

THE DYSTONIA SOCIETY

**Report of the Trustees for the year ended 31 March 2021
(incorporating the Directors' Report)**

THE DYSTONIA SOCIETY

**A company limited by guarantee
Financial Statements
31 March 2021**

THE DYSTONIA SOCIETY

Report of the Trustees for the year ended 31 March 2021 (incorporating the Directors' Report)

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Report of the Trustees for the year ended 31 March 2021 (incorporating the Directors' Report)

Reference and administrative information

Royal Patron

HRH Princess Alexandra

Patron

Tully Kearney

Trustees and Directors

Daniel Berry
Christopher Bradshaw
Timothy Gannicliffe
Nick Morgan
Penny Ritchie Calder MBE
Andrew Russell
Robert Semple
Ian Silvester
Katie Wells
James Wishart
Andy Young

Chair

From 1st March 2021

From 1st March 2021
From 1st March 2021
From 14th Jan 2021
From 1st March 2021

Vice-chair

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

Independent Examiner

Michael Williams ACA
30 Retford Drive
Sutton Coldfield
B76 1DG

Bankers

CAF Bank
Kings Hill
West Malling
Kent ME19 4TA

Registered Office

3rd Floor
89 Albert Embankment
London
SE1 7TP

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

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Report of the Trustees for the year ended 31 March 2021 (incorporating the Directors' Report)

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 2021 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 was established to promote the welfare of people who are affected by any form of the neurological movement disorder known as dystonia. The Society aims to do this by providing information and support, promoting awareness of the disorder and by supporting research. It does this on a national level and through its network of local support groups.

Review of Activity

We exist to give hope and support to those living with dystonia. Creating UK and worldwide awareness.

Under our new operating name of Dystonia UK, we are the only national charity dedicated to supporting people with dystonia throughout the UK. During the last year and in spite of the impact that the Covid-19 pandemic has had on our activities, we have made significant progress in developing the charity to meet the needs of both members and the wider dystonia community. This has included:

- Providing support and information to the dystonia community about the impact of Covid-19
- Relaunching our website with more accessible information
- Working with partners to ensure that clinical services restart as quickly as possible
- Developing our Reach Out Reach All programme with webinars, podcasts and online conferences
- Creating mutually beneficial partnerships with the major providers of pharmaceuticals and medical devices for the treatment of dystonia
- Enhancing online fundraising and awareness raising
- Ensuring that the voice of the dystonia community is heard as part of policy developments in the NHS

We are now in a strong position to ensure the growth and development of the charity to meet the needs of everyone affected by dystonia in the future.

Covid-19 pandemic

The impact of Covid-19 began in March 2020 with the first national lockdown. For people with dystonia, the effect of the pandemic was enormous. As the NHS responded to the emergency, neurology clinics were cancelled or moved to telephone consultations. Many specialist neurology staff were redeployed in hospitals and injection clinics were postponed for several months. Access to primary care was restricted and will inevitably have resulted in even longer delays to diagnosis and treatment. The restrictions imposed on people generally have exacerbated the isolation and mental health consequences for the dystonia community.

Our heartfelt thanks go to everyone in the NHS, care workers and key workers who have shown such fantastic dedication and support to people during these very difficult times. We extend our sympathy to everyone in the dystonia community, the NHS and other sectors who have lost loved ones.

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Our medical advisers responded quickly to provide guidance and reassurance to the dystonia community about the implications of Covid-19 on their health and treatment. We were able to make information from The Association of British Neurologists available through our website. Dr Marie-Helene Marion gave a webinar on Dystonia During The Pandemic with advice for people whose Botulinum Neurotoxin injections were being delayed.

All our staff were required to work from home, and this has continued throughout the year. Fortunately, our core information systems are available online and we were able to adapt our operational procedures quickly. Virtual meetings using Zoom became the norm, both within the staff team and with our partner organisations. Trustee meetings also took place using Zoom.

The pandemic has directly affected the way in which we can operate as a charity. Many events that we were planning were put on hold as they were either not allowed by restrictions or not safe for people with dystonia. These restrictions also had an impact on our fundraising as challenge events such as marathons were cancelled and the many smaller activities within groups could not take place.

Website relaunch

We relaunched our website in July 2020. The improved layout and accessibility of the new website have been widely welcomed. This now provides a platform on which people will be able to search for information, see videos and listen to podcasts. The internet is the place where most people now search for information. We will continue to add content in response to the many enquiries that people make.

But we know that online information is not the preferred choice or accessible to many members. Dystonia Matters will continue to be published regularly. Last year we also issued a special Letter From The Chair including the advice we had about Covid-19 as well as general updates on our activities.

Restarting clinical services after lockdown

After the first lockdown, we worked with the British Neurotoxin Network on its plans for restarting injection clinics. Trustees have joined a number of web-conferences with clinicians in order to ensure that the voice of the dystonia community is fully considered including issues with travel, the need for carers to support patients, and lack of access to digital communications.

We worked with the Neurological Alliance (in England) in promoting its survey about the impact of the pandemic and in producing its Neuro Restart report. People with dystonia were one of the largest neurological patient groups that responded to the survey ensuring that their concerns, such as virtual appointments replacing face to face meetings with clinicians, were recognised. We also contributed to the Neurological Alliance of Scotland's report Neurological Voices: Living Through Lockdown.

Reach Out Reach All

This is our programme to improve and modernise the information and advice available for people with dystonia, for example new videos and other content that is easily accessed and shared on social media. Such a programme is highly attractive when seeking funding. During the year we received funding from the National Lottery Community Fund and from several of the manufacturers of Botulinum Neurotoxin and Deep Brain Stimulation equipment to further this campaign. The programme has included:

Lockdown Unlocked

- Tully Kierney, Gemma-Louise Stevenson and Tegan Vincent-Cooke talking about living with dystonia and the impact of the pandemic in a series of video shorts

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Dystonia Matters Webinars:

- Dystonia During The Pandemic with Dr Marie-Helene Marion
- Taking Control Of Your Dystonia – A Physiotherapy Focus with Richmond Stace and Sally Glover
- Answering Your Questions with Prof Mark Edwards
- Understanding Personal Independence Payments with Janet Ireland from The Brain Charity

Dystonia Matters Podcasts

- Episode 1: Faces Of The Dystonia Community – Louise, Katie and Andy
- Episode 2: Working With Dystonia – Gemma and Nick

Online conferences

- Dystonia Matters Digital was our first ever online conference. Over two days at the end of Dystonia Awareness Month in September 2020 its four sessions were: Campaigning for Change, Mental Health Matters, The Future Of Neurology and Knowing Your Rights
- Dystonia Matters Digital: For Kids, Carers & Families in March 2021 covered the launch of Dani Explains Dystonia, a new animation for children about dystonia, treatment in childhood and transitioning to adulthood for both treatment and educational support.

Working with pharmaceutical and medical device businesses

Over the last year, we have strengthened our relationships with these key corporate organisations. Their support to our work through grants has enabled us to take forward much of our Reach Out Reach All programme. In addition, we bring the voices of people living with dystonia to inform their research and development programmes.

Fundraising and awareness raising

We continue to be supported by many loyal members and donors along with a several charitable trusts and foundations. This support creates a base on which we can build our other fundraising initiatives.

This year, many of the events that would normally promote awareness of dystonia alongside fundraising have been cancelled due to the pandemic. We have switched our fundraising to online activities where we can. The 2.6 Challenge, a national initiative to replace the London Marathon, gave us a significant start.

We created our own challenge event – Dystonia Around The World – which both raised awareness about dystonia and generated over £14,000 in donations. This introduced a lot of new supporters to us, and we look forward to their continued help as Covid-19 restrictions are lifted.

We continue to build and expand our presence on social media to support people as well as to raise awareness. During Dystonia Awareness Month, one infographic that we produced saw over 5,000 reactions and had a reach of over 50,000.

Working for improved services

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Raising 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.

We have increased our involvement in the work of the various neurological alliances in England, Wales, Scotland and Northern Ireland and have ensured that dystonia is recognised equally with other major neurological conditions in the overarching work to lobby for improved services. Our members provide valuable support by responding to surveys and giving their personal stories to provide evidence for the need for change. Representatives from all four countries neurological alliances took part in our Dystonia Matters Digital conference.

Where appropriate we provide comments and evidence to NICE (the National Institute for Health and Care Excellence) on clinical guidelines. This year, we ensured that dystonia was specifically recognised in their quality standard for suspected neurological disorders, especially concerning the frequently mentioned misdiagnosis of dystonia as either a musculoskeletal or psychological condition. This increases the awareness of dystonia, especially in primary care, as well as providing vital evidence that services are improving.

Research

We contributed funding towards the Queen's Square Brain Bank at the UCL Institute for Neurology. This work, led by Professor Tom Warner, will enable significant research to be undertaken into the causes and possible treatments for dystonia. The Queen's Square Brain Bank collects, curates and studies brain tissue for research into many neurological conditions including dystonia. This can help identify mechanisms that affect the brain and lead to dystonic movement.

We have also allocated research funding to UCL to help complete a large ongoing study looking at the predictors of long-term efficacy of deep brain stimulation in the management of dystonia. Part of this 3-year research project involves genotyping the participants for novel genetic causes of dystonia.

We are supporting research by neurologists on the effects of the lockdown and delays in injection cycles on patients. This is an observation study using established survey forms coordinated by the Walton Centre in Liverpool.

Staff and Trustees

The loyalty and commitment of our staff is very much appreciated. They are a strong team with great spirit and focus on the needs of people with dystonia. Due to the Covid-19 restrictions, everyone has worked from home throughout the year including new staff who have joined the team.

Senior staff report on a day to day basis to the Chair of Trustees, with other trustees being actively involved in supporting our work in responding to enquiries, engaging with strategic partners, supporting groups, fundraising and administration. Without this commitment, given the reduced numbers of employed staff, we could not achieve our objectives.

We have expanded our board of trustees to ensure continuity as the charity grows and develops. During the year, we welcomed Nick Morgan, Andrew Russell, Robert Semple, Ian Silvester and Katie Wells. There are currently eleven trustees of which five have a diagnosis of dystonia and three have direct family experience of dystonia. The remaining three, while not having previous experience of dystonia, have been involved in charities for people with other neurological conditions or disabilities.

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Plans for the coming year

In spite of the setback presented by the Covid-19 pandemic, we aim to move forward and build on the new groundwork that we have done this year.

Awareness raising and lobbying for change – building on our collaboration with the neurological alliances and other charities to ensure that the voice of people with dystonia is recognised by health commissioners, providers, government and other agencies. This is especially important as health services recover from the impact of Covid-19.

Reach Out Reach All – ensuring that our resources are relevant and accessible to the whole dystonia community. We will continue producing information in a variety of formats to support people with dystonia. This will include further webinars and podcasts, new animations aimed at children with dystonia, refreshing our information leaflets for use in hospital clinics as well as responding to enquiries, and updating our website with additional information including a section on Frequently Asked Questions.

Social networks - we will work with group leaders and coordinators so that they can support the charity's work better at a local level. We hope that groups will be able to meet in person as soon as it is safe to do so, especially enabling members to share their lived experience of dystonia. We will continue the development of social media for networking and sharing information.

Research - we hope to establish sufficient funds to make a call for a new research proposal into dystonia.

Financial Review

Our financial position for the year ending 31st March 2020 was a deficit of £111,875 compared to a deficit of £50,709 in the previous year. Income was £421,975 (2020: £221,737). Increased income was mainly due to legacy income and grants especially from the National Lottery Community Fund (NLCF) and medical companies, offset by reduced community fundraising as a consequence of these activities being reduced due to Covid-19 restrictions. Expenditure was £310,100 (2020 £272,446). Increased expenditure was mainly due to the activities funded by the NLCF and medical companies.

With increased legacy and grant income, the Society was able to increase staffing slightly during the year. 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 ensure our income streams enable us to operate at break-even financially without reliance on legacy income and the trustees have agreed a budget on this basis which depends on improvement in fundraising from charitable trusts, foundations and corporate sponsorship as well as the continued support of our many members and supporters. Trustees consider that increased income is realistically attainable as it is less than was achieved historically. Nevertheless, 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 monthly in conjunction with the trustees' review of the financial position. The trustees have not designated any of the unrestricted reserves for specific future activities.

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The level of unrestricted reserves at 31st March 2021 represented 104% of expenditure in the year (2020 65%) due to the receipt of a substantial legacy. We would expect reserves to return to normal levels unless further significant legacy income were to be received.

Certain grants and donations received by the Society are given for specific projects or initiatives. Funds held in respect of these activities are carried forward if they are unspent or uncommitted. At 31st March 2020, funds of £56,741 were carried forward (2020: £43,871).

Investment Policy

The Society does not have sufficient resources to make long term investments. Surplus funds are held in deposit facilities however interest rates on such facilities are currently very low.

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.

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. We aim to give new trustees a programme of induction and training. Further training is available when required and relevant.

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.

The most recent review identified the key risk to be its ability to achieve sufficient fundraising in light of the Covid-19 pandemic and therefore maintain financial sustainability. The Society undertakes careful monitoring of its projected cash flows and levels of reserves so that it can meet its financial duties.

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.

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Report of the Trustees for the year ended 31 March 2021 (incorporating the Directors' Report)

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.

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Report of the Trustees for the year ended 31 March 2021 (incorporating the Directors' Report)

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

We are very grateful indeed to the Society's staff team, volunteers, donors and fundraisers, to the charitable trusts, corporate partners and the National Lottery Coronavirus Recovery Fund that have given grant funding, and to clinicians and other professionals who have attended meetings during the year, donating their time and expertise. Their support is very much appreciated by our members.

Approval

This report was approved by the Board of Trustees on 10th June 2021 and signed on its behalf by



Chris Bradshaw

Chair of Trustees

THE DYSTONIA SOCIETY

Report of the Trustees for the year ended 31 March 2021 (incorporating the Directors' Report)

Small company exemption

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Thanks

We are very grateful indeed to the Society's staff team, volunteers, donors and fundraisers, to the charitable trusts, corporate partners and the National Lottery Coronavirus Recovery Fund that have given grant funding, and to clinicians and other professionals who have attended meetings during the year, donating their time and expertise. Their support is very much appreciated by our members.

Approval

This report was approved by the Board of Trustees on 10th June 2021 and signed on its behalf by

Chris Bradshaw

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 2021.

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 section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(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 section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants in England and Wales (ICAEW), 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:

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
Chartered Accountant
30 Retford Drive
Sutton Coldfield
West Midlands
B76 1DG
Date:

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Statement of financial activities for the year ended 31 March 2021

| | Notes | Restricted funds | General funds | Total 2020/21 | Restricted funds | General funds | Total 2019/20 |
|--|-----------|------------------|----------------|----------------|------------------|----------------|----------------|
| | | £ | £ | £ | £ | £ | £ |
| Income from | | | | | | | |
| Donations and subscriptions | | 565 | 133,988 | 134,553 | 14,117 | 139,724 | 153,841 |
| Grants | 15 | 80,500 | 42,894 | 123,394 | 17,281 | 35,696 | 52,977 |
| Legacies and in memoriam gifts | | 355 | 161,458 | 161,813 | 0 | 11,918 | 11,918 |
| Total donations, subscriptions, grants and legacies | 3 | 81,420 | 338,340 | 419,761 | 31,398 | 187,338 | 218,736 |
| Other trading activities | | 0 | 2,167 | 2,167 | 0 | 2,857 | 2,857 |
| Investments | | 0 | 48 | 48 | 0 | 144 | 144 |
| Total income | | 81,420 | 340,555 | 421,975 | 31,398 | 190,339 | 221,737 |
| Expenditure on | 5 | 0 | 53,896 | 53,896 | 0 | 63,567 | 63,567 |
| Raising funds | | 0 | 53,896 | 53,896 | 0 | 63,567 | 63,567 |
| Charitable activities | 3, 15 | 67,866 | 188,338 | 256,204 | 37,787 | 171,092 | 208,879 |
| Total expenditure | | 67,866 | 242,234 | 310,100 | 37,787 | 234,659 | 272,446 |
| Net income/(expenditure) | 7 | 13,554 | 98,321 | 111,875 | -6,390 | -44,320 | -50,709 |
| Transfers between funds | | -684 | 684 | 0 | -3,818 | 3,818 | 0 |
| Net movement in funds | | 12,870 | 99,005 | 111,875 | -10,208 | -40,501 | -50,709 |
| Reconciliation of funds | | | | | | | |
| Total funds brought forward | | 43,871 | 153,061 | 196,932 | 54,079 | 193,562 | 247,641 |
| Total funds carried forward | 14 | 56,741 | 252,066 | 308,807 | 43,871 | 153,061 | 196,932 |
| Unrestricted reserves % of expenditure | | | 104.1% | | | 65.2% | |

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Balance sheet at 31 March 2021

| | Notes | 31 March 2021 | 31 March 2020 |
|---|-------|----------------|----------------|
| | | £ | £ |
| Non-current assets | | | |
| Tangible fixed assets | 8 | 0 | 1,147 |
| Investment in subsidiary company | 8 | 1 | 1 |
| Current assets | | | |
| Debtors | 9 | 34,779 | 4,980 |
| Cash at bank and in hand | 10 | 307,891 | 217,695 |
| | | 342,670 | 222,675 |
| Creditors: amounts falling due within one year | 11 | -33,864 | -26,890 |
| Net current assets | | 308,807 | 195,785 |
| Net assets | | 308,808 | 196,932 |
| Represented by | | | |
| General funds | | 153,745 | 193,562 |
| I&E 2020/21 | | 98,321 | -40,501 |
| Designated funds | 15 | 0 | 0 |
| Total unrestricted funds | | 252,066 | 153,061 |
| Restricted funds | 15 | 56,741 | 43,871 |
| Total funds | 13 | 308,807 | 196,932 |

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.

Chris Bradshaw
Chair

Andy Young
Vice-chair

Company Registration Number: 03309777

The notes on pages 14 to 20 form part of these financial statements.

THE DYSTONIA SOCIETY

Statement of cash flows for the year ended 31 March 2021

| | 2020/21 | 2019/20 |
|--|----------------|----------------|
| | £ | £ |
| Net income/(expenditure) as per the statement of financial activities | 111,875 | -50,709 |
| Adjustments for | | |
| Depreciation charges | 1,146 | 2,583 |
| Interest from investments | -48 | -144 |
| (Increase)/decrease in debtors | -29,799 | 17,096 |
| Increase/(decrease) in creditors | 6,973 | -11,045 |
| Net cash generated /(used) in operating activities | 90,149 | -42,219 |
| Cash flows from investing activities | | |
| Interest from investments | 48 | 144 |
| Purchase of equipment | 0 | 0 |
| Net cash provided by/(used in) investing activities | 48 | 144 |
| Net increase/(decrease) in cash and cash equivalents | 90,196 | -42,075 |
| Cash and cash equivalents at the beginning of the year | 217,696 | 259,771 |
| Cash and cash equivalents at the end of the year | 307,892 | 217,696 |

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Notes to the financial statements for the year ended 31 March 2021

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.

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Notes to the financial statements for the year ended 31 March 2021

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.

2 **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.

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Notes to the financial statements for the year ended 31 March 2021

3 Analysis of income and expenditure by charitable activity

| | 2021 | | 2020 | |
|-----------------------------|---------------|-----------------|---------------|----------------|
| | Income | Expenditure | Income | Expenditure |
| | £ | £ | £ | £ |
| Awareness and best practice | 0 | -60,121 | 0 | 97,442 |
| Support and information | 81,420 | -173,997 | 29,113 | 67,003 |
| Research | 0 | -6,451 | 2,285 | 18,785 |
| | 81,420 | -240,569 | 31,398 | 183,230 |

Income is analysed according to restrictions imposed by donors and funders.

4 Net incoming resources

| | 2021 | 2,020 |
|--|--------|--------|
| | £ | £ |
| Net incoming resources are stated after charging | | |
| Operating lease - land and buildings | 21,976 | 22,043 |
| Independent examiner's fees | 1,500 | 1,500 |

5 Total resources expended

| | Support costs | Awareness & best practice | Information & support | Research | Fundraising | Total |
|---|---------------|---------------------------|-----------------------|---------------|---------------|----------------|
| | £ | £ | £ | £ | £ | £ |
| Year to March 2021 | | | | | | |
| Employment and training | 28269 | 40954 | 61031 | 0 | 35940 | 166194 |
| Premises and general overheads | 39355 | 0 | 0 | 0 | 0 | 39355 |
| Printing and communications | 0 | 4895 | 2664 | 0 | 0 | 7559 |
| Independent examination and accountancy | 1867 | 0 | 0 | 0 | 0 | 1867 |
| Conferences, meetings and travel | 241 | 0 | 0 | 0 | 0 | 241 |
| Direct project costs | 0 | 753 | 71176 | 0 | 0 | 71929 |
| Fundraising and prize draw expenses | 0 | 0 | 0 | 0 | 17956 | 17956 |
| Grants awarded/(recovered) | 0 | 0 | 0 | 5000 | 0 | 5000 |
| Apportioned support costs | -69732 | 13519 | 39127 | 1451 | 15635 | 0 |
| Total | 0 | 60121 | 173997 | 6451 | 69531 | 310100 |
| Year to March 2020 | | | | | | |
| Employment and training | 24825 | 50419 | 34669 | 0 | 39050 | 148963 |
| Premises and general overheads | 44657 | 0 | 0 | 0 | 0 | 44657 |
| Printing and communications | 0 | 17024 | 2664 | 0 | 0 | 19688 |
| Independent examination and accountancy | 2900 | 0 | 0 | 0 | 0 | 2900 |
| Conferences, meetings and travel | 5944 | 0 | 0 | 0 | 0 | 5944 |
| Direct project costs | 0 | 1985 | 10408 | 0 | 0 | 12392 |
| Fundraising and prize draw expenses | 0 | 0 | 0 | 0 | 24517 | 24517 |
| Grants awarded/(recovered) | 0 | 0 | 0 | 13384 | 0 | 13384 |
| Apportioned support costs | -78325 | 28014 | 19263 | 5400 | 25649 | 0 |
| Total | 0 | 97,442 | 67,003 | 18,785 | 89,216 | 272,446 |

| | 2021 | 2020 |
|---|-------|-------|
| | £ | £ |
| Support costs include governance costs of | 1,800 | 7,188 |

Grants awarded included

| | | |
|------------------|-------|--------|
| To individuals | 0 | 0 |
| To organisations | 5,000 | 13,385 |

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Notes to the financial statements for the year ended 31 March 2021

| 6 | Staff costs | 2020/21 | 2019/20 |
|---|--|----------------|----------------|
| | | £ | £ |
| | Salaries and wages | 140,424 | 122,619 |
| | Social security costs | 9,833 | 9,250 |
| | Pension contributions | 7370 | 5,589 |
| | | 157,627 | 137,458 |
| | Staff employed under service contracts | 0 | 0 |
| | Other employment and training costs | 59 | 784 |
| | Total employment and training costs | 157,686 | 138,242 |

The average number of employees during the year was 4.2 (2020: 3.8) of whom 3.2 were full-time. The full-time equivalent was 3.7 (2020: 3.2). No employee earned more than £60,000 during the year (2020: nil). The total of employee benefits paid to key management personnel was £85,000 (2020: £19,875 for the Chief Executive for part of the year only).

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 2021, the Society owed £962 (2020: £635) to these pension schemes.

7 Trustees' remuneration and expenses

The trustees received no remuneration for their services (2020: nil). No trustees (2020: two) were reimbursed for travel expenses and other costs (2020: £2,657).

| 8 | Non-current assets | |
|---|--|--------------|
| | Office equipment and fixtures | £ |
| | Cost at 1 April 2020 | 22317 |
| | Additions | 0 |
| | Cost at 31 March 2021 | 22317 |
| | Depreciation at 1 April 2020 | 21171 |
| | Charge for the year | |
| | Depreciation at 31 March 2020 | 21171 |
| | Net book value at 1 April 2020 | 1146 |
| | Net book value at 31 March 2021 | 1146 |
| | Investment in subsidiary | |
| | Investment in Dystonia UK Ltd | 1 |

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Notes to the financial statements for the year ended 31 March 2021

| | | | | |
|-----------|---|-------------------------|----------------------|--------------------|
| 9 | Debtors | | | |
| | | 2021 | 2020 | |
| | | £ | £ | |
| | Prepayments | 9498 | 4,980 | |
| | Other debtors and accrued income | 23952 | 0 | |
| | | 33,450 | 4,980 | |
| 10 | Cash at bank and in hand | | | |
| | | 2021 | 2020 | |
| | | £ | £ | |
| | Bank investment accounts | 226046 | 95,999 | |
| | Other bank and building society accounts | 79493 | 118,880 | |
| | Petty cash and groups | 2352 | 2,816 | |
| | | 307,891 | 217,695 | |
| 11 | Creditors: Amounts falling due within one year | | | |
| | | 2021 | 2020 | |
| | | £ | £ | |
| | Taxation and social security costs | 3811 | 3,555 | |
| | Other creditors | 18407 | 13,785 | |
| | Accruals | 11645 | 9,550 | |
| | | 33,864 | 26,890 | |
| 12 | Commitments under operating leases | | | |
| | | 2021 | 2020 | |
| | | £ | £ | |
| | | 33176 | 54900 | |
| 13 | Analysis of net assets between funds | | | |
| | | Restricted funds | General funds | Total funds |
| | | £ | £ | £ |
| | Fixed assets | 0 | 1 | 1 |
| | Current assets | 64,622 | 278,048 | 342,670 |
| | Creditors | -7,881 | -25,983 | -33,864 |
| | | 56,741 | 252,066 | 308,808 |

14. Contingent liabilities

The Society has received a claim from a former employee as a result of their redundancy. The claim is being rigorously defended. At the date of this report the amount cannot be quantified.

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Notes to the financial statements for the year ended

31 March 2021

| 15 Activity on restricted funds | | Opening balance | Income | Transfers | Expenditure | Closing balance |
|---------------------------------|-----------------------------|--------------------|--------|-----------|-------------|--------------------|
| | | £ | £ | £ | £ | £ |
| | | 3,000 | 0 | 0 | 0 | 3,000 |
| | Awareness and best practice | 25,770 | 81,420 | -684 | -67,866 | 38,640 |
| | Information and support | 15,100 | 0 | 0 | 0 | 15,100 |
| | Research | 43,870 | 81,420 | -684 | -67,866 | 56,740 |

16 Related party transactions

The Chair is a governor of Queen Alexandra College (a registered charity). No transactions occurred in the year to 31st March 2021 (2020: the Society paid QAC £1,089 in respect of the hire of a conference facilities and catering for its General Meeting in October 2019).