

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.

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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.

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- 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.

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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

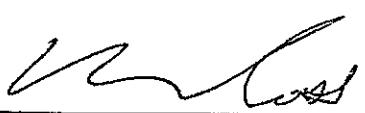
	<u>Notes</u>	<u>Unrestricted</u>	<u>Restricted</u>	<u>Total</u> <u>2024</u>
Donations		540	-	540
Grants		-	19,974	19,974
Total receipts		<u>540</u>	<u>19,974</u>	<u>20,514</u>
Expenditure in furtherance of the objects of the charity	2	1,340	-	1,340
Governance and support costs of the Charity		1,127	-	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>

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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

 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.