new All Party Parliamentary Group, organising and supporting the meetings and work of the APPGDS and providing lived experience. In 2023 the NDSPG applied for charity status and was accepted. Dr Corcoran is also a trustee for the NDSPG and represents the NDSPG on medical policy issues and ensuring the importance of research is not forgotten.



e. The Down Syndrome Act 2022 and Guidance Development

In June 2021, Dr. Liam Fox MP introduced the Down Syndrome Bill to Westminster during the Parliamentary session. We are proud to report that in 2022, the Down Syndrome Act was passed into UK law, a historic achievement that enshrines specific provisions for education, social, and healthcare support for individuals with Down syndrome. This Act marks a transformative step toward ensuring that the unique needs of people with Down syndrome are not only acknowledged but met with tailored services and policies.

As we look ahead, our focus is on ensuring that the statutory guidance accompanying the Down Syndrome Act is as comprehensive and impactful as possible. We are actively working alongside civil servants, policymakers, and advocacy groups to shape robust guidelines that will bring the full weight of the Act into practice. Throughout 2023, we have been deeply involved in consultations with the Department of Health and Social Care regarding the Call for Evidence, a critical process that will shape the final framework.

Dr. Elizabeth Corcoran, representing our organisation, continues to attend the Down Syndrome Statutory Guidance Advisory Group, working closely with key government stakeholders, including the then Minister, Maria Caulfield MP.

Next steps in this process include deepening our collaboration with researchers, healthcare professionals, and education specialists to generate evidence-based recommendations that inform the DS Act's implementation. We are committed to facilitating research that addresses gaps in knowledge, especially in the areas of mental health, long-term care, and educational needs for individuals with Down syndrome. As we continue to engage with policymakers, we aim to ensure that the statutory guidance not only reflects the best available evidence but also promotes ongoing research and development in Down syndrome care, education, and quality of life.

f. Assisted Dying Bill

Towards the end of 2024 we were made aware that Kim Leadbeater MP had proposed a Terminally Ill Adults (End of Life) Bill, details of which were only just published earlier in the week after public pressure – despite the intention to put this Bill to vote at the Second Reading on Friday 29th November 2024. Only eighteen days' notice were given for the public to examine what was at stake: a very stunted window of opportunity in which to investigate and voice concerns. If the Bill passes, it is likely to have catastrophic effects on the ability to uphold the rights of terminally ill people with Down syndrome and those with other intellectual disabilities. The change that is being proposed to UK law is enormous and the approach has been undemocratic. With only two weeks away from the deadline the DSRF UK joined its voice to a groundswell of concerned advocacy groups for people with disabilities, asking for urgent attention and action on this matter by posting details on our websites blog post, emailing, sharing on our social media platforms and uniting with all concerned groups. Sadly the Bill passed its second reading in the House of Commons on November 29, 2024. Continued efforts to monitor, update, educate and encourage all affected to let their voices be heard by writing their MP's continue throughout the year and will continue going forward into 2025.



Consultations with Intellectual Disability and Palliative Care Professor Irene Tuffrey-Wijne highlighted that failures of care for people with intellectual disabilities are widespread. This new Bill proposes that ethical norms will be changed, before addressing existing problems that need urgent attention. We recently lived through the exposure of multiple failures and weaknesses in the current healthcare system which significantly failed our community. Inquiries using evidence from witnesses about treatment of people with intellectual disabilities during the Covid-19 pandemic brought disturbing evidence to light that other concerns and assumptions had clearly outweighed human rights and the Equality Act during Covid. Evidence has emerged that there was inappropriate use of DNACPR (Do not attempt cardiopulmonary resuscitation) decisions during the pandemic applied to people with intellectual disabilities, sometimes in the total absence of consultation with either the patient or carers. For reasons that we do not fully know yet – which are likely to include failures of due care – people with intellectual disabilities died at a much higher rate than other people during the pandemic, at a rate of 3-4 times the rate of the general population.

There are important reasons why people with intellectual disabilities would likely become more vulnerable to the abuse of euthanasia laws than many of their peers.

Risk of Coercion and Autonomy Issues:

Studies indicate that vulnerable populations may be more susceptible to undue influence. This raises ethical concerns around consent for people with intellectual disabilities, and proponents of the Bill have been unable to give reassurances about how it could be known whether or not someone was coerced into assisted dying.

Need for Supportive Care:

Government reports advocate for enhanced health and social support for disabled individuals (Department of Health and Social Care, 2020), emphasising care improvement over assisted death options. Euthanasia should never be posed as an alternative to due care.

Societal Impact and Stigmatisation:

Legalising assisted dying can devalue lives with disabilities, which may reinforce negative stereotypes. Ableist measures used to judge quality of life are frequently applied to the disabled, despite the way disabled individuals value their own lives.

Financial review

At the beginning of 2024 the charity had net reserves of £142,996 consisting of unrestricted reserves of £142,996. Following a surplus of £20,639 (2023: 35,778) the charity ended the year with reserves of £163,635. Included in these unrestricted funds is a designated balance of £16,588 for the menstrual health research. This leaves an undesignated balance of £147,047.

Legacies

i) The estate of Ms. Gladys Cullis

Towards the end of 2014 it was confirmed that the charity would receive the benefit of the legacy of the estate of Ms. Gladys Cullis, estimated to be £60,000. The monies received from this legacy in total were £85,556.26, with the final cheque for £1,787.50 sent in January 2024.



ii) Robert Thomas Plato

In 2021 our charity, along with forty other charities, received notice that we have been included in the will of the late Robert Thomas Plato. Mr. Plato's estate consists of property, bank accounts and personal possessions. They will be valued and sold in due course. The solicitors, Huggins Lewis Foskett, will then divide the proceeds amongst the charities listed in his will. We received a letter stating Mr. Plato's property had been sold and our portion of the estate was enclosed. A distribution check in the amount of £7,500.00 was deposited June 2023. One final cheque was received in February 2024 in the amount of £1,274.78.

iii) The Estate of Katherine Lucy Aucott

At the end of 2024 we were informed we were a beneficiary in the Estate of the late Katherine Lucy Aucott in the amount of £10,000.00. This has not yet been paid, but has been accrued for in these accounts.

iv) The Estate of the late Mr. Robert Eric Lister

Towards the end of 2024 we were informed we were a beneficiary in the Estate of the late Mr. Robert Eric Lister in the amount of £42,375.77. This has not been paid out as yet in 2024, but has been accrued for in these accounts.

Fund-raising activity continued in 2024, with income from monthly donations, fundraising, legacies and interest, totaling £91,158 (2023: £83,313). At the end of 2024 the charity had £163,635 (2023: £142,996) unrestricted reserves and nil restricted funds.

Reserves policy

The accumulation of funds (reserves) donated for medical research is a necessary strategy when donations are very small, and the cost of clinical research is very great. The process by which these funds are accumulated is described as a 'war chest' for medical research.

Our Reserves policy is to accumulate sufficient funds to fund appropriate medical research projects as approved by the trustees. Our funds could also be used as 'seed money' but it will attract other funders to support these projects i.e. by matched funding. There is always the expectation that research needs more funds that we can raise in a single year and some of that income is needed to fund ongoing operations. We believe a charity should give assurance to lenders and creditors that we can meet our financial commitments by holding an appropriate amount of reserves. Funds that we receive as a result of a grant for a specific project are spent immediately and/or within the guidelines for the project. The same rule applies for any grant that has a restriction on how it must be used.



Statement of Trustees' Responsibilities

The law applicable to incorporated charities in England and Wales requires the trustees, who are also directors of the company, to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of its financial activities during the year. In preparing those financial statements, the trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Make judgments and estimates that are reasonable and prudent;
- State whether applicable accounting standards and statements of recommended practice have been followed subject to any departures disclosed and explained in the financial statements;
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in operation.

The trustees are responsible for maintaining proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The financial statements have been prepared in accordance with current statutory requirements, the current Statement of Recommended Practice, and the Financial Reporting Standard (FRS) 102.

Approved on behalf of the trustees:

.....
Dr. E. J. Corcoran nee Elliott (Chair)

22 September 2025



I report to the trustees on my examination of the financial statements of The Down's Syndrome Research Foundation Limited (the charity) for the year ended 31 December 2024.

Responsibilities and basis of report

As the trustees of the charity (and also its directors for the purposes of company law) you are responsible for the preparation of the financial statements in accordance with the requirements of the Companies Act 2006 (the 2006 Act).

Having satisfied myself that the financial statements of the charity are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of the charity's financial statements carried out under section 145 of the Charities Act 2011 (the 2011 Act). In carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5) (b) of the 2011 Act.

Independent examiner's statement

I have completed my examination. I confirm that no 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 charity as required by section 386 of the 2006 Act; or
2. the financial statements do not accord with those records; or
3. the financial statements do not comply with the accounting requirements of section 396 of the 2006 Act 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; or
4. the financial statements have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

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.

_____ 22 September 2025

Ashleigh Martin
Simple Support Solutions Ltd
90 St Catherine's Road
Southampton
SO18 1LU

THE DOWN'S SYNDROME RESEARCH FOUNDATION LIMITED
STATEMENT OF FINANCIAL ACTIVITIES
INCLUDING INCOME AND EXPENDITURE ACCOUNT
FOR THE YEAR ENDED 31 DECEMBER 2024



		TOTAL	TOTAL
		2024	2023
		£	£
	Notes		
Income			
Donations and legacies	3	89,257	82,257
Investments	4	1,901	874
Total Income		<u>91,158</u>	<u>83,131</u>
Expenditure			
Raising Funds	5	20,016	9,322
Charitable Activities	6	50,503	38,031
Total Expenditure		<u>70,519</u>	<u>47,353</u>
Net expenditure for the year/ Net movement in funds		20,639	35,778
Fund balances at 1 January 2024		142,996	107,218
Fund balances at 31 December 2024		<u>163,635</u>	<u>142,996</u>

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

The notes of pages 17 - 20 form an integral part of these financial statements.

THE DOWN'S SYNDROME RESEARCH FOUNDATION LIMITED
BALANCE SHEET
AS AT 31 DECEMBER 2024



		2024		2023	
		£	£	£	£
	Notes				
Current assets					
Debtors	11	52,376		602	
Investments	12	48,123		47,367	
Cash at bank and in hand	13	64,961		96,577	
		<u>165,460</u>		<u>144,546</u>	
Creditors: amounts					
due within one year	14	<u>(1,825)</u>		<u>(1,550)</u>	
Net current assets			<u>163,635</u>		<u>142,996</u>
Unrestricted Income funds					
Designated funds	15		16,588		-
Undesignated funds			<u>147,047</u>		<u>142,996</u>
			<u>163,635</u>		<u>142,996</u>

The notes of pages 17 - 20 form an integral part of these financial statements.

The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 31 December 2024. The directors acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

The members have not required the company to obtain an audit of its financial statements for the year in question in accordance with section 476. These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The financial statements were approved by the Trustees on 12th September 2025.

Dr E J Corcoran

Dr E J Corcoran

Chair Company registration number 3228419



1 Accounting policies Charity information

The Down's Syndrome Research Foundation Limited is a private company limited by guarantee incorporated in England and Wales. The registered office is DSRF-Uk, P.O. Box 576, Tunbridge Wells, Kent, TN2 9WJ.

1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's governing document, the Companies Act 2006, FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" ("FRS 102") and the Charities SORP "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (effective 1 January 2019). The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP for charities not to prepare a Statement of Cash Flows.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention. The principal accounting policies adopted are set out below.

1.2 Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives.

Designated funds are a subdivision of unrestricted funds, set aside by the trustees.

Restricted funds are subject to specific conditions by donors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements. Expenditure which meets these criteria is drawn from the fund.

Endowment funds are subject to specific conditions by donors that the capital must be maintained by the charity.



1.4 Income

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

The value of services provided by volunteers is not incorporated into these financial statements. Where services are provided to the charity as a donation that would normally be purchased from our suppliers, this contribution is included in the financial statements at an estimate based on the value of the contribution to the charity.

1.5 Expenditure

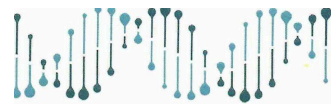
Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, it is probable that a transfer of economic benefits will be required in settlement, and the amount of the obligation can be measured reliably.

Expenditure is classified by activity. The costs of each activity are made up of the total of direct costs and shared costs, including support costs involved in undertaking each activity. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs which contribute to more than one activity and support costs which are not attributable to a single activity are apportioned between those activities on a basis consistent with the use of resources. Central staff costs are allocated on the basis of time spent, and depreciation charges are allocated on the portion of the asset's use.

Expenditure includes irrecoverable VAT.

1.6 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.



1.7 Financial instruments

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

Basic financial liabilities

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

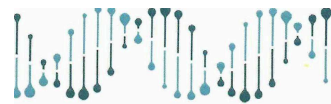
Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or **less**. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

Derecognition of financial liabilities

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

1.8 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.



Termination benefits are recognised immediately as an expense when the charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

2 Critical accounting estimates and judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated 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 ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods.

3 Donations and legacies

	Unrestricted Funds	Unrestricted Funds
	2024	2023
	£	£
Donations and gifts	33,819	10,276
Legacies	55,438	62,981
Grants receivable	-	9,000
	<u>89,257</u>	<u>82,257</u>

4 Investments

	Unrestricted Funds	Unrestricted Funds
	2024	2023
	£	£
Interest receivable	<u>1,901</u>	<u>874</u>



5 Raising Funds

	Unrestricted Funds	Unrestricted Funds
	2024	2023
	£	£
Fundraising costs	20,016	9,322
	<u>20,016</u>	<u>9,322</u>

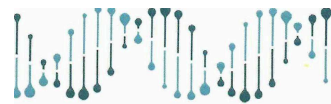
6 Charitable Activities

	2024	2023
	£	£
Research	9,168	1,000
	<u>9,168</u>	<u>1,000</u>
Share of support costs (see note 7)	40,385	36,431
Share of governance costs (see note 7)	950	600
	<u>50,503</u>	<u>38,031</u>

7 Support costs

	Support costs	Governance costs	2024	Support costs	Governance costs	2023
	£	£	£	£	£	£
Staff	37,256	-	37,256	34,159	-	34,159
Office costs	2,048	-	2,048	2,518	-	2,518
Website and internet	1,081	-	1,081	754	-	754
Legal and professional fees	-	500	500	-	-	-
Independent Examiner's Fees	-	450	450	-	600	600
TOTAL	<u>40,385</u>	<u>950</u>	<u>41,335</u>	<u>37,431</u>	<u>600</u>	<u>38,031</u>

THE DOWN'S SYNDROME RESEARCH FOUNDATION LIMITED
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FOR THE YEAR ENDED 31 DECEMBER 2024



	Support costs	Governance costs	2024	Support costs	Governance costs	2023
	£	£	£	£	£	£
Staff	37,256	-	37,256	34,159	-	34,159

8 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year except as detailed in note 14.

9 Financial Instruments

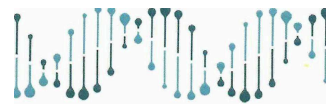
	2024	2023
	£	£
Carrying amount of financial assets		
Instruments measured at fair value through profit or loss	<u>48,123</u>	<u>47,367</u>

10 Debtors

	2024	2023
	£	£
Amounts falling due within one year:		
	<u>52,376</u>	<u>603</u>
Prepayments and accrued income	<u>52,376</u>	<u>603</u>

11 Creditors: amounts falling due within one year

	Total	Unrestricted Funds
	2024	2023
	£	£
Creditors	<u>1,824</u>	<u>1,550</u>
	<u>1,824</u>	<u>1,550</u>



12 Designated funds

The income funds of the charity have included unrestricted funds comprising the following unexpended balances of donations and grants held on trust for specific purposes designated by the trustees.

	Balance at 1 January 2024	Incoming Resources	Outgoing Resources	Balance at 31 December 2024	Balance at 31 December 2023
	£	£	£	£	£
Menstrual health research	16,558	-	-	16,588	16,588

Menstrual health research is a project investigating the menstrual health-related experiences of 10-19yr olds with Down Syndrome in the UK.

13 Analysis of net assets between funds

	Undesignate d funds 2024	Designate d funds 2024	Total 2024	Undesignat ed funds 2023	Designate d Funds 2023	Total 2023
	£	£	£	£	£	£
Fund balances at 31 December 2024 are represented by:	147,047	16,588	163,635	126,408	16,588	142,996
TOTAL	147,047	16,588	163,635	126,408	16,588	142,996

14 Related party transactions

Transactions with related parties

During the year the charity entered into the following transactions with related parties:

Ms Christine Elliott is the sister of two of the trustees, Dr E J Corcoran Elliott (Chair) and Dr P C Elliott, and daughter of the trustee Ms S M Elliott. On 12 March 2015 the other trustees, including the two independent trustees, appointed Ms Christine Elliott as the charity's Office Manager on a freelance basis at the rate of £25 per hour for 20-30 hours per week. This was ratified by the current trustees during 2017. Fees of £37,256 were paid during the year ended 31 December 2024 (£34,727 in 2023), and nil expenses (2023: £1,093).

DOWNS SYNDROME RESEARCH FOUNDATION LIMITED

England & Wales - Charity number 1058548

Accounts

Charity registration number 1058548

Company registration number 3228419 (England and Wales)

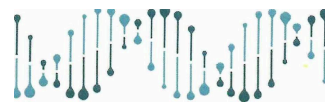


Downs Syndrome
Research Foundation UK

THE DOWN'S SYNDROME RESEARCH FOUNDATION LIMITED
ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023



Trustees	Dr E J Corcoran Mrs S M Elliott Dr P C Elliott Mrs L Murray Mrs M Kato-Kmiec Mrs S Costerton Mrs A Morley
Secretary	Mrs S M Elliott
Charity Number	1058548
Company Number	3228419
Registered Address	Dsrf-UK P.O. Box 576 Tunbridge Wells Kent TN2 9WJ
Independent Examiner	Ashleigh Martin Simple Support Solutions 90 St Catherine's Road Southampton SO18 1LU
Bankers	CAF Bank Ltd 25 Kings Hill Avenue Kings Hill West Malling Kent ME19 4JQ



Trustees' Annual Report:

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Financial Statements

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The financial statements have been prepared in accordance with the accounting policies set out in the notes to the financial statements and comply with the charity's governing document, the Companies Act 2006 and 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)' effective 1 January 2019.

Governance

Legal Status

The charitable company was incorporated on 23 February 1996 and registered with the Charity Commission on 9 October 1996. The charitable company has no share capital but is limited by the guarantee of its members. The liability of the members is restricted to £10 each. The charitable company is governed by its revised Articles of Association which were adopted on 5th July 2010.

The Trustees, who are also the directors and the members for the purpose of the Companies Act, present this report and the un-audited financial statements of the charity for the year ended 31st December 2023.

Objects

The Charity's objects are to relieve the sickness of persons with Down's syndrome in particular through the provision of grants and funding for research into Down's syndrome for the purpose of finding treatments and cures, and to publish the results of such research widely and for the public benefit.

Organisation

The charity's activity is organised by the trustees, appointed by the members.

Financial Controls

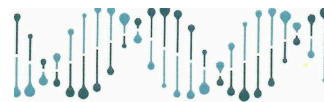
The trustees have considered the key financial risks and have systems in place to mitigate those risks.

Registered address

PO Box 576, Tunbridge Wells, TN2 9WJ

Email: elizabeth.corcoran@dsrf-uk.org

Website: www.dsrf-uk.org



Trustees

The trustees, who served throughout the year ending 31 December 2023 and up to the date of the signing of this report, are:

Dr. E. J. Corcoran nee Elliott (Chair)
Mrs. S. M. Elliott (Secretary)
Mr. P. C. Elliott
Mrs. L. Murray
Mrs. M. Kato-Kmiec
Mrs. Sarah Costerton
Mrs. Alison Morely

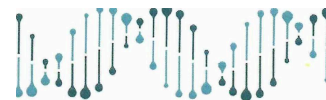
As a charity our policy is to retain existing proven trustees in order to ensure continuity of the research aims and have within the charity those skills and experience essential for the work that we do.

When we seek a new trustee, it is always to improve the quality and efficiency of the work we do and to add to the skill set of the trustees. This includes the need to have additional trustees monitoring the day-to-day operations and finances of the charity. We can also use social media and email lists to advise interested people to apply.

Any person who is willing to act as a trustee, and is permitted by law to do so, may be appointed to be a trustee by a decision of the trustees. No person may be appointed as a trustee unless he or she has reached the age of 18 years. A trustee may not appoint an alternate director or anyone to act on his or her behalf at meetings of the trustees.

We may invite parents or individuals who show an interest in the aims of the charity and who do not have conflicts of interests in performing their duties of trustee. Every trustee is selected very carefully and must read the essential trustee guide from the Charity Commission, the governing document, the Articles of Association of the charity and agree to abide by these rules. Once elected as trustees they are trained on the job and can always resign or be asked to resign. In the year ahead we would like to invite a trustee who has Down's syndrome to join us.

The trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake.



Activities and Achievements

The DSRF UK is the only charity in the UK focused purely on medical research for the collection of biomedical difficulties caused by Trisomy 21, known as Down's syndrome (DS). The backbone of our work is the belief that people with DS also deserve the scientific innovations afforded to other conditions and illnesses over the last 50 years.

In all activities throughout 2023 due consideration towards the public benefit was made by the trustees, with reference to the Charity Commission's guidance on public benefit.

Our activities during 2023

Transcranial Photobiomodulation with Near-Infrared Light for Language in Individuals With Down Syndrome (TransPhoM-DS)

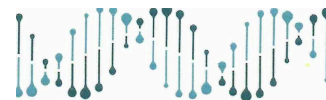
In early 2018 Dr. Corcoran began discussions with Dr Paolo Cassano, Assistant Professor of Psychiatry, (Harvard Medical School) and Director of Photobiomodulation (PMB) (Massachusetts General Hospital - Division of Neuropsychiatry) about the possibilities of a pilot study of PBM in DS. Throughout 2020 there were multiple revisions and an external protocol review by PBM experts. In August 2020, the final protocol and budget was approved for DSRF UK funding by the board of trustees. In January 2021, the funding contract was signed to fund USD \$415,420 over 2 years (2021, 2022). Financial support was distributed in two payments; the first one, for the amount of \$211,000 (£151,323) and the second payment was made in September 2022, for the amount of \$203,629 (£184,313). Dr. Corcoran hosted a FB Live webinar with Paolo covering the study which had approximately 850 views adding to the increasing interest in this cutting-edge field. It was agreed that there would be a one year no cost extension to analyze and formalize the results. The work was ongoing in 2023.

Systematic review of treatment modalities for obstructive sleep apnoea (OSA) in children with Down's syndrome

This piece of work forms part of on-going research led by Dr. Cathy Hill and her team at the University Hospital Southampton. Our funding of the Systematic Review will allow Dr. Hill and her team to make further improvements. A Systematic Review of Research is a 'deep dive' into all published and unpublished research looking to answer a specific question. The scope of the search has been OSA treatments in children with Down syndrome, how best to diagnose it and what impact it has on children's sleep and developing brains. Dr Rina Cianfaglione, research fellow to Dr Hill, will scrutinise the papers and systematically review the research that we have to date on OSA treatments in children with DS.

The Foundation have given Dr. Hill's team two grants: £12,375 in 2019 to support the writing of the Systematic Review (including a professionals' workshop for potential research collaborators) and £10,465 in 2020 for a piece of work building evidence for a multi-centre treatment trial for obstructive sleep apnoea in children with Down's syndrome.

Our support strengthens the case for funding from a large body such as the NIHR as the next stage of research will be very costly and outside of the Foundation funding capabilities. Additionally, The Foundation hosted a well-attended webinar on "Down's Syndrome and Sleep" with expert guest speakers Prof. Cathy Hill, Dr. Rina Cianfaglione and Dr. Lizzie Hill.



The publishing of the Systemic Review has been delayed due to gathering all data from the researchers for the analysis. Southampton hosted a national online meeting with Sleep Researchers and the team in Dublin have put together an impressive protocol testing different sleep interventions for people with DS and they are looking to open more sleep study centers. Funding for a nurse may be looked into in the future. Talks continued and expanded into 2023 with Prof. Cathy Hill, Dr. Rina Cianfaglione and Dr. Lizzie Hill regarding the possibility of funding a refreshed sleep study. Once a budget is put together it will be discussed with the trustees.

Down Syndrome and Sleep Research Network

In late 2023, following extensive discussions with leading experts in Down syndrome (DS) and sleep disorders, Dr. Elizabeth Corcoran identified a significant and long-standing need for a dedicated research network focused on sleep issues within this community. Recognizing the global gap in this area, Dr. Corcoran initiated plans to establish the world's first Down Syndrome and Sleep Research Network.

This pioneering network will bring together researchers specializing in both adult and pediatric care, focusing on diagnosing and treating sleep disorders in individuals with Down syndrome across the UK. The early stages of planning and budgeting have been completed, and fundraising efforts are currently underway. The official launch of the Sleep Network is tentatively scheduled for May 2025.

Menstrual Health Research

Talks began with Dr Katie Greenland, Assistant Professor with the London School of Hygiene. Dr. Greenland was seeking funding for a project investigating the menstrual health-related experiences of 10-19 year olds with Down Syndrome in the UK. This study could be an extremely beneficial training tool around menstruation. In 2024 we approved a budget for the study of £16,588.

The research will generate important evidence on the unmet menstrual-related requirements and identify opportunities for interventions to improve the menstrual health of people with Down syndrome in the UK. Details of how to participate in this study will be forthcoming for carers and adolescents aged 10-19 years. Through comprehensive online surveys and in-depth interviews with adolescents with Down syndrome and their caregivers, the project seeks to uncover the unique challenges and needs of these young individuals.

"I am so glad this complex aspect of life is being researched. It is important for Health Care Professionals to understand the challenges people with Down's syndrome and their families face regarding menstruation and its management" L (mum to daughter with DS and Autism)

People with learning disabilities experience a wide range of health inequities, and menstrual health is no exception. The well-being of adolescents during their menstrual cycle impacts not only their physical health but also their schooling, mental and social well-being. Despite its importance, there is a stark lack of evidence and guidance available to support individuals with Down syndrome and their caregivers or doctors in managing menstrual health well.



The team will include experts Sarah Polack, Associate Professor in Disability Research at the International Centre for Evidence in Disability (ICED) at LSHTM and Dr Jane Wilbur, Assistant Professor at the International Centre for Evidence in Disability (ICED) at the LSHTM, focusing on disability and water, sanitation and hygiene (WASH).

Sarah Pollock has a wealth of experience in discovering the health experiences and needs of those with disabilities, critically with those with living experience at the heart of her research methods. Dr Wilbur has research expertise in the area of menstrual health in those with learning disabilities developing the Bishesta campaign (in Nepal) and the Veivanua campaign for Vanuatu's humanitarian responses.

This partnership also marks a significant step forward in our commitment to supporting underserved communities and addressing health inequities faced by individuals with learning disabilities.

Going to Hospital

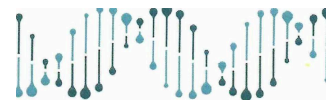
'Going to Hospital' is an accessible publication for patients with learning disability or autism and aims to help children & young people with additional needs to know what they might expect to see when visiting hospital for an appointment or when being admitted for a procedure. Trustees granted £1,000 towards its publication in 2023.

Advocacy and Campaign work



a. Don't Screen Us Out (DSUO) campaign activities

Since 2016, we have been dedicated to supporting the Don't Screen Us Out (DSUO) campaign, which addresses the ethical concerns surrounding current prenatal screening policies. The UK's obligations under the Convention on the Rights of Persons with Disabilities (CRPD) affirm that society must accommodate, include, and support disabled individuals and their families. Yet, there is significant evidence that parents of unborn children diagnosed with disabilities are not provided with the necessary information and resources to make an informed choice about continuing their pregnancy and raising a disabled child. This lack of support undermines the rights of both the child and their family, and we stand firmly against such practices.



b. Embracing Complexity Coalition (was the Neurodevelopmental Coalition Policy Group)

In March 2017 we became a part of a coalition of medical research charities representing various neurodevelopmental conditions/disabilities. Multi-morbidity is increasingly being recognised as the norm for people diagnosed with a neurodevelopmental condition.

We believe that priorities should be guided by the people we serve, with diagnosis being timely, accurate, and accessible. Clinical diagnosis should not be a prerequisite for receiving support or adjustments, which must be personalized, easily accessible, and rooted in the best available evidence. Research should shift away from predefined diagnostic categories and instead reflect the priorities of the neurodivergent community. Improving the lives of neurodivergent individuals is a responsibility shared by all public services and sectors of society. Ultimately, we achieve more when we collaborate and work together.

The current project is the Top 10 Priorities for Research on Neurodivergence.

c. NHS Fetal Anomaly Screening Programme (FASP) Information and Education Sub-Group

As a stakeholder in the antenatal screening programme, we are requested to provide our thoughts on any changes to the current antenatal screening pathways.

d. National Down Syndrome Policy Group (NDSPG)

In 2021 the National Down Syndrome Policy Group was formed comprising of people from a wide range of other charities and support groups: all with the common aim of ensuring that the voice of people with Down syndrome is heard in society and reflected in government policy. A third of the founding officers have Down's syndrome. Three of the DSRF UK trustees are Founding Officers; Lynn Murray, Elizabeth Corcoran and Sarah Costerton. The NDSPG is the Secretariat to the new All Party Parliamentary Group, organising and supporting the meetings and work of the APPGDS and providing lived experience. In 2023 the NDSPG applied for charity status and has been accepted. Dr Corcoran is also a trustee for the NDSPG and represents the NDSPG on medical policy issues and ensuring the importance of research is not forgotten.

e. The Down Syndrome Act 2023 and Guidance Development

In June 2021, Dr. Liam Fox MP introduced the Down Syndrome Bill to Westminster during the Parliamentary session. We are proud to report that in 2022, the Down Syndrome Act was passed into UK law, a historic achievement that enshrines specific provisions for education, social, and healthcare support for individuals with Down syndrome. This Act marks a transformative step toward ensuring that the unique needs of people with Down syndrome are not only acknowledged but met with tailored services and policies.



As we look ahead, our focus is on ensuring that the statutory guidance accompanying the Down Syndrome Act is as comprehensive and impactful as possible. We are actively working alongside civil servants, policymakers, and advocacy groups to shape robust guidelines that will bring the full weight of the Act into practice. Throughout 2023, we have been deeply involved in consultations with the Department of Health and Social Care regarding the Call for Evidence, a critical process that will shape the final framework. Dr. Elizabeth Corcoran, representing our organisation, continues to attend the Down Syndrome Statutory Guidance Advisory Group, working closely with key government stakeholders, including the then Minister, Maria Caulfield MP.

Next steps in this process include deepening our collaboration with researchers, healthcare professionals, and education specialists to generate evidence-based recommendations that inform the DS Act's implementation. We are committed to facilitating research that addresses gaps in knowledge, especially in the areas of mental health, long-term care, and educational needs for individuals with Down syndrome. As we continue to engage with policymakers, we aim to ensure that the statutory guidance not only reflects the best available evidence but also promotes ongoing research and development in Down syndrome care, education, and quality of life.

Financial review

At the beginning of 2023 the charity had net unrestricted reserves of £107,218. Following a surplus of £35,778 (2022: deficit 206,348) the charity ended the year with reserves of £142,996. The trustees have designated £16,588 towards the menstrual health research, leaving an undesignated balance of £126,408.

Legacies

i) The estate of Ms. Gladys Cullis

In 2014 it was confirmed that the charity would receive the benefit of the legacy of the estate of Ms. Gladys Cullis, which was then estimated to be £60,000. In 2017 the charity was advised that there was uncertainty over the total amount due. In 2022 a cheque was received in December and deposited in January 2023 for the amount of £8,591.60. A final cheque of £1,787.50 was deposited in 2024. The monies received from this legacy in total are £85,556.26.

ii) The estate of Raymond Harry Thompson

In 2015 our charity, along with seven other charities, was included in the will of the late Raymond Harry Thompson. The money on this estate will be paid upon the passing of Mr. Thompson's son Keith, and until that time is being held in trust. Trust assets are valued at £538,353 in February 2018. £300,000 is currently invested in an old mutual wealth collective investment bond. A further £200,000 is invested in NS & I (income bonds) with the balance of funds in a trust bank account. As of June 29, 2020, Shorts Chartered Accountants (overseers of trust) report that due to the economic impact of Covid19 there has been a decrease in the value of one of the main trust investments of about 7.5% which is a loss of about £23,000 bringing it down to £277,000. The NS&I investment remains the same at £200,000. There has since been some recovery in the value of the investment, which now stands at £324,856.86. Sadly, Principal beneficiary of trust (Raymond "Keith" Thompson) died on the 11 July 2022. A final distribution check in the amount of £51,101.12 was deposited April 2023.



iii) Robert Thomas Plato

In 2021 our charity, along with forty other charities, received notice that we have been included in the will of the late Robert Thomas Plato. Mr. Plato's estate is comprised of a property, bank accounts and personal possessions. They will be valued and sold in due course. The solicitors, Huggins Lewis Foskett, will then divide the proceeds amongst the charities listed in his will. We received a letter stating Mr. Plato's property had been sold and our portion of the estate was enclosed. A distribution check in the amount of £7,500.00 was deposited June 2023. One final check was received in the amount of £1,274.78.

iv) The Estate of Kay Johnston

At the end of 2023 we were notified we were a beneficiary from the Estate of Kay Johnston in the amount of £4,379.41.

Fund-raising activity continued in 2023, with income from monthly donations, fundraising, legacies and interest, totaling £83,313. At the end of 2023 the charity had £142,996 unrestricted reserves and nil restricted funds totaling £142,996.

Reserves policy

The accumulation of funds (reserves) donated for medical research is a necessary strategy when donations are very small, and the cost of clinical research is very great. The process by which these funds are accumulated is described as a 'war chest' for medical research.

Our Reserves policy is to accumulate sufficient funds to fund appropriate medical research projects as approved by the trustees. Our funds could also be used as 'seed money' but it will attract other funders to support these projects i.e. by matched funding. There is always the expectation that research needs more funds that we can raise in a single year and some of that income is needed to fund ongoing operations. We believe a charity should give assurance to lenders and creditors that we can meet our financial commitments by holding an appropriate amount of reserves. Funds that we receive as a result of a grant for a specific project are spent immediately and/or within the guidelines for the project. The same rule applies for any grant that has a restriction on how it must be used.



Statement of Trustees' Responsibilities

The law applicable to incorporated charities in England and Wales requires the trustees, who are also directors of the company, to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of its financial activities during the year. In preparing those financial statements, the trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Make judgments and estimates that are reasonable and prudent;
- State whether applicable accounting standards and statements of recommended practice have been followed subject to any departures disclosed and explained in the financial statements;
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in operation.

The trustees are responsible for maintaining proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The financial statements have been prepared in accordance with current statutory requirements, the current Statement of Recommended Practice, and the Financial Reporting Standard (FRS) 102.

Approved on behalf of the trustees:

.....
Dr. E. J. Corcoran nee Elliott (Chair)

24 September 2024

**THE DOWN'S SYNDROME RESEARCH FOUNDATION LIMITED
INDEPENDENT EXAMINER'S REPORT
TO THE TRUSTEES OF THE DOWN'S SYNDROME RESEARCH
FOUNDATION LIMITED**



I report to the trustees on my examination of the financial statements of The Down's Syndrome Research Foundation Limited (the charity) for the year ended 31 December 2023.

Responsibilities and basis of report

As the trustees of the charity (and also its directors for the purposes of company law) you are responsible for the preparation of the financial statements in accordance with the requirements of the Companies Act 2006 (the 2006 Act).

Having satisfied myself that the financial statements of the charity are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of the charity's financial statements carried out under section 145 of the Charities Act 2011 (the 2011 Act). In carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5) (b) of the 2011 Act.

Independent examiner's statement

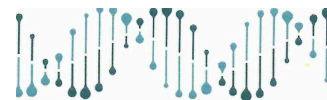
I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the charity as required by section 386 of the 2006 Act; or
2. the financial statements do not accord with those records; or
3. the financial statements do not comply with the accounting requirements of section 396 of the 2006 Act 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; or
4. the financial statements have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

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.

Ashleigh Martin
Simple Support Solutions Ltd (Company number 14947423)
90 St Catherine's Road
Southampton
SO18 1LU

THE DOWN'S SYNDROME RESEARCH FOUNDATION LIMITED
STATEMENT OF FINANCIAL ACTIVITIES
INCLUDING INCOME AND EXPENDITURE ACCOUNT
FOR THE YEAR ENDED 31 DECEMBER 2023



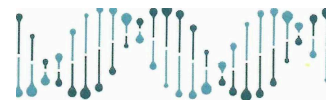
		Unrestricted Funds	Restricted Funds	TOTAL	Unrestricted Funds	Restricted Funds	TOTAL
		2023	2023	2023	2022	2022	2022
			£	£	£	£	£
Notes							
Income							
Donations and legacies	3	82,257	-	82,257	20,104	-	20,104
Investments	4	874	-	874	484	-	484
Total Income		83,131	-	83,131	20,588	-	20,588
Expenditure							
Raising Funds	5	9,322	-	9,322	513	-	513
Charitable Activities	6	38,031	-	38,031	226,423	6,650	233,586
Total Expenditure		47,353	-	47,353	226,936	6,650	233,586
Net expenditure for the year/ Net movement in funds		35,778	-	35,778	(206,348)	(6,650)	(212,998)
Fund balances at 1 January 2023		107,218	-	107,218	313,566	6,650	320,216
Fund balances at 31 December 2023		142,996	-	142,996	107,218	-	107,218

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

THE DOWN'S SYNDROME RESEARCH FOUNDATION LIMITED
BALANCE SHEET
AS AT 31 DECEMBER 2023



		2023		2022	
		£	£	£	£
	Notes				
Current assets					
Debtors	11	602		9,194	
Investments	12	47,367		46,859	
Cash at bank and in hand	13	96,577		54,603	
		<u>144,546</u>		<u>110,656</u>	
Creditors: amounts					
due within one year	14	<u>(1,550)</u>		<u>(3,438)</u>	
Net current assets			<u>142,996</u>		<u>107,218</u>
Unrestricted Income funds					
Designated funds	15		-		-
Undesignated funds			<u>142,996</u>		<u>107,218</u>
			<u>142,996</u>		<u>107,218</u>

The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 31 December 2023.

The directors acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

The members have not required the company to obtain an audit of its financial statements for the year in question in accordance with section 476.

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The financial statements were approved by the Trustees on 24 September 2024.

Dr E J Corcoran
 Dr E J Corcoran

Chair

Company registration number 322841



1 Accounting policies Charity information

The Down's Syndrome Research Foundation Limited is a private company limited by guarantee incorporated in England and Wales. The registered office is Dsrf-Uk, P.O. Box 576, Tunbridge Wells, Kent, TN2 9WJ.

1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's governing document, the Companies Act 2006, FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" ("FRS 102") and the Charities SORP "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (effective 1 January 2019). The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP for charities not to prepare a Statement of Cash Flows.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention. The principal accounting policies adopted are set out below.

1.2 Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives.

Designated funds are a subdivision of unrestricted funds, set aside by the trustees.

Restricted funds are subject to specific conditions by donors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements. Expenditure which meets these criteria is drawn from the fund.

Endowment funds are subject to specific conditions by donors that the capital must be maintained by the charity.



1.4 Income

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

The value of services provided by volunteers is not incorporated into these financial statements. Where services are provided to the charity as a donation that would normally be purchased from our suppliers, this contribution is included in the financial statements at an estimate based on the value of the contribution to the charity.

1.5 Expenditure

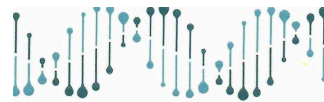
Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, it is probable that a transfer of economic benefits will be required in settlement, and the amount of the obligation can be measured reliably.

Expenditure is classified by activity. The costs of each activity are made up of the total of direct costs and shared costs, including support costs involved in undertaking each activity. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs which contribute to more than one activity and support costs which are not attributable to a single activity are apportioned between those activities on a basis consistent with the use of resources. Central staff costs are allocated on the basis of time spent, and depreciation charges are allocated on the portion of the asset's use.

Expenditure includes irrecoverable VAT.

1.6 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.



1.7 Financial instruments

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

Basic financial liabilities

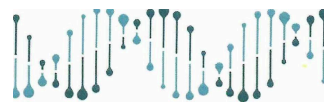
Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or *less*. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

Derecognition of financial liabilities

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.



1.8 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

2 Critical accounting estimates and judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

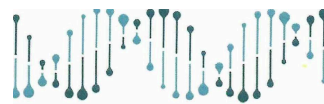
The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current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

3 Donations and legacies

	Unrestricted Funds	Unrestricted Funds
	2023	2022
	£	£
Donations and gifts	10,276	11,512
Legacies	62,981	8,592
Grants receivable	9,000	-
	<u>82,257</u>	<u>20,104</u>

4 Investments

	Unrestricted Funds	Unrestricted Funds
	2023	2022
	£	£
Interest receivable	874	484
	<u>874</u>	<u>484</u>

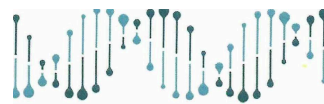


5 Raising Funds

	Unrestricted Funds	Unrestricted Funds
	2023	2022
	£	£
<u>Fundraising and publicity</u>		
Other fundraising costs	9,322	513
Support costs	-	-
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Fundraising and publicity	9,322	513
	<hr/>	<hr/>
	9,322	513
	<hr/>	<hr/>

6 Charitable Activities

	2023	2022
	£	£
Research	1,000	184,312
Advocacy	-	10,063
	<hr/>	<hr/>
	1,000	194,375
Grant Funding Activities (see note 7)	-	900
Share of support costs (see note 8)	36,431	37,042
Share of governance costs (see note 8)	600	756
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	38,031	233,073
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Analysis by fund		
Unrestricted funds	38,031	226,423
Restricted funds	-	6,650
	<hr/>	<hr/>
	38,031	233,073
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7 Grants Payable

	2023	2022
	£	£
Grants to institutions	-	-
Grants to individuals	-	900
	<u>-</u>	<u>900</u>

8 Support costs

	Support costs	Governance costs	2023	Support costs	Governance costs	2022
	£	£	£	£	£	£
Office management	34,159	-	34,159	33,480	-	33,480
Office costs	2,518	-	2,518	2,199	-	2,199
Website and internet	754	-	754	870	-	870
Other overheads	-	-		493	-	493
Independent Examiner's Fees	-	600	600	-	756	756
	<u>37,431</u>	<u>600</u>	<u>38,031</u>	<u>37,042</u>	<u>756</u>	<u>37,798</u>

9 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year except as detailed in note 17.

10 Financial Instruments

	Total	Unrestricted Funds
	2023	2022
	£	£
Carrying amount of financial assets		
Instruments measured at fair value through profit or loss	<u>47,367</u>	<u>46,859</u>



11 Debtors

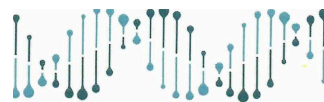
	Total	Unrestricted Funds
	2023	2022
	£	£
Amounts falling due within one year:		
Prepayments and accrued income	<u>603</u>	<u>9,194</u>

12 Current asset investments

	Total	Unrestricted Funds
	2023	2022
	£	£
Unlisted investments	<u>47,367</u>	<u>46,859</u>

13 Creditors: amounts falling due within one year

	Total	Unrestricted Funds
	2023	2022
	£	£
Other creditors	32	32
Accruals and deferred income	<u>1,528</u>	<u>3,406</u>
	<u>1,550</u>	<u>3,438</u>



14 Designated funds

The income funds of the charity have included unrestricted funds comprising the following unexpended balances of donations and grants held on trust for specific purposes designated by the trustees.

	Balance at 1 January 2022	Incoming Resources	Balance at 1 January 2023	Incoming Resources	Balance at 31 December 2023
	£	£	£	£	£
Menstrual health research	-	-	-	16,588	16,588

Menstrual health research - a project investigating the menstrual health-related experiences of 10-19yr olds with Down Syndrome in the UK.

15 Analysis of net assets between funds

	Undesignate d funds 2023	Designate d funds 2023	Total 2023	Undesignat ed funds 2022	Designate d Funds 2022	Total 2022
	£	£	£	£	£	£
Fund balances at 31 December 2023 are represented by:	126,408	16,588				
Current assets/liabilities	<u>126,408</u>	<u>16,588</u>	<u>142,996</u>	<u>107,218</u>	<u>-</u>	<u>107,218</u>

16 Related party transactions

Transactions with related parties

During the year the charity entered into the following transactions with related parties:

Ms Christine Elliott is the sister of two of the trustees, Dr E J Corcoran Elliott (Chair) and Dr P C Elliott, and daughter of the trustee Ms S M Elliott. On 12 March 2015 the other trustees, including the two independent trustees, appointed Ms Christine Elliott as the charity's Office Manager on a freelance basis at the rate of £25 per hour for 20-30 hours per week. This was ratified by the current trustees during 2017. Fees of £34,727 were paid during the year ended 31 December 2023 (£34,200 in 2022), and expenses of £1,093 (2022: £nil).