

The Dystonia Society

A company limited by guarantee

Trustees Report & Financial Statements for the
year ended 31 March 2024

Contents

Reference and administrative information	2
Report of the trustees	3 - 15
Independent examiner's report	16
Statement of financial activities	17
Balance sheet	18-19
Statement of cash flows	20
Notes to the financial statements	21-29

Reference and administrative information

Charity registration number

1062595 (England and Wales) and SC042127 (Scotland)

Company registration number

03309777

Patron

Tully Kearney MBE

Trustees and Directors

Amit Batla	From November 2023
Daniel Berry	Until September 2023
Emily Birden	From August 2023
Christopher Bradshaw (Chair)	Until 31 st March 2024
Timothy Gannicliffe	
Ross Grant	
Qamar Khan, MBE (Chair)	From 1 st April 2024
Antonella Macerollo	From November 2023
Nick Morgan	Until June 2023
Sophie Norman	From August 2023
Fernanda Perez	From August 2023
Penny Ritchie Calder MBE	
Andrew Russell	Until July 2023
Robert Semple	
Katie Wells	Until January 2024
James Wishart	Until September 2023

Secretary

Roger Edmonds FCA

Medical Advisers

Prof. Mark Edwards
Mr. Daniel Ezra
Ms. Lucy Hicklin
Dr Jean-Pierre Lin
Dr. Marie-Helene Marion
Dr. Kathryn Peall
Prof. Tom Warner

Registered Office

3rd Floor
89 Albert Embankment
London
SE1 7TP

Independent Examiner

Michael Williams ACA
30 Retford Drive
Sutton Coldfield
B76 1DG

Bankers

CAF Bank
Kings Hill
West Malling
Kent ME19 4TA

Bank of Scotland
14/16 Cockspur Street
London SW1Y 5B

Objectives & Activities

The trustees, who are also the directors of the company, submit their report and the financial statements of The Dystonia Society ("the Society") for the year ended 31 March 2024 on the basis of the accounting policies set out in Note 1 to the financial statements, and comply with the requirements of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial reporting Standard in the UK and Republic of Ireland (FRS102) (effective 1 January 2015) (Charities SORP, FRS102). The reference and administrative information on the previous page forms part of this report.

Principal Objective

The Society, as derived from the objects set out in our Articles of Association, are to promote the welfare of people who living with any form of the neurological movement disorder known as dystonia, or from similar or related conditions and to advance the education of the public about all aspects of the said conditions. Under our operating name of Dystonia UK, we provide support and information for our community both nationally and locally. We are the only national charity dedicated to supporting people with dystonia throughout the UK.

Review of Activity

Our mission is "We exist to give hope and support to those living with dystonia. Creating UK and worldwide awareness." During year 2023-24 we have continued in developing the charity to meet the needs of both members and the wider dystonia community.

Our goals have been:

- **Reach Out, Reach All**
-Providing support and information for people living with dystonia.
- **Your Voice Heard**
-Influencing national policies and promoting best practice to meet the needs of the dystonia community
- **Ensuring Dystonia Matters**
-Raising awareness about dystonia and Dystonia UK
- **Dystonia Research**
-Supporting research and development for improved treatment and management of dystonia

The Annual Report of the Trustees for 2023/24 is set out under our four strategic goals.

Reach Out, Reach All

-Providing support and information for people living with dystonia.

Dystonia UK is committed to becoming a more equal, diverse and inclusive organisation. We believe this commitment is key to delivering our strategy, and our organisational mission to be there for the whole dystonia community. Our 'Reach Out, Reach All' programme to improve and modernise the information and advice available for people with dystonia continues to grow and develop. We aim to make information as accessible as possible to people by using a variety of different channels – online, in print and in person.

In person –

Dystonia Matters Live 2023 was the largest community event for people living with dystonia in the UK. The event brought content usually found in our Dystonia Matters magazine to an audience live. The aim of the event was to support people living with dystonia across the UK with information and to provide an opportunity for them to connect with others.

"Excellent day, thank you so much for organising it! We spoke to others who felt the same!"

The event was held over 2 days in Newcastle at the end of June 2023, we hosted around 200 people – a mixture of adult and children with dystonia, family & friends, carers, and professionals. On our 'Main Stage' we hosted an assortment of sessions including interactive workshops, panel discussions and presentations. Our 'Acoustic Stage' was the setting for more informal sessions including live demonstrations, film screenings and deep dive workshops. We had 24 sessions and in total 33 patient & professional speakers.

"What a fabulous event, thank you to everyone involved and all the amazing speakers, such an open and honest event."

We also included a 40th anniversary party where we celebrated with our success and impact over the years with members of the community at an 80s themed party.

We continued to run our **local support groups** across the country with the support of volunteer group coordinators. With a mix of content, some including more formal speaker sessions and others more social, these small meet ups provide the opportunity for people to share experiences, meet others with dystonia and to find out more about dystonia. In 2023-24, we ran 24 meet ups in 6 counties.

Online –

Our **website** continues to serve as the primary source of information for people looking for information about dystonia with over 209,000 views across the year. Since the launch of our Info Hub in early 2023, we have had 1956 views also. Through our website we were also able to release recordings from Dystonia Matters Live 2023, with the first recording '100,000 voices' receiving nearly 300 views.

Our [webinars](#) enable people to access up to date information without the need to attend conferences or in-person events. Where people can access these in real time there is also an opportunity to put questions to our experts. They are also available on our website and YouTube channel to view later. This year, we hosted a further 4 in the 'Reach Out Reach All' series reaching 1000 views and attendees:

- Get involved with research
- Your Questions Answered with Dr Marie-Helene Marion
- Your Questions Answered with Dr Miles Humberstone
- Your Questions Answered: Dystonia and the cerebellum

"This webinar has been outstanding. I feel so much more positive. The support out there is amazing!" (Attendee of 'Your Questions Answered with Dr Miles Humberstone)

In our [Dystonia Matters Podcasts](#), people with dystonia and their families can share their stories in their own words as well as offering useful tips for their listeners. During 2023 we released Series 3 featuring Tajana, Beccy, Katie and Claire and we began releasing Series 4 in 2024 with stories from Rebecca, Hayley, Jason and Mark.

[In print –](#)

We continued our commitment to producing printed materials to reach those in particular who could be digitally excluded from information and support. As part of this we distributed our [Dystonia Matters magazine](#) to members 3 times across the year with updates on activities, research and news & stories from the community. We also sent out over 1000 of our '[What is dystonia?](#)' [booklet](#) which includes an overview of dystonia symptoms, causes and the different forms and types of dystonia.

"Thank you for the amazing booklet on dystonia. My husband who doesn't have dystonia said it was very informative and simple to understand."

Additionally, we responded to 561 [support enquiries](#) by phone, email and post.

[Your Voice Heard](#)

[-Influencing national policies and promoting best practice to meet the needs of the dystonia community.](#)

As the only UK-wide charity representing people living with dystonia, Dystonia UK uses its position to ensure your voice is heard. Our policy work and medical network are an important part of helping to raise awareness of dystonia at governmental and national level to help you get the best possible support, care and treatment. Some of the key work in which we have been involved is summarised below:

- We joined The Neurological Alliance and other member organisation representatives at the #BackThe1in6 petition hand in. - The parliamentary event was attended by 22 MPs or their representatives.
- We attended The Brain Charity's parliamentary drop in event to launch their report 'It's all in your head'. The report focussed on the importance of early diagnosis in neurological conditions and featured a dystonia story.
- We responded to the Major health conditions strategy call for evidence. We noted neurology has not been included in this, although few neurological conditions such as stroke and dementia have. Our response outlined the importance of including neurological communities particularly in the context of co-existing mental health issues (an area that has been included in the strategy).
- We co-signed the National Voices report Vision for the Future of Primary Care.
- We co-signed an open Letter to Secretary of State for Health and Social Care from Huntington's Disease Association on mental health.
- 'NeuroLifeNow' findings, included experiences of people with dystonia, were used to inform neurology transformation programmes nationally, influence major Government health initiatives and influence healthcare practice. 'NeuroLifeNow' is a social research platform owned by The Brain & Spine Foundation in collaboration with the Neurological Alliance.
- We presented to around 100 clinicians, many of whom specialise in movement disorders, at the British Neurotoxin Network's annual meeting, highlighting the importance of treating non-motor symptoms of dystonia.
- We were asked to contribute to the updates to the NHS inform (Scotland's equivalent of the online NHS condition page) page on dystonia.
- We took part as the patient representative in a NICE Scientific Advice project for Tardive Dyskinesia (TD).

Magnifying the voice of the dystonia community is of vital importance. Too often we hear that delays in diagnosis and treatment or support in education and employment are due to a lack of knowledge and understanding of the condition in its many forms. Our members provide valuable support by responding to surveys and giving their personal stories to provide evidence for the need for change. Throughout the year we have publicised surveys and policy related events to provide opportunities to magnify the voice of our community. We are members of more than 10 organisations working together on issues that will improve lives for people living with dystonia.

Ensuring Dystonia Matters

Raising awareness about dystonia and Dystonia UK

It's been 40 years since Dystonia UK was first founded, and the importance of raising awareness of dystonia is still one of our most important goals. 'What is dystonia?' is more than just a question on repeat for our community. It impacts the time to diagnosis, access to treatment and increases stigma and isolation. As part of our mission to combat this every September we run [Dystonia Awareness Month](#) in the UK with the aim to raise as much awareness of dystonia in the general public and across health services. During this month:

- Our social media content was seen 75,175 times
- There were 9846 views of our 'What is dystonia?' mini animation
- We had 10,000 visitors to our website
- We spoke to 30 MPs or their representatives at Houses of Parliament
- 733,731 subscribers were reached through an article in The Telegraph
- We presented to around 100 injectors at the British Neurotoxin Network meeting

Outside of this awareness raising never stops and we continuously push with the dystonia matters movement. We were pleased to support Alliance's across the country with their 'Brain Awareness Week' digital campaign, attend the Dystonia Ireland patient day and Brain Charity's Head Matters day, and also record an interview with the BBC to be aired on BBC Breakfast.

For the second year running we hosted the [Dystonia UK Awards](#). Shining a spotlight on our community, our awards applaud outstanding individuals making a difference to the community. We were delighted to announce the winners of the Dystonia Superstar Award, Masked Hero Award and Popular Podcast Award and at an awards ceremony held during Dystonia Awareness month where we further combined 40th anniversary celebrations.

Dystonia Research

Supporting research and development for improved treatment and management of dystonia

As a small charity, our support of research is often based around patient recruitment, general guidance and support and dissemination activities. We do this to promote research into dystonia research and to ensure that people with dystonia have opportunities to directly contribute to research as patients or by sharing their own experiences. In addition to this, when we have funds available, we will support projects with a financial contribution. We currently hold funds for research into blepharospasm will be reviewing how best to utilise these funds when resources allow.

Every year we endeavour to support a wide range of support studies that focus on different aspects of dystonia. Examples of activities we have supported this year are:

- Following a pilot study which we funded a couple of years ago, a full study is being conducted by Manchester Metropolitan University with a commercial sponsor. This study is developing computer machine-learning aided imaging of

neck muscles to enable greater accuracy in targeting the correct muscles for botulinum toxin injections. Dystonia UK is supporting this study by publicising the study to recruit the volunteer patients needed for the project.

- We have partnered with the British Paediatric Neurology Association and sit on the steering group for a project designed to establish Consensus Standards for the use of medications in paediatric dystonia. We think that in setting these standards, it will help to improve the quality of care for children with dystonia, and help reassure parents, carers and clinicians alike navigating the dystonia journey that management is on the right track.
- Dystonia UK has a history of working with students on the Clinical Psychology doctoral course at Lancaster University to support their research projects focused on the psychological effects of dystonia. We continue our support with the advertising and dissemination of several projects including most recently 'How are coping strategies used and experienced by people with cervical (neck) dystonia?'.
- We supported international research in attending the Dystonia Medical Research Foundation's 6th International Symposium.
- We were also pleased to share a survey from a group of researchers in Ireland examining the use and effectiveness of complementary therapies, such as acupuncture, in focal dystonia.
- Additionally, we were pleased to support Medtronic's event revealing the latest advances in deep brain stimulation devices including the BrainSense™ technology.

Feedback

In 2023 we surveyed our community on their views of our current services and future needs in our '[Your Voice Heard](#)' survey. We were pleased to capture a broad range of responses and to understand how our service users interact with our support. For example, when we asked respondents how satisfied they were with each of our services, our website and leaflets or booklets performed best with a positive satisfaction rating for each of 82%. We plan to use the full findings to help guide decisions about our future plans and services. We would like to take the opportunity to thank all of the people who took part and shared their views.

Fundraising

Despite a challenging landscape for the sector, we have had some great successes throughout the year. This is in part due to the increase in legacy donations as well as the increased revenue associated with Dystonia Matters Live 2023. Activities of note include:

- The London Marathon where our runner raised £2305
- The Great North Run where we had 12 runners who raised over £5990
- An increase in Dystonia UK members
- Raising £1020 at The Research Club's black-tie dinner and dance
- An increase in support from Trust and Foundations & Corporate sponsors through their support of Dystonia Matters Live 2023

We would also like to take the opportunity to thank the incredible generosity of people remembering us in their wills through Legacy gifts.

Our Future Plans

We aim to continue building on what we have achieved over the last few years with a strategy centred on four long term goals:

- [Connect our Community](#)

Dystonia UK will create a connected community for people living with dystonia that acts as both a source of support and movement for change. We will do this through local support groups, national events, and by building our community of members.

- [Enhance quality care & support](#)

Dystonia UK is continually working towards ensuring that no matter who they are or where they come from, everyone living with dystonia receives a timely diagnosis, has access to the best possible information, care, and treatment and has the tools and support to live a good life. We will continue to deliver improved information resources, support research and collaborate with relevant organisations and networks.

- [Reach Out, Reach All](#)

Dystonia UK seeks to reach the whole of the dystonia community across the UK and be an inclusive organisation that is accessible to all. We want to ensure that no one who needs our support goes without it. We will aim to achieve this through maintaining a varied offering of support, clinical outreach and increased public events.

- [Ensure our future](#)

We will endeavour to increase revenue by mobilising all communities affected by dystonia, engaging with individuals, corporations, and organisations to accelerate our progress and maximise the impact we make. We will strive to accomplish this through campaigns, partnerships and increased awareness.

Financial Review

Our financial position for the year ending 31st March 2024 was a surplus of £371,077 compared to a deficit of £8,363 in the previous year. Income was £692,353 (2023: £277,412) including £414,380 of legacy income (2023: £37,892). These exceptionally generous bequests have allowed the Charity to deliver our services, while investing in the future. Expenditure totalled £321,276 (2023: £285,775). This has increased due to higher level of activity (including Dystonia Matters Live) as well as inflation.

Fundraising continues to be challenging, but the impact that we have achieved from our new initiatives will, we hope, demonstrate the benefit of grants and donations. We will continue to promote the welfare of those living with the impact of dystonia and those who support them. To do this, we need to work to ensure that our income streams enable us to operate at break-even financially without reliance on legacy income. The trustees and staff have agreed a budget which assumes improvement in fundraising from charitable trusts, foundations and corporate sponsorship as well as the continued support of our many members and supporters. They will continue to monitor this income closely and to take action to ensure that reserves are sufficient to ensure that the charity can meet its obligations as they fall due.

Reserves

The trustees feel it is prudent to maintain the Society's general unrestricted reserves at a level sufficient to cover commitments such as property rental, creditors and other liabilities and to reflect the relative uncertainty of income and potential restrictions on its use. The level of reserves is reviewed as part of the budget setting process and at Board meetings in conjunction with the trustees' review of the financial position.

As the Charity benefited from significant legacy income in 2023/24, the trustees reviewed The Dystonia Society's reserves policy and designated £410,000 (total legacy income received in the year) from unrestricted reserves. This designated fund is made up of 2 elements:

- £350,000 - invested separately post year-end to earn additional income and to support future development of our services for the dystonia community, recognising that the Charity's non-legacy income does not currently cover all its expenditure.
- £60,000 – to be used as a reserve for DM Live in 2025 to be released in the 2025/26 Financial Year ensure that the event can go ahead as planned.

The level of unrestricted and undesignated reserves at 31st March 2024 represented 43% of unrestricted expenditure in the year (2023 97%).

Certain grants and donations received by the Society are given with for specific projects or initiatives. Restricted funds held in respect of these activities are carried forward if they are unspent or uncommitted. At 31st March 2024, funds of £157,315 were carried forward (2023: £108,764).

Investment Policy

Trustees reviewed the Charity's Investment policy in October 2023. Trustees agreed that their priorities for investing surplus funds are to earn a reasonable return at low risk while being able to access funds immediately if needed.

Trustees approved using a combination of CCLA's COIF Charities Deposit Fund (low-risk money market investments via the UK's leading specialist Charity Fund Manager) and bank deposit facilities to invest legacy income when received.

Structure, Governance and Management

The Society is a company limited by guarantee and is registered with the Charity Commission (Number 1062595) and with the Office of the Scottish Charity Regulator (SC042127). It is constituted by its Memorandum and Articles of Association. In the event of the insolvency of the Society, members can be asked to pay a maximum of £10 towards any unpaid debt.

Trustees

Control of The Dystonia Society is vested in the trustees, each of whom is a member of the Society. All decisions are made by the board of trustees, and at the present time no sub-committees are in operation.

Existing trustees encourage potential trustees to stand for election to maintain an appropriate balance of skills and experience. Where specific skills are needed the recruitment of potential trustees may be expanded to look beyond the current membership. Where there are more candidates than vacancies, trustees are elected by the members at an AGM or by a postal ballot. Trustees serve for a three-year term and then stand for re-election. A minimum of a third of the trustees stand for re-election each year. If less than a third of the trustees are due for re-election, then those nearest to the expiry of their term stand for re-election. Trustees serve for a maximum of three terms. A trustee may be appointed by the Board if a vacancy becomes available during the financial year and the trustee would then stand for re-election at the year end. The maximum number of trustees is twelve and the minimum is three. All trustees are given a programme of induction and training. Further training is available when required and relevant.

Staff

The board delegates operational planning and day-to-day management of the charity to the Senior Leadership Team (SLT), supported by the Chair of the Board. The SLT is formed of the Director of Fundraising and Communications and the Director of Operations and Development. This authority is delegated within approved limits. The Chair of the Board oversees the SLT's performance through reports and briefings. The SLT presents reports at board meetings and as part of the planning and budgeting process. The Chair of the Board carries out the appraisals for the SLT annually, on behalf of the board. The chair can involve another trustee in this appraisal work should they wish.

The SLT are supported by a small team of staff. They are a highly motivated team with dedication to the needs of people with dystonia. We have found that hybrid working is a viable and efficient way of working as it allows staff to work flexibly and adapt

appropriately to the needs of the organisation. Some trustees are more actively involved than their governance duties, supporting in work in responding to enquiries, developing information and support and finance and administration. We are very grateful for this additional support.

Risk

The trustees identify and review the major risks to which the Society is exposed and have established appropriate systems to anticipate further risks that may arise. The trustees consider that implementation of agreed actions and procedures will significantly reduce the probability and impact of these risks.

Principal risks & uncertainties

The most recent review identified the key risks to be an Income and financial risk, namely our ability to achieve sufficient fundraising and therefore maintain financial sustainability and People risk, namely our ability to avoid burnout while delivering planned activities.

It was recognised that our financial risk will be mitigated by significant legacy income. The Society undertakes careful monitoring of its projected cash flows and levels of reserves so that it can meet its financial duties. And our people risk will be mitigated by onboarding of new staff. We continue to review our staffing to ensure we have the right organisation, capacity and capabilities to deliver our ambitious plans.

Public Benefit

The trustees have referred to the Charity Commission's guidance on public benefit, and the guidance "Meeting the Charity Test" published by the Office of the Scottish Charity Regulator, when reviewing their aims and objectives, and planning the Society's future activity.

Statement of trustees' responsibilities

The trustees (who are also directors of the Society for the purposes of company law) are responsible for preparing the Trustees' Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (UK Generally Accepted Accounting Practice (UK GAAP)).

Company law requires the trustees to prepare financial statements for each financial year. Under that law the trustees have elected to prepare the financial statements in accordance with UK GAAP. Under company law, the trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and of the surplus or deficit of the charitable company for that period. In preparing those financial statements, the trustees are required to:

- Select suitable accounting policies and then apply them consistently.
- Observe the methods and principles in the Statement of Recommended Practice "Accounting and Reporting by Charities".
- Make judgements and estimates that are reasonable and prudent.
- State whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements.
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The trustees are responsible for keeping adequate accounting records which are sufficient to show and explain the charitable company's transactions and which disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006 and the charity's constitution. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the trustees are aware:

- There is no relevant information of which the charitable company's independent examiner is unaware.
- The trustees have taken all steps that they ought to have taken to make themselves aware of any relevant information and to establish that the independent is aware of that information.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Small company exemption

This report has been prepared in accordance with the special provisions for small companies under Section 15 of the Companies Act 2006.

Thanks

It is sadly not possible to thank every single person or organisation who has supported us, but we hope they are all aware of our huge gratitude. We would like to take the opportunity to give particular thanks to our outgoing Chair, Chris Bradshaw, for the time, dedication and commitment he made to Dystonia UK during his time as both a trustee and Chair. Additionally, we would like to thank:

Our Patron & Ambassadors

We're privileged to work with many individuals who help us by increasing awareness and encouraging others to support us. Our special thanks go to:

- Tully Kearney, MBE
- Gemma Stevenson
- Ella Middleton

Our Staff & Volunteers

We are very grateful indeed to the Society's staff team and volunteers. Their loyalty and commitment is invaluable.

Our Medical Network

We would like to thank our medical advisory group and other professionals who have attended meetings during the year and supported our work. They have donated both their time and expertise which is much appreciated by our members.

Our Members & Donors

Thank you to everyone who joined Team Dystonia UK or renewed their membership in 2023-24. The more members we have, the bigger the difference we can make and we are appreciative for all of your support. We are also grateful to everyone who supported us with a donation this year.

Those who remembered Dystonia UK in their Will

Once again, legacies were extremely important to our charity with the gifts we received representing more than half our income. We are enormously grateful to all those people who remember Dystonia UK with a gift in their Will allowing the charity to continue its work and support people living with dystonia.

Our Fundraisers

Thank you to all the groups and individuals across the UK and beyond for your efforts to raise funds.

Charitable Trusts & Foundations

We continue to value the generous support of all the grant makers that support Dystonia UK.

Companies and other organisations

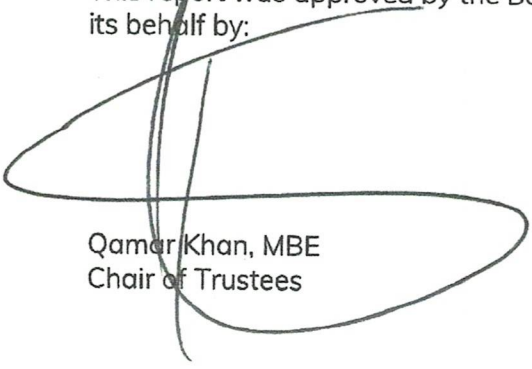
The contribution of our corporate supporters and partnership work remains vital to our success.

The Dystonia Society
Report of the Trustees for the year ended 31 March
2024 (Incorporating the Directors' Report)



Approval

This report was approved by the Board of Trustees on 12 November 2024 and signed on its behalf by:



Qamar Khan, MBE
Chair of Trustees

The Dystonia Society
Independent Examiner's Report to the trustees of
The Dystonia Society ('the Company')



I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 March 2024.

Responsibilities and basis of report

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

Having satisfied myself that the accounts of the Company 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 your charity's accounts as carried out under the Charities Act 2011, s145 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under s145(5)(b) of the 2011 Act.

Independent examiner's statement

Since the Company's gross income exceeded £250,000 your examiner must be a member of a body listed in s145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am member of the Institute of Chartered Accountants in England and Wales, which is one of the listed bodies.

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:

- (1) accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
- (2) the accounts do not accord with those records; or
- (3) the accounts 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 accounts 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 accounts to be reached.

Michael A. Williams

Michael A Williams ACA.,
Chartered Accountant
30 Retford Drive, Sutton Coldfield, West Midlands, B76 1DG
Date: 6 December 2024

	Notes	Restricted funds £	General funds £	Total 2023/24 £	Restricted funds £	General funds £	Total 2022/23 £
Income from							
Donations and subscriptions		562	154,627	155,189	423	136,571	136,994
Grants	14	54,478	54,751	109,229	47,000	33,274	80,274
Legacies and in memoriam gifts		-	417,059	417,059	(323)	57,950	57,627
Total donations, subscriptions, grants and legacies	3	55,040	626,437	681,477	47,100	227,795	274,895
Other trading activities		-	1,958	1,958	-	1,134	1,134
Investments		-	8,918	8,918	-	1,383	1,383
Total income		55,040	637,313	692,353	47,100	230,312	277,412
Expenditure on							
Raising funds	4		75,741	75,741	-	50,961	50,961
Charitable activities	4,14	6,489	239,046	245,535	56,068	178,746	234,814
Total expenditure		6,489	314,787	321,276	56,068	229,707	285,775
Net income/(expenditure)	4	48,551	322,526	371,077	(8,968)	605	(8,363)
Transfers between funds		-	-	-	-	-	-
Net movement in funds		48,551	322,526	371,077	(8,968)	605	(8,363)
Reconciliation of funds							
Total funds brought forward		108,764	222,454	331,218	117,732	221,849	339,581
Total funds carried forward	12	157,315	544,980	702,295	108,764	222,454	331,218

	Notes	31 March 2024	31 March 2023
		£	£
Non-current assets			
Tangible fixed assets	7	-	-
Investment in subsidiary company	7	1	1
Current assets			
Debtors	8	100,455	46,479
Cash at bank and in hand	9	636,559	306,082
		<u>737,014</u>	<u>352,561</u>
Creditors: amounts falling due within one year	10	(34,720)	(21,344)
Net current assets		<u>702,294</u>	<u>331,217</u>
Net assets		<u>702,295</u>	<u>331,218</u>
Represented by			
General funds		134,980	222,454
Designated funds		410,000	-
Total unrestricted funds		<u>544,980</u>	<u>222,454</u>
Restricted funds	14	157,315	108,764
Total funds	12	<u>702,295</u>	<u>331,218</u>

The Trustees are satisfied that the Charitable Company is entitled to exemption from the provisions of the Companies Act 2006 (the Act) relating to the audit of the financial statements for the year by virtue of section 477, and that no member or members have requested an audit pursuant to section 476 of the Act.

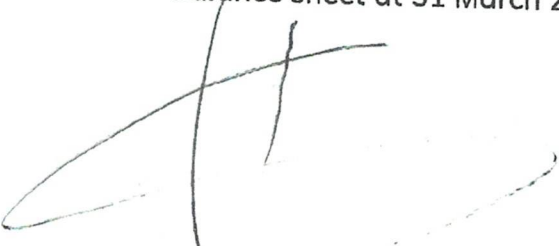
The Trustees acknowledge their responsibilities for

- (i) ensuring that the charitable company keeps adequate accounting records which comply with section 386 of the Act, and
- (ii) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of the financial year and of its results for the financial year in accordance with the requirements of sections 394 and 395, and which otherwise comply with the requirements of the Act relating to financial statements, so far as applicable to the charitable company.

These financial statements have been prepared in accordance with the special provisions for Small Companies under Part 15 of the Companies Act 2006.

The Dystonia Society
Balance sheet at 31 March 2024

Dystonia
UK



Qamar Khan, MBE
Chair of Trustees



Robert Semple
Treasurer

Company Registration Number: 03309777

The notes on pages 20 to 29 form part of these financial statements.

The Dystonia Society
Statement of cash flows for the year
ended 31 March 2024



	2024	2023
	£	£
Net income/(expenditure) as per the statement of financial activities	371,077	(8,364)
Adjustments for		
Depreciation charges	-	-
Interest from investments	(8,918)	(1,383)
(Increase)/decrease in debtors	(53,976)	(28,953)
Increase/(decrease) in creditors	13,376	1,494
Net cash generated /(used) in operating activities	321,559	(37,206)
Cash flows from investing activities		
Interest from investments	8,918	1,383
Purchase of equipment	-	-
Net cash provided by/(used in) investing activities	8,918	1,383
Net increase/(decrease) in cash and cash equivalents	330,477	(35,823)
Cash and cash equivalents at the beginning of the year	306,082	341,905
Cash and cash equivalents at the end of the year	636,559	306,082
Check total	636,559	306,082

1. Accounting policies

a) Basis of preparation of financial statements

- The financial statements have been prepared in accordance with 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 2015), the Companies Act 2006 and the Charities and Trustees Investment (Scotland) Act 2005.
- The Charity constitutes a public benefit entity as defined by FRS 102.
- The accounts include the balances and transactions of 30 of the Society's support groups.
- The preparation of the financial accounts requires the Society's management to make reasonable and prudent judgements, estimates and assumptions that affect the amounts reported for assets and liabilities as at the balance sheet date and the amounts reported for income and expenses during the year. These judgements are detailed in these accounting policies.

b) Income

Income is received by way of grants, donations and subscriptions. The income from fundraising ventures is shown gross in the period in which the event occurs, with the associated costs included in costs of raising funds. From time to time the Society receives donations of goods and services in kind and where there is a measurable material value to the Society, which can be ascertained with reliability, they are included as both income and expenditure. Equipment given for use by the Society is included as a donation at estimated value when received.

Legacy income is included in the period in which it is received, or, if earlier, the period in which the Society receives confirmation of entitlement and amount. If there is uncertainty as to the amount and timing of payment, the legacy is not recognised as income, but disclosed as a contingent asset.

Subscriptions are included in the accounts in the year in which they are received.

Revenue grants are credited to incoming resources on the date they are received or when they are receivable, unless they relate to a specific period, in which case they are deferred.

c) Expenditure

Expenditure is recognised on an accruals basis and includes VAT which the charity cannot recover.

Direct expenditure on charitable activities is allocated to the Society's objectives in five streams of work.

Support costs are allocated to each of the charitable activities (and to the associated restricted funds) based on staff salary costs.

Costs of raising funds relate to expenditure incurred in approaching and facilitating people and organisations to contribute financially to the Society's work.

Grants payable are accounted for when paid or when the Society has, by communicating a commitment, created a valid expectation that it will make future payments.

Those costs shown as governance relate to the management of the Society's assets, organisational administration and compliance with constitutional and statutory requirements.

d) Pension contributions

The Society makes contributions to defined contribution personal pension schemes held by employees. Contributions are a percentage of gross salary and are charged to the same restricted or unrestricted funds, and in same the accounting periods, as the related salary costs.

e) Tangible fixed assets

Items of equipment are capitalised if their cost exceeds £1,000 and if they have an expected useful life of more than two years. Depreciation is then charged at a uniform rate over that life.

f) Operating leases

Rentals applicable to operating leases where substantially all the benefits and risks of ownership remain with the lessor are reflected in the Statement of Financial Activities on a straight-line basis over the period of the lease.

g) Fund accounting

Restricted funds are to be used for specific purposes as stated by the donor. Expenditure which meets these criteria is charged to the fund.

Designated funds are unrestricted funds earmarked by the trustees for specific purposes.

Unrestricted funds are donations and other incoming resources receivable or generated for charitable purposes, in line with the objects of the Society, but not restricted to any specific activity.

h) Financial instruments

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

Income and expenditure account

A separate income and expenditure account has not been prepared as the figures comprising net income for the year shown in the Statement of Financial Activities give the information required under the Companies Act 2006, together with details of other recognised gains and losses.

2	Analysis of income and expenditure by charitable activity	2024		2023	
		Income £	Expenditure £	Income £	Expenditure £
	Awareness and best practice	-	80,660	-	55,503
	Support and information	55,040	164,875	47,423	155,505
	Research	-	-	(323)	-
	Restricted Income and Expenditure on Charitable Activities	55,040	245,535	47,100	211,008
	Unrestricted Income	626,437	-	227,795	-
	Fundraising Expenditure	-	75,741	-	74,767
	Total Income and Expenditure	681,477	321,276	274,895	285,775
	Income is analysed according to restrictions imposed by donors and funders.	-	-		
3	Net incoming resources			2024	2023
				£	£
	Net incoming resources are stated after charging				
	Operating lease - land and buildings			16,492	20,553
	Independent examiner's fees			1,800	1,800

4	Total resources expended	Support costs	Awareness & best practice	Information & support	Research	Fundraising	Total
		£	£	£	£	£	£
4A	Year to March 2024						
	Employment and training	32,301	34,638	69,922	-	24,887	161,748
	Premises and general overheads	39,491	-	1,549	-	-	41,040
	Printing and communications	4,795	5,401	5,608	-	707	16,511
	Independent examination and accountancy	1,800	-	-	-	-	1,800
	Conferences, meetings and travel	4,142	4,028	1,242	-	-	9,412
	Direct project costs	-	15,446	45,029	-	3,298	63,773
	Fundraising and prize draw expenses	-	-	-	-	26,992	26,992
	Grants awarded/(recovered)	-	-	-	-	-	-
	Apportioned support costs	(82,529)	21,147	41,525	-	19,857	-
	Total	-	80,660	164,875	-	75,741	321,276
4B	Year to March 2023						
	Employment and training	25,383	30,814	63,213	-	38,056	157,466
	Premises and general overheads	39,014	-	-	-	3,551	42,565
	Printing and communications	6,468	3,683	28,686	-	1,152	39,989
	Independent examination and accountancy	2,272	-	-	-	-	2,272
	Conferences, meetings and travel	-	3,335	3,134	-	4,938	11,407
	Direct project costs	-	-	28,812	-	-	28,812
	Fundraising and prize draw expenses	-	-	-	-	3,264	3,264
	Grants awarded/(recovered)	-	-	-	-	-	-
	Apportioned support costs	73,137	17,671	31,660	-	23,805	-
	Total	0	55,503	155,505	-	74,766	285,775

5	Staff costs	2024	2023
		£	£
	Salaries and wages	131,880	133,537
	Social security costs	8,662	8,957
	Pension contributions	6,808	7,100
		147,350	149,594
	Staff employed under service contracts	-	-
	Other employment and training costs	16,198	10,512
	Total employment and training costs	163,548	149,594

The average number of employees during the year was 3.6 (2023: 4.1) of whom 3.1 were full-time. No employee earned more than £60,000 during the year (2023: nil).

The Society contributes to defined contribution personal pension schemes. The assets of these schemes are held separately from those of the Society in independently administered funds. At 31st March 2024, the Society owed £891 (2023: £827) to these pension schemes.

6 Trustees' remuneration and expenses

The trustees received no remuneration for their services (2023: nil). Four trustees (2023: two) were reimbursed £811 for travel expenses and other costs (2023: £249).

7	Non-current assets	
	Office equipment and fixtures	
		£
	Cost at 1 April 2023	22,317
	Additions	-
	Cost at 31 March 2024	22,317
	Depreciation at 1 April 2023	22,317
	Charge for the year	
	Depreciation at 31 March 2024	22,317
	Net book value at 1 April 2023	-
	Net book value at 31 March 2024	-
	Investment in subsidiary	
	Investment in Dystonia UK Ltd	1

8	Debtors		2024	2023
			£	£
	Prepayments		11,780	10,087
	Other debtors and accrued income		88,675	36,392
			100,455	46,479
9	Cash at bank and in hand		2024	2023
			£	£
	Bank investment accounts		446,059	187,354
	Other bank and building society accounts		189,017	117,039
	Petty cash and groups		1,483	1,689
			636,559	306,082
			-	
10	Creditors: Amounts falling due within one year		2024	2023
			£	£
	Taxation and social security costs		3,805	3,122
	Other creditors		15,046	12,426
	Accruals + Deferred Income		15,869	5,796
			34,720	21,344
11	Commitments under operating leases		2024	2023
			£	£
	Office Lease + Service Charge		12,436	21,690

12A	Analysis of net assets between funds (2024)	Restricted funds £	Designated funds £	General funds £	Total funds £
	Fixed assets	-		1	1
	Current assets	157,315	410,000	169,699	737,014
	Creditors	-		(34,720)	(34,720)
		157,315	410,000	134,980	702,295
12B	Analysis of net assets between funds (2023)				
	Fixed assets			1	1
	Current assets		108,764	243,797	352,561
	Creditors		-	(21,344)	(21,344)
			108,764	222,454	331,218

13. Contingent liabilities

No contingent liabilities exist as of 31st March 2024 and the date of this Annual Report & Accounts

14 Related party transactions

There have been no related party transactions in the year ending 31st March 2024 (prior year nil).

15A	Movement In Funds (2024)	Opening balance £	Income £	Transfers £	Expenditure £	Closing balance £
	Restricted Funds					
	Awareness and best practice	3,000	-	-	-	3,000
	Information and support	24,499	55,040	-	(6,489)	73,050
	Research	81,265	-	-	-	81,265
		108,764	55,040	-	(6,489)	157,315
	Unrestricted Funds					
	Designated Fund: Legacy Reserve Fund	-	-	410,000	-	410,000
	General Funds	222,454	637,313	(410,000)	(314,787)	134,980
		222,454	637,313	-	(314,787)	544,980
	Total Funds	331,218	692,353	-	(321,276)	702,295
15B	Movement In Funds (2023)					
	Restricted Funds					
	Awareness and best practice	3,000	-	-	-	3,000
	Information and support	33,144	47,423	-	(56,068)	24,499
	Research	81,588	(323)	-	-	81,265
		117,732	47,100	-	(56,068)	108,764
	Unrestricted Funds					
	General Funds	221,849	230,312	-	(229,707)	222,454
		221,849	230,312	-	(229,707)	222,454
	Total Funds	339,581	277,412	-	(285,775)	331,218