

NATIONAL DOWN SYNDROME POLICY GROUP

England & Wales · Charity number 1204298

Details

Status Registered

Legal form CIO

Registered 2023-08-10

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

Contact

Address Po Box 576 Po Box
Tunbridge Wells
TN2 9WJ

Phone 07515121733

Email contact@ndspg.org

Website <https://ndspg.org/>

Activities

Objects: TO RELIEVE THE NEEDS OF PEOPLE WITH DOWN SYNDROME, THEIR PARENTS, FAMILIES, AND CARERS, IN ENGLAND, SCOTLAND AND WALES, IN PARTICULAR BUT NOT EXCLUSIVELY BYA) THE PROVISION OF FORUMS TO FACILITATE DISCUSSION BETWEEN PEOPLE WITH DOWN SYNDROME, ORGANISATIONS THAT REPRESENT THEM, AND ORGANISATIONS THAT PROVIDE SUPPORT, CARE, OR SERVICES TO PEOPLE WITH DOWN SYNDROME.B) THE COLLATION AND DISSEMINATION OF INFORMATION AND BEST PRACTICE IN THE SUPPORT OF PEOPLE WITH DOWN SYNDROME IN ACCESSING SERVICES, IN PARTICULAR, BUT NOT EXCLUSIVELY, IN MATERNITY CARE, HEALTHCARE, EDUCATION, HOUSING, SOCIAL CARE AND EMPLOYMENT.C) THE PROVISION OF SUPPORT TO LOCAL SUPPORT GROUPS TO FACILITATE CLOSER NETWORKING AND HELP IMPROVE KNOWLEDGE AND SKILLS WITH THE AIM TO HELP THEM BE MORE EFFECTIVE IN THE WORK THEY DO.

Activities: To relieve the needs of people with Down syndrome, their parents, families, and carers by the provision of forums to facilitate discussion between people with Down syndrome, organisations that represent them, and organisations that provide support, care, or services to people with Down syndrome.

Classification

- **How:** Provides Advocacy/advice/information
- **What:** Disability
- **Who:** People With Disabilities

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£1,624	£8,718	-	-
2024-03-31	£20,514	£2,467	-	-

Trustees

Name	Role	Appointed
Julie Duff	Chair	2025-05-27
Angie Emrys-Jones		2025-05-27
CAROLINE WARREN		2023-08-10
Dr ELIZABETH JANE CORCORAN		2023-08-10
Florence Garrett		2025-09-08
Jonathan Angus		2025-08-19
Ken Ross OBE		2023-08-10
Lucienne Cooper		2023-08-10
Lynn Murray		2025-05-27
Nicola Enoch		2023-08-10
PETER BRACKETT		2023-08-10
Rachael Ross		2023-08-10
Thomas Fionn Crombie Angus		2025-08-19

NATIONAL DOWN SYNDROME POLICY GROUP

England & Wales - Charity number 1204298

Accounts



National Down Syndrome Policy Group

Annual Report for the year ended 31 March 2025

National Down Syndrome Policy Group

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National Down Syndrome Policy Group

Trustees' Report and Financial Statements period ended 31 March 2025

Introduction

We are pleased to produce the annual reports and accounts for the National Down Syndrome Policy Group (NDSPG). The past Year has been a very busy for the NDSPG as we continue to engage with government and the civil services around the guidance in relation to the Down Syndrome Act 2022. Many of our members and trustees have been engaged with policymakers about the form and content of the guidance.

We continue to expand our Advisory Group networks and are delighted at the formation of dedicated groups in Cheshire and Cornwall; we look forward to the creation of additional groups elsewhere in the UK. We were also very pleased to hold our inaugural summit of the Advisory Group, hosted by law firm A&O Shearman in central London on 27th March 2025.

This report provides details on our aims and highlights some of the activities undertaken to achieve them.

In addition, as Chair, I am hugely grateful for the dedicated and passionate work carried out by all of our group members, who tirelessly work to improve the lives of people with Down syndrome.

Objects

To relieve the needs of people with Down syndrome, their parents, families, and carers, in England, Scotland and Wales, in particular but not exclusively by:

- A) The provision of forums to facilitate discussion between people with Down syndrome, organisations that represent them, and organisations that provide support, care, or services to people with Down syndrome.
- B) The collation and dissemination of information and best practice in the support of people with Down syndrome in accessing services, in particular, but not exclusively, in maternity care, healthcare, education, housing, social care and employment.
- C) The provision of support to Local Support Groups to facilitate closer networking and help improve knowledge and skills with the aim of helping them be more effective in the work they do.

Activities

We are delighted that the work of the NDSPG has been supported by over 125 Down syndrome regional and national organisations and thousands of individuals.

The NDSPG is further supported by an Advisory Group consisting of over 120 members who meet regularly and actively feed into our work. This is the only policy group led by people with Down syndrome in the UK.

The NDSPG continues to create and support additional Advisory Groups across the UK. Advisory Groups directly address the first of our objects and they develop forums for adults with Down syndrome to gather – either in person or online – to discuss a wide range of topics.

Over its first year as a charitable organisation, the NDSPG has created additional Advisory Groups across the UK. Advisory Groups directly address the first of our objects, and they develop forums for adults with Down syndrome to gather—either in person or online—to discuss a wide range of topics.

We have been actively working with Ministers, the Department of Health and Social Care and the Department of Education to create guidance for the Down Syndrome Act, which is discussed in more detail below.

National Down Syndrome Policy Group

Trustees' Report and Financial Statements period ended 31 March 2025

How our activities deliver public benefit

All our charitable activities focus on relieving the needs of people with Down syndrome, their parents, families, and carers in England, Scotland and Wales.

We were pleased to see the successful enactment of the Down Syndrome Act in 2022, which received Royal Assent on 28 April 2022, to improve access to services and life outcomes for people with Down's syndrome. The Act requires the government to develop and consult on guidance that authorities must have regard to when providing specific health, social care, education and housing services. The NDSPG has been working with the civil service to shape the formulation of the guidance to the Act. Representatives of the NDSPG have participated in a formal working group led by the Department of Health and Social Care (DHSC). Working in collaboration with the DHSC, the NDSPG also created several online and in-person forums for adults with Down syndrome to help shape the content for guidance.

The direct involvement of people with Down syndrome in the discussions around the guidance's shape is essential to its success, and we are delighted to have facilitated this. Below, we provide more detail on the specifics of our achievement.

Achievements and performance

The following highlights activities of the charity and the Advisory Group:

- The NDSPG is the Secretariat for the All-Party Parliamentary Group on Down Syndrome (APPGDS). In line with the dissolution of Parliament for the elections on 4th July 2024, the APPGDS was also formally closed but was reformed at the inaugural meeting on 8th October 2024. We are delighted that Damian Hinds MP and Andrew Cooper MP agreed to co-chair the APPG. Further meetings took place in November 2024, January and March 2025. Minutes of the meetings can be found at <https://appg-ds.org/minutes/>.
- The APPG covered topics such as the case for including Down syndrome within the education census, progress on the guidance to the Down Syndrome Act, the Assisted Dying Bill, DS-specific training. Members of the Advisory Group of the NDSPG presented at these meetings.
- We were also very pleased to hold our inaugural summit of the Advisory Group, hosted by law firm A&O Shearman in central London on 27th March 2025. The words of Ed Daly, one of our speakers on the day summarised the event beautifully: "I felt connected to everyone and afterwards I was happy to hear that members were inspired to find their local ICB and work with them to make the Act meaningful and powerful. The atmosphere at the Summit was buzzing with special friendship and a mission to help improve the lives of everyone with Down syndrome."

National Down Syndrome Policy Group

Trustees' Report and Financial Statements period ended 31 March 2025



- Civil servants and NDSPG trustees frequently met, with additional ad hoc meetings regarding the content and progress of the Down Syndrome Act guidance and other relevant policies.
- Agreement for Down syndrome to be part of the annual school census, commencing in January 2025.
- On March 4th, 2025, we held our fourth annual awareness reception in Westminster. It was a fantastic turnout, with over 150 advocates and Down syndrome charity leaders attending from all over the UK.

Financial review

The opening balance of the accounts as at 31 March 2024 was £20,532. During the period under review, the charity accumulated income of £1,624 and incurred expenditure of £8,718. Expenses for the Advisory Group totalled £7,409 with administration for the World Down Syndrome Day being the main source of expense at £2,440. National travel costs for the AG totalled £1,090. In addition, £1,237 was spent on IT services relating to website and email, the same amount incurred by NDSPG. The closing balance in the account at the end of the period was £13,438.

Reserves Policy

While we are happy to have been granted funds to support the Advisory Group's activity, we recognise the need to build up non-restricted reserves. Given the charity's 'virtual' nature, the most significant costs relate to updating the website and email communications.

National Down Syndrome Policy Group

Trustees' Report and Financial Statements period ended 31 March 2025

Structure, governance and management

The NDSPG's governing document is a foundation-based constitution, and the organisation is constituted as a Charitable Incorporated Organisation ("CIO"). The first charity trustees were appointed via the creation of the CIO. Apart from the first charity trustees, every trustee must be appointed for three years by a resolution passed at a properly convened meeting of the charity trustees.

The trustees meet regularly—typically every other week—via Zoom. All trustees are involved in critical decisions facing the charity. Decisions regarding the day-to-day management of social media are delegated to a communications committee. Similarly, day-to-day implementation and facilitation of the Advisory Group are delegated to a subgroup.

Reference and administrative details

Charity name: National Down Syndrome Policy Group, also called NDSPG.

Charity number: 1204298

Registered address: PO Box 576, Tunbridge Wells, TN2 9WJ

Trustees in office for the duration of the reporting period

Peter Brackett	Chair
Nicola Enoch	Vice Chair
Rachael Ross MBE	Co-Treasurer
Ken Ross OBE	Co-Treasurer
Dr Elizabeth Corcoran	
Lucienne Cooper	
Caroline Warren	

Trustees appointed after the year end

Julie Duff	- appointed 27 May 2025
Angie Emrys-Jones	- appointed 27 May 2025
Lynn Murray	- appointed 27 May 2025
Jonathan Angus	- appointed 19 August 2025
Thomas Angus	- appointed 19 August 2025

Exemptions from disclosure

No exemptions were applied for this report.

Funds held as custodian trustee on behalf of others.

This is not applicable.

Declarations

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

Signed on behalf of the charity's trustees:

Peter Brackett

P Brackett - Trustee

Date 28 / 08 / 2025

National Down Syndrome Policy Group

Independent Examiner's Report to the Trustees on the Unaudited Financial Statements of the National Down Syndrome Policy Group

I report to the Trustees on my examination of the financial statements of the National Down Syndrome Policy Group for the year ended 31 March 2025 set out on pages 6 to 9.

Respective responsibilities of trustees and examiner

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 2011 Act).

It is my responsibility to:

- examine the accounts under Section 145 of the 2011 Act
- to follow the procedures laid down in the General Directions given by the Charity Commission (under Section 145(5)(b) of the 2011 Act); and
- to state whether particular matters have come to my attention.

Basis of the independent examiner's report

My examination was carried out in accordance with the General Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statements below.

Independent examiner's statement

In connection with my examination, no matter has come to my attention:

- (1) which gives me reasonable cause to believe that, in any material respect, the requirements
 - to keep accounting records in accordance with Section 130 of the 2011 Act; and
 - to prepare accounts which accord with the accounting records and to comply with the accounting requirements of the 2011 Act

have not been met; or

- (2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.



Mrs J D Watts FCCA, ACA
James Todd & Co
Furzehall Farm
110 Wickham Road
Fareham
Hampshire
PO16 7JH

Date: 03 / 09 / 2025

National Down Syndrome Policy Group

Receipts and Payments for the period ended 31 March 2025

	<u>Notes</u>	<u>Unrestricted</u>	<u>Restricted</u>	<u>Total 2025</u>	<u>Total 2024</u>
Donations	2	1,624	-	1,624	540
Grants	2	-	-	-	19,974
Total receipts		1,624	-	1,624	20,514
Expenditure in furtherance of the objects of the charity	3	1,309	6,554	7,863	2,467
Governance and support costs of the Charity	4	-	855	855	-
Total Payments		1,309	7,409	8,718	2,467
Excess of Receipts over Payments		315	(7,409)	(7,094)	18,047
Bank accounts at 31 March 2024		558	19,974	20,532	2,485
Bank accounts at 31 March 2025		873	12,565	13,438	20,532

National Down Syndrome Policy Group
Statement of Assets and Liabilities as at 31 March 2025

	<u>Unrestricted</u>	<u>Restricted</u>	<u>2025</u>	<u>2024</u>
Funds at Bank	873	12,565	13,438	20,532
Total Funds	<hr/> 873 <hr/>	<hr/> 12,565 <hr/>	<hr/> 13,438 <hr/>	<hr/> 20,532 <hr/>

Approved by the trustees on 28 / 08 / 2025 and signed on its behalf.

Peter Brackett P Brackett - TRUSTEE

J Duff J Duff – TRUSTEE

National Down Syndrome Policy Group

Notes to the financial statements for the period ended 31 March 2025

ACCOUNTING POLICIES

Basis of Preparation of Accounts

The financial statements are prepared on a receipts and payments basis and incorporate the results of the principal activity which is described in the trustees report and which is continuing.

The accounts have been prepared in accordance with the Charities Act 2011, and with applicable Accounting Standards and the Statement of Recommended Practice.

Donations and Grants

Donations are recognised in the accounts when they are received. Donations and grants are recognised as restricted or unrestricted as required.

Expenditure

Resources expended are accounted for on a payments basis.

Governance Costs

Only those costs specifically identified as for the administration and management of the charity are included in the accounts as such costs.

2. DONATIONS AND GRANTS

	<u>2025</u>	<u>2024</u>
Donations	1,624	540
Grants	-	19,974
	<u>1,624</u>	<u>20,514</u>

3. CHARITABLE ACTIVITIES

	<u>2025</u>	<u>2024</u>
Admin support	488	-
External practitioner costs	650	-
Insurance	320	-
Subscriptions	402	-
WDSD 2025 event	2,440	1,127
Travel	1,090	-
IT software and consumables	2,473	1,340
	<u>7,863</u>	<u>2,467</u>

National Down Syndrome Policy Group

Notes to the financial statements for the period ended 31 March 2025

4. GOVERNANCE COSTS

	<u>2025</u>	<u>2024</u>
Accountancy	840	-
Bank charges	15	-
	855	-

5. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	<u>2025</u> <u>Unrestricted</u>	<u>2025</u> <u>Restricted</u>	<u>Total</u> <u>2025</u>	<u>Total</u> <u>2024</u>
Fixed Assets	-	-	-	-
Current Assets	873	12,565	13,438	20,532
Current Liabilities	-	-	-	-
	873	12,565	13,438	20,532

MOVEMENT IN FUNDS	<u>At 1.4.24</u>	<u>Incoming</u>	<u>Resources</u>	<u>At 31.3.25</u>
Unrestricted Funds				
General Fund	558	1,624	(1,309)	873
Restricted Funds				
Advisory Group	19,974	-	(7,409)	12,565
	20,532	1,624	(8,718)	13,438

RESTRICTED FUND – NATIONAL DOWN SYNDROME ADVISORY GROUP

The National Down Syndrome Advisory Group is comprised of over 120 adults with Down syndrome from across the UK who meet regularly and work the National Down Syndrome Policy Group. Led by individuals with Down syndrome who are successful advocates in their own right, the group shares lived experiences to influence policy and shape government guidance, including the Down Syndrome Act. They advise MPs, take part in consultations, present and contribute regularly to the All-Party Parliamentary Group on Down Syndrome, and advocate for meaningful inclusion in education, healthcare, employment, and social care, working to ensure improved outcomes for people with Down syndrome.

6. TRANSACTIONS WITH TRUSTEES

The charity's trustees do not receive remuneration or expenses.

National Down Syndrome Policy Group
Registered Charity No. 1204298
Principal Office: PO Box 576, Tunbridge Wells, TN2 9WJ

James Todd and Co
Furzehall Farm
110 Wickham Road
Fareham
Hampshire
PO16 7JH

Dear Sirs

During the course of your independent examination of the financial statements of the Charity for the period ended 31 March 2025, the following representations were made to you by management and trustees.

1. We have fulfilled our responsibilities as trustees under the Charities Act 2011, for preparing financial statements, in accordance with the applicable financial reporting framework (FRS102 Charity SORP), that give a true and fair view and for making accurate representations to you for the financial statements which you have prepared on our behalf for the Charity.
2. We confirm that all accounting records have been made available to you for the purpose of your independent examination, in accordance with your terms of engagement, and that all the transactions undertaken by the Charity have been properly reflected and recorded in the accounting records. All other records and related information, including minutes of all management, trustees' and members' meetings have been made available to you. We have given you unrestricted access to persons within the Charity in order to obtain your evidence and have provided any additional information that you have requested for the purposes of your examination.
3. We confirm that significant assumptions used by us in making accounting estimates, including those measured at fair value, are reasonable.
4. We confirm that all known actual or possible litigation and claims whose effects should be considered when preparing the financial statements have been disclosed to you and accounted for and disclosed in accordance with the applicable financial reporting framework.
5. We confirm there have been no events since the balance sheet date which require disclosure or which would materially affect the amounts in the financial statements, other than those already disclosed or included in the financial statements.
6. We confirm that we are aware that a related party of the Charity is a person or organisation with either (directly or indirectly) controls, has joint control of, or significantly influences the Charity or vice versa and as a result will include trustees, other key management, close family and other business interests of the previous. We confirm that the related party relationships and transactions set out below are a complete list of such relationships and transactions and that we are not aware of any further related parties or transactions.

<u>Party</u>	<u>Relationship</u>	<u>Nature of transaction</u>
P Brackett	Trustee	None
N Enoch	Trustee	None
R Ross	Trustee	None
K Ross	Trustee	None
Dr E Corcoran	Trustee	None
L Cooper	Trustee	None
C Warren	Trustee	None

7. We confirm that all related party relationships and transactions have been accounted for and disclosed in accordance with the applicable financial reporting framework.
8. We confirm that the Charity has had, at no time during the year, any arrangement transaction or agreement to provide credit facilities (including advances and credits granted by the Charity) for trustees, nor to provide guarantees of any kind on behalf of the trustees.
9. We confirm that the Charity has not contracted for any capital expenditure other than as disclosed in the financial statements.
10. We confirm that we are not aware of any possible or actual instance of non-compliance with those laws and regulations which provide a legal framework within which the Charity conducts its activities and which are central to the Charity's ability to conduct its activities, except as explained to you in the financial statements.

11. We acknowledge our responsibility for the design and implementation of internal controls to prevent and detect fraud. We confirm that we have disclosed to you the results of our own risk assessment that the financial statements may be misstated as a result of fraud.
12. We confirm that there have been no actual or suspected instances of fraud involving trustees, management or employees who have a significant role in internal control or that could have a material effect on the financial statements. We also confirm that we are not aware of any allegations of fraud by former trustees, employees, regulators or others.
13. We confirm that, having considered our expectations and intentions for the next 12 months and the availability of unrestricted reserves, the Charity is a going concern.
14. We confirm that all grants, donations and other income, including those subject to special terms or conditions or received for restricted purposes, have been notified to you. There have been no breaches of terms or conditions during the period regarding the application of such income.
15. We confirm that we are not aware of any matters of material significance that should be reported to the Charity Commission.

We confirm that the above representations are made on the basis of enquiries of management and staff with relevant knowledge and experience (and, where appropriate of supporting documentation) sufficient to satisfy us that we can properly make each of the above representations to you and that to the best of our knowledge and belief they accurately reflect the representations made to you by the trustees during the course of your audit.

Yours faithfully

Peter Brackett

.....
P Brackett – Trustee

Signed on behalf of the Board of Trustees

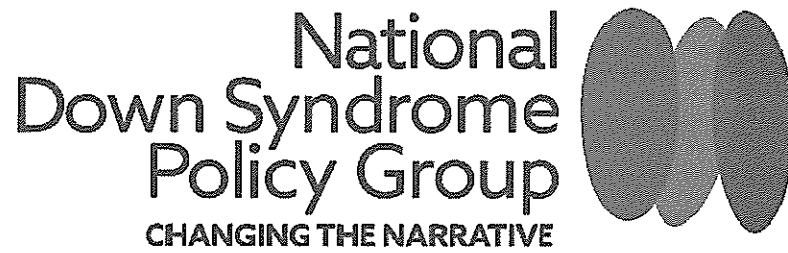
28 / 08 / 2025

.....
Date

NATIONAL DOWN SYNDROME POLICY GROUP

England & Wales - Charity number 1204298

Accounts



National Down Syndrome Policy Group

**Annual Report for the period 10th August 2023 to 31 March
2024**

National Down Syndrome Policy Group

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National Down Syndrome Policy Group

Trustees' Report and Financial Statements period ended 31 March 2024

Introduction

We are pleased to produce the inaugural annual reports and accounts for the National Down Syndrome Policy Group (NDSPG). Although the group has been in operation for several years now, we applied for and were granted charitable status in August 2023. The past two years in particular, have been very busy for the NDSPG following the enactment of the Down Syndrome Act in 2022 and many of our members and trustees have been engaged with policymakers about the form and content of the guidance that underpins the Act. The recent Parliamentary elections have created a temporary pause of that work, but we look forward to engaging with the new ministers to ensure the successful publication of the guidance. We continue to expand our Advisory Group networks and are delighted at the formation of dedicated groups in Cheshire and Cornwall; we look forward to the creation of additional groups elsewhere in the UK.

This report provides details on our aims and highlights some of the activities undertaken to achieve them. In addition, as Chair, I am hugely grateful for the dedicated and passionate work carried out by all of our group members, who tirelessly work to improve the lives of people with Down syndrome.

Objects

To relieve the needs of people with Down syndrome, their parents, families, and carers, in England, Scotland and Wales, in particular but not exclusively by:

A) The provision of forums to facilitate discussion between people with Down syndrome, organisations that represent them, and organisations that provide support, care, or services to people with Down syndrome.

B) The collation and dissemination of information and best practice in the support of people with Down syndrome in accessing services, in particular, but not exclusively, in maternity care, healthcare, education, housing, social care and employment.

C) The provision of support to Local Support Groups to facilitate closer networking and help improve knowledge and skills with the aim of helping them be more effective in the work they do.

Activities

We are delighted that the work of the NDSPG has been supported by over 125 Down syndrome regional and national organisations and thousands of individuals.

The NDSPG is further supported by an Advisory Group consisting of over 120 members who meet regularly and actively feed into our work. This is the only policy group led by people with Down syndrome in the UK.

Over its first year as a charitable organisation, the NDSPG has created additional Advisory Groups across the UK. Advisory Groups directly address the first of our objects, and they develop forums for adults with Down syndrome to gather—either in person or online—to discuss a wide range of topics.

We have been actively working with Ministers, the Department of Health and Social Care and the Department of Education to create guidance for the Down Syndrome Act, which is discussed in more detail below.

The NDSPG is the Secretariat for the All-Party Parliamentary Group on Down Syndrome (APPGDS). The APPGDS continues to enjoy cross-party support. Meetings were held in September 2023 and January 2024. Minutes of the meetings can be found at <https://appg-ds.org/minutes/>. Topics covered included the case for including Down syndrome within the education census, progress on the guidance to the Down Syndrome Act, DS-specific training, and interactions with the Integrated Care Board lead on Down syndrome. Members of the Advisory Group of the NDSPG presented at these meetings.

National Down Syndrome Policy Group

Trustees' Report and Financial Statements period ended 31 March 2024

How our activities deliver public benefit

All our charitable activities focus on relieving the needs of people with Down syndrome, their parents, families, and carers in England, Scotland and Wales.

We were pleased to see the successful enactment of the Down Syndrome Act in 2022, which received Royal Assent on 28 April 2022, to improve access to services and life outcomes for people with Down's syndrome. The Act requires the government to develop and consult on guidance that authorities must have regard to when providing specific health, social care, education and housing services. The NDSPG has been working with the civil service to shape the formulation of the guidance to the Act. Representatives of the NDSPG have participated in a formal working group led by the Department of Health and Social Care (DHSC). Working in collaboration with the DHSC, the NDSPG also created several online and in-person forums for adults with Down syndrome to help shape the content for guidance.

The direct involvement of people with Down syndrome in the discussions around the guidance's shape is essential to its success, and we are delighted to have facilitated this. Below, we provide more detail on the specifics of our achievement.

Achievements and performance

The first year as a charitable organisation has been a busy one. The following highlights activities of the charity and the Advisory Group:

- At least weekly meetings were held between civil servants and NDSPG trustees, with additional ad hoc meetings regarding the content and progress of the Down Syndrome Act guidance and other relevant policy.
- Regular update meetings were held with relevant Ministers regarding the progress of the guidance, the school census and other relevant policy.
- Regular meetings were held with the All-Party Parliamentary Group on Down Syndrome Chair Sir Liam Fox, regarding the administration and agendas for the APPGDS meetings.
- The Policy Advisory Group had seven regular monthly meetings and nine meetings of the facilitators' forum. The average number of attendees was 20 people with Down syndrome and 12 supporters (6 and 6 at the facilitators' meetings).
- We collaborated in forming two local groups that meet monthly in person, both with DS leadership, in Cheshire (Sept 23) and Cornwall (Feb 24).
- We met twice online with the National Down Syndrome Society's Ambassadors Group to compare UK and United States policy initiatives.
- We partnered with the Books Beyond Words team with Baroness Hollins to create a new book on 'Brain Health and Dementia Awareness for people with Down syndrome'. The team continues to seek funding for this project.

National Down Syndrome Policy Group

Trustees' Report and Financial Statements period ended 31 March 2024

- The chair of the Advisory Group gave presentations about our work at multiple conferences, including a self-advocacy gathering in Birmingham, Down Syndrome UK in Leamington Spa, online with Disability Rights UK, and others in Belfast, Brussels, Utrecht, Copenhagen and Vienna. He was also interviewed about our work on multiple radio shows and podcasts.
- In November, we co-hosted the ICB leads meeting in London with the NDSPG and the DHSC, with both the Secretary of State and the Under Secretary of State for Health and Social Care in attendance. The symposium was deemed a success with 26 ICBs represented. Local ICB officer asked two of our members to help establish Down syndrome Stakeholders Groups, and further connections were established with local groups.
- We sent two representatives to the DHSC Down Syndrome Statutory Guidance Advisory Group, which includes most people with Down syndrome.
- On behalf of the DHSC, we then ran three Lived Experience Engagement focus groups (Cheshire, London, and online).
- Lived Experience Engagement focus groups totalled 60 people with Down syndrome.
- During this period, three of our members presented to the All-Party Parliamentary Group on Down Syndrome meetings, reporting to the members on our work.
- On World Down Syndrome Day, we co-hosted with the Secretary of State reception at 10 Downing Street, where our work was commended repeatedly in the speech by Minister Maria Caulfield and by the Chair of the APPGDS, Sir Liam Fox. Our patron, actor Tommy Jessop, delivered a speech highlighting the need for more opportunities for people with Down syndrome in all areas of society, particularly employment, which was well received. With over 200 guests in attendance from supporting Down syndrome organisations across the UK, this was the largest gathering in the history of people with Down syndrome at the prime minister's residence.
- The group has continued to effectively heighten awareness about Down syndrome and learning disabilities. A notable achievement occurred when three members of our Advisory Group were interviewed by Down Street Press and participated in an iconic photo shoot. Subsequently, these individuals were featured on the social media platforms of both the Prime Minister and Mrs. Murty, further amplifying our message.

Financial review

The charity opened its accounts with a bank balance of £2,485. During the period under review, the charity accumulated income of £20,514 and incurred expenditure of £2,467. The income comprised £19,974 of restricted funds and £540 general donations (unrestricted). There were two main items of expenditure. £1,340 was spent on IT services relating to website and email. We held a very successful event for World Down Syndrome Day on 21st March, which 10 Downing Street hosted, and the incidental costs of this event were £1,127. The closing balance in the account at the end of the period was £20,532.

National Down Syndrome Policy Group

Trustees' Report and Financial Statements period ended 31 March 2024

Reserves Policy

While we are happy to have been granted funds to support the Advisory Group's activity, we recognise the need to build up non-restricted reserves. Given the charity's 'virtual' nature, the most significant costs relate to updating the website and email communications.

Structure, governance and management

The NDSPG's governing document is a foundation-based constitution, and the organisation is constituted as a Charitable Incorporated Organisation ("CIO"). The first charity trustees were appointed via the creation of the CIO. Apart from the first charity trustees, every trustee must be appointed for three years by a resolution passed at a properly convened meeting of the charity trustees.

The trustees meet regularly—typically every other week—via Zoom. All trustees are involved in critical decisions facing the charity. Decisions regarding the day-to-day management of social media are delegated to a communications committee. Similarly, day-to-day implementation and facilitation of the Advisory Group are delegated to a subgroup.

Reference and administrative details

Charity name: National Down Syndrome Policy Group, also called NDSPG.

Charity number: 1204298

Registered address: PO Box 576, Tunbridge Wells, TN2 9WJ

Trustees in office for the duration of the reporting period

Peter Brackett	Chair
Nicola Enoch	Vice Chair
Rachael Ross MBE	Co-Treasurer
Ken Ross OBE	Co-Treasurer
Dr Elizabeth Corcoran	
Lucienne Cooper	
Caroline Warren	

Exemptions from disclosure

No exemptions were applied for this report.

Funds held as custodian trustee on behalf of others.

This is not applicable.

Declarations

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

Signed on behalf of the charity's trustees:



Mr K Ross - Trustee

Date

18/11/24

National Down Syndrome Policy Group

Independent Examiner's Report to the Trustees on the Unaudited Financial Statements of the National Down Syndrome Policy Group

I report on the accounts for the period ended 31 March 2024 set out on pages 6 to 8.

Respective responsibilities of trustees and examiner

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year (under Section 144(2) of the Charities Act 2011 (the 2011 Act)) and that an independent examination is required.

It is my responsibility to:

- examine the accounts under Section 145 of the 2011 Act
- to follow the procedures laid down in the General Directions given by the Charity Commission (under Section 145(5)(b) of the 2011 Act); and
- to state whether particular matters have come to my attention.

Basis of the independent examiner's report

My examination was carried out in accordance with the General Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statements below.

Independent examiner's statement

In connection with my examination, no matter has come to my attention:

(1) which gives me reasonable cause to believe that, in any material respect, the requirements

- to keep accounting records in accordance with Section 130 of the 2011 Act; and
- to prepare accounts which accord with the accounting records and to comply with the accounting requirements of the 2011 Act

have not been met; or

(2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.



Mrs J D Watts FCCA, ACA
James Todd & Co
24 Landport Terrace
Portsmouth
Hampshire
PO1 2RG

Date: 9 December 2024

National Down Syndrome Policy Group

Receipts and Payments for the period ended 31 March 2024

	<u>Notes</u>	<u>Unrestricted</u>	<u>Restricted</u>	<u>Total</u> <u>2024</u>
Donations		540	-	540
Grants		-	19,974	19,974
Total receipts		<u>540</u>	<u>19,974</u>	<u>20,514</u>
Expenditure in furtherance of the objects of the charity	2	1,340	-	1,340
Governance and support costs of the Charity		1,127	-	1,127
Total Payments		<u>2,467</u>	<u>-</u>	<u>2,467</u>
Excess of Receipts over Payments		(1,927)	19,974	18,047
Bank accounts at 10 August 2023		2,485	-	2,485
Bank accounts at 31 March 2024		<u>558</u>	<u>19,974</u>	<u>20,532</u>

National Down Syndrome Policy Group
Statement of Assets and Liabilities as at 31 March 2024

	<u>Unrestricted</u>	<u>Restricted</u>	<u>2024</u>
Funds at Bank	558	19,974	20,532
Total Funds	<u>558</u>	<u>19,974</u>	<u>20,532</u>

Approved by the trustees on *18/11/24* and signed on its behalf.

Rachael Ross Ms R Ross - TRUSTEE

K Ross Mr K Ross – TRUSTEE

National Down Syndrome Policy Group

Notes to the financial statements for the period ended 31 March 2024

1. ACCOUNTING POLICIES

Basis of Preparation of Accounts

The financial statements are prepared on a receipts and payments basis and incorporate the results of the principal activity which is described in the trustees report and which is continuing.

The accounts have been prepared in accordance with the Charities Act 2011, and with applicable Accounting Standards and the Statement of Recommended Practice.

Donations and Grants

Donations are recognised in the accounts when they are received. Donations and grants are recognised as restricted or unrestricted as required.

Expenditure

Resources expended are accounted for on a payments basis.

Governance Costs

Only those costs specifically identified as for the administration and management of the charity are included in the accounts as such costs.

2. GOVERNANCE COSTS OF THE CHARITY

	<u>2024</u> £
Computer costs and subscriptions	1,340

3. RESTRICTED FUNDS

	<u>2024</u> £
Grants received from:	
National Lottery Community Fund	19,974

4. TRANSACTIONS WITH TRUSTEES

The charity's trustees do not receive remuneration or expenses.