

**THE DYSTONIA SOCIETY**

**Report of the Trustees for the year ended 31 March 2020  
(incorporating the Directors' Report)**

**THE DYSTONIA SOCIETY**

**A company limited by guarantee  
Financial Statements  
31 March 2020**

# **THE DYSTONIA SOCIETY**

## **Report of the Trustees for the year ended 31 March 2020 (incorporating the Directors' Report)**

<b>Contents</b>	<b>Page</b>
Reference and administrative information	2
Report of the trustees	3 - 9
Independent examiner's report	10
Statement of financial activities	11
Balance sheet	12
Statement of cash flows	13
Notes to the financial statements	14 - 20

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2020 (incorporating the Directors' Report)

### Reference and administrative information

#### Royal Patron

HRH Princess Alexandra

#### Patron

Tully Kearney

#### Trustees and Directors

Christopher Bradshaw  
Andy Young  
James Wishart  
Daniel Berry  
Penny Ritchie Calder MBE  
Timothy Gannicliffe

Chair  
Vice-chair

From 12<sup>th</sup> Sept 2019

#### Secretary

Roger Edmonds FCA

#### Independent Examiner

Michael Williams ACA  
30 Retford Drive  
Sutton Coldfield  
B76 1DG

#### Medical Advisers

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

#### Bankers

CAF Bank  
Kings Hi  
West Ma  
Kent ME

#### Registered Office

3<sup>rd</sup> Floor  
89 Albert Embankment  
London  
SE1 7TP

Bank of :  
14/16 Cc  
London :

# **THE DYSTONIA SOCIETY**

## **Report of the Trustees for the year ended 31 March 2020 (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 2020 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**

Under our new operating name of Dystonia UK, we continue to be the only national charity dedicated to supporting people with dystonia in the UK. Following the restructuring that took place in early 2019, the last year has been one of rebuilding the team while working to ensure that we continue to deliver the best possible value for our members and the many other people with dystonia that contact us or access our website. In December we celebrated the 100th edition of Dystonia Matters including a timeline of the history of The Dystonia Society. By the end of the year, we had stabilised the financial position and were looking forward to several events and new types of support to members with potential to attract new funding. However, as we write this report, the world is a very different place as a result of the Covid-19 pandemic and many of our plans have been disrupted. We have shifted our attention to working with our medical advisers and partner organisations to support members whose treatment has been affected by lock-down and temporary closure of hospital services. Much of this has been achieved through the use of digital technology.

### **Awareness and Best Practice**

In July 2019, we co-hosted a major conference in London with Dystonia Europe, bringing together clinicians, scientists drug companies and patients from all over Europe. Many members were involved in telling the story of their own dystonia journey. Presentations from the conference are available on YouTube and have informed much of our work during the year.

Our patron, Tully Kearney, the Paralympic gold medal swimmer, and ambassador, Gemma-Louise Stevenson, a disability sports journalist, continue helping us raise the profile of dystonia and with other members have been at the forefront of our fundraising initiatives such as the Aviva Community Fund, 2.6 Challenge and Dystonia Around the World.

In England, we have been working with the National Neurological Advisory Group to develop the best practice pathway for movement disorders. Through this we have ensured that dystonia is fully recognised alongside other neurological movement disorders. Our medical advisers have supported us in this work.

In Wales, members with dystonia had a significant input into the cross-party group inquiry into the delivery of the Welsh Government's Neurological Delivery Plan. Funding was obtained for the first full-time specialist nurse for dystonia in Wales. The aim is to establish a hub and spoke network of botulinum toxin injection clinics, with the spoke provided by nurse specialists.

We actively participate with other stakeholder organisations in each neurological alliance in England, Wales, Scotland and Northern Ireland, to promote greater understanding of dystonia and to influence

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2020 (incorporating the Directors' Report)

the work of the NHS and NICE in developing improved treatment pathways. This is the most effective way to ensure that the voice of people with dystonia reaches and influences key decision makers.

We have been invited to speak and represent the patient experience at several professional meetings, including those for researchers working for a botulinum toxin manufacturer and leaders of Healthwatch organisations.

### Support and information

December saw the publication of the 100<sup>th</sup> print edition of Dystonia Matters, 35 years after the charity was registered in 1984 and 30 years after the first edition of the Newsletter in 1989. Dystonia Matters enables us to publish short articles, often based on conference presentations or research work, so that members can see the results of our work and their support.

Our e-newsletter reaches over 4000 people. This also provides updates on our activities and useful links to research projects or surveys in which people with dystonia actively participate.

For much of this year, we have also been working on the upgrade of our website to give a more contemporary format and feel with the emphasis on our new operating name of Dystonia UK. The website was launched in July 2020.

Our members continue to report their frustrations at accessing treatments and support, including pressure on NHS services resulting in delays and cancellations, and difficulty in accessing disability benefits or education support. Our team, including trustees, continues to review and respond to enquiries from patients and others seeking information about dystonia and support in coping with their condition.

Generally, we direct enquiries either to information on our website or in our literature as well as linking to groups or social media accounts. We signpost callers to other charities such as Citizen's Advice Bureau, IPSEA, ACAS, Disability Rights UK etc. where they are better able to provide support, for example regarding benefits.

The consequences of the Covid-19 pandemic and its impact on NHS services has, of course, been a great concern for people with dystonia, reflected in a temporary increase in enquiries. We have been delighted to work with clinicians and the British Neurotoxin Network to provide support and information for patients. Our first live webinar, and the recording of this, were viewed by over 5000 people. Subsequently, we were involved in advising the BNN on its recommendations for resuming injection clinics. We produced a further webinar addressing how patients may alleviate their symptoms using mindfulness and physiotherapy. And in September of 2020, we organised a two day online conference with speakers covering our work to improve services, the future of neurology, mental health issues and the rights of disabled people.

Our network of around 30 local groups and our virtual groups on Facebook continue to be valuable in supporting individuals. We know, however, that these often rely on just a few dedicated members who organise events. We are grateful for the work that many of our group coordinators do, but we hope to encourage new members to relieve them of some of the pressures and reinvigorate some of the less active groups in the future. We look forward to these groups meeting again as soon as it is safe to do so.

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. We are, however, also aware of the need to maintain communication with those who are unable to access information online and issued a Chair's Letter this year to keep people in touch.

# **THE DYSTONIA SOCIETY**

## **Report of the Trustees for the year ended 31 March 2020 (incorporating the Directors' Report)**

### **Research.**

Research funded at Manchester Metropolitan University looking at computer mapping of the neck muscles in cervical dystonia has been published this year and is an exciting springboard for further research. The research team, led by Professor Ian Loram, has been developing a computer-aided technique using ultrasound to accurately detect dystonic muscles. The researchers have applied for further funding from grant awarding bodies to refine the technique and test it in clinics.

We have 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 are also 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. This work is being coordinated by the Walton Centre in Liverpool.

### **Staff and Trustees**

The loyalty and commitment of our staff is very much appreciated. They have formed a strong team with great spirit and focus on supporting people with dystonia. This has paid dividends since the need for them all to work from home during the Covid-19 restrictions.

Our former Chief Executive, Andrea West, left us for a new role in July 2019 and her post has not been directly replaced. Senior staff now report on a day to day basis to the Chair of Trustees, with other trustees being actively involved in supporting the Society's 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.

During the year, we welcomed Tim Gannicliffe as a new trustee. Tim is a member with oromandibular dystonia. His previous scientific experience has been a great addition to the skills and experience of the board.

### **Future Plans**

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

Reach Out Reach All – this project aims to focus on ensuring that we can be as inclusive as possible knowing that physical and social isolation are significant problems for many people, both young and old.

Events – we will resume the events that were previously planned for this year as soon as we feel it is safe to do so. Our aim is to ensure that these take place around the country with a major event being planned for the North East. Meanwhile, we will also continue to build on our experience of presenting digital events as an alternative.

Groups - we aim to improve our communications 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 and will work to support this.

Working digitally – we will build on the redevelopment of our website and social media channels so that support and information is accessible for as many people as possible. However, we will continue to provide print information for people who are not able to access digital communications.

# **THE DYSTONIA SOCIETY**

## **Report of the Trustees for the year ended 31 March 2020 (incorporating the Directors' Report)**

Research - we are establishing funds to enable us to make a call later this year for a new research proposal into dystonia.

Awareness raising and lobbying for change – we will build 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.

### **Financial Review**

Our financial position for the year ending 31st March 2020 was a deficit of £50,709 compared to a deficit of £132,896 in the previous year. Income was £221,737 (2019: £294,690). Reductions in income were mainly due to lower legacy income. Expenditure was £272,446 (2019 £427,586). Reduced expenditure was due to the lower employment costs following restructuring in the previous year.

The Society has significantly reduced its recurrent cost base in order to maintain its viability. Even so, fundraising continues to be challenging, even without the impact of the pandemic. This now makes our position more uncertain. 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 with adequate reserves 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. Our team is working on innovative approaches to raising funds in the absence of previous approaches that are no longer possible due to restrictions in social distancing. 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.

The level of unrestricted reserves at 31st March 2020 represented 65% of expenditure in the year (2019 62%).

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 £43,871 were carried forward (2018: £54,079).

### **Investment Policy**

The Society does not have sufficient resources to make long term investments. Surplus funds are held in deposit facilities with appropriate notice terms based on cash flow forecasts.

### **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

# **THE DYSTONIA SOCIETY**

## **Report of the Trustees for the year ended 31 March 2020 (incorporating the Directors' Report)**

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.



# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2020 (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.

# **THE DYSTONIA SOCIETY**

## **Report of the Trustees for the year ended 31 March 2020 (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 that have given grant funding, and to clinicians and other professionals who have attended meetings during the year, donating their time and expertise. Their presence is very much appreciated by our members.

### **Approval**

This report was approved by the Board of Trustees on 22<sup>nd</sup> October 2020 and signed on its behalf by

A handwritten signature in black ink, appearing to read 'Chris Bradshaw', is written over a light blue rectangular background.

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 2020.

### 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:

# THE DYSTONIA SOCIETY

## Statement of financial activities for the year ended 31 March 2020

	Notes	Restricted funds	Designated funds	General funds	Total 2020	Restricted funds	Designated funds	General funds	Total 2019
		£	£	£	£	£	£	£	£
<b>Income from</b>									
Donations and subscriptions		14,117	0	139,724	153,841	6,010	0	186,540	192,550
Grants	15	17,281	0	35,696	52,977	18,250	0	10,436	28,686
Legacies and in memoriam gifts		0	0	11,918	11,918	2,868	0	69,281	72,149
<b>Total donations, subscriptions, grants and legacies</b>	<b>3</b>	<b>31,398</b>	<b>0</b>	<b>187,338</b>	<b>218,736</b>	<b>27,128</b>	<b>0</b>	<b>266,257</b>	<b>293,385</b>
Other trading activities		0	0	2,857	2,857	0	0	1,214	1,214
Investments		0	0	144	144	0	0	91	91
<b>Total income</b>		<b>31,398</b>	<b>0</b>	<b>190,339</b>	<b>221,737</b>	<b>27,128</b>	<b>0</b>	<b>267,562</b>	<b>294,690</b>
<b>Expenditure on</b>	<b>5</b>								
Raising funds		0	0	63,567	63,567	0	0	84,938	84,938
Charitable activities	3, 15	37,787	0	171,092	208,879	114,624	0	228,024	342,648
<b>Total expenditure</b>		<b>37,787</b>	<b>0</b>	<b>234,659</b>	<b>272,446</b>	<b>114,624</b>	<b>0</b>	<b>312,962</b>	<b>427,586</b>
<b>Net income/(expenditure)</b>	<b>7</b>	<b>-6,390</b>	<b>0</b>	<b>-44,320</b>	<b>-50,709</b>	<b>-87,496</b>	<b>0</b>	<b>-45,400</b>	<b>-132,896</b>
Transfers between funds		-3,818		3,818	0	55,879	-100,000	44,121	0
<b>Net movement in funds</b>		<b>-10,208</b>	<b>0</b>	<b>-40,501</b>	<b>-50,709</b>	<b>-31,617</b>	<b>-100,000</b>	<b>-1,279</b>	<b>-132,896</b>
<b>Reconciliation of funds</b>									
Total funds brought forward		54,079	0	193,562	247,641	85,696	100,000	194,841	380,537
<b>Total funds carried forward</b>	<b>14</b>	<b>43,871</b>	<b>0</b>	<b>153,061</b>	<b>196,932</b>	<b>54,079</b>	<b>0</b>	<b>193,562</b>	<b>247,641</b>
<b>Unrestricted reserves % of expenditure</b>				65.2%				61.8%	

# THE DYSTONIA SOCIETY

## Balance sheet at 31 March 2020

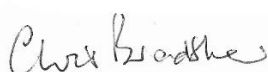
	Notes	31 March 2020	31 March 2019
		£	£
<b>Non-current assets</b>			
Tangible fixed assets	8	1,147	3,729
Investment in subsidiary company	8	1	0
<b>Current assets</b>			
Debtors	9	4,980	22,076
Cash at bank and in hand	10	217,695	259,770
		222,675	281,846
<b>Creditors: amounts falling due within one year</b>	11	-26,890	-37,935
<b>Net current assets</b>		195,785	243,911
<b>Net assets</b>		<b>196,932</b>	<b>247,640</b>
<b>Represented by</b>			
General funds		193,562	193,562
I&E 2019/20		-40,501	0
Designated funds	15	0	0
<b>Total unrestricted funds</b>		<b>153,061</b>	<b>193,562</b>
Restricted funds	15	43,871	54,079
<b>Total funds</b>	13	<b>196,932</b>	<b>247,641</b>

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.

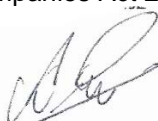
The Trustees acknowledge their responsibilities for

- (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 2020

	2020	2019
	£	£
<b>Net income/(expenditure) as per the statement of financial activities</b>	<b>-50,709</b>	<b>-132,896</b>
Adjustments for		
Depreciation charges	2,583	2,583
Interest from investments	-144	-91
(Increase)/decrease in debtors	17,096	229,493
Increase/(decrease) in creditors	-11,045	-2,675
<b>Net cash used in operating activities</b>	<b>-42,219</b>	<b>96,414</b>
<b>Cash flows from investing activities</b>		
Interest from investments	144	91
Purchase of equipment	0	0
<b>Net cash provided by/(used in) investing activities</b>	<b>144</b>	<b>91</b>
<b>Net increase/(decrease) in cash and cash equivalents</b>	<b>-42,075</b>	<b>96,505</b>
Cash and cash equivalents at the beginning of the year	259,771	163,266
<b>Cash and cash equivalents at the end of the year</b>	<b>217,696</b>	<b>259,771</b>

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2020

### 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.

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2020

### **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.



# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2020

<b>3</b>	<b>Analysis of income and expenditure by charitable activity</b>						
		<b>2020</b>		<b>2019</b>			
		<b>Income</b>	<b>Expenditure</b>	<b>Income</b>	<b>Expenditure</b>		
		<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>		
	Awareness and best practice	0	97,442	5,000	136,440		
	Support and information	29,113	67,003	18,260	147,011		
	Research	2,285	18,785	3,868	33,500		
		<b>31,398</b>	<b>183,230</b>	<b>27,128</b>	<b>316,951</b>		
	Income is analysed according to restrictions imposed by donors and funders.						
<b>4</b>	<b>Net incoming resources</b>						
				<b>2020</b>	<b>2019</b>		
				<b>£</b>	<b>£</b>		
	Net incoming resources are stated after charging						
	Operating lease - land and buildings			22,043	25,961		
	Independent examiner's fees			1,500	1,800		
<b>5</b>	<b>Total resources expended</b>		<b>Support costs</b>	<b>Awareness &amp; best practice</b>	<b>Information &amp; support</b>	<b>Research</b>	<b>Fundraising</b>
			<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>
	<b>2020</b>						
	Employment and training		24825	50419	34669	0	39050
	Premises and general overheads		44657	0	0	0	0
	Printing and communications		0	17024	2664	0	0
	Independent examination and accountancy		2900	0	0	0	0
	Conferences, meetings and travel		5944	0	0	0	0
	Direct project costs		0	1985	10408	0	0
	Fundraising and prize draw expenses		0	0	0	0	24517
	Grants awarded/(recovered)		0	0	0	13384	0
	Apportioned support costs		-78325	28014	19263	5400	25649
	<b>Total</b>		<b>0</b>	<b>97442</b>	<b>67003</b>	<b>18785</b>	<b>89216</b>
	<b>2019</b>		<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>
	Employment and training		34467	77472	92157	18940	68617
	Premises and general overheads		51585	0	0	0	0
	Printing and communications		3301	24609	3861	0	0
	Independent examination and accountancy		2682	0	0	0	0
	Conferences, meetings and travel		3845	0	0	0	0
	Direct project costs		0	5477	16638	0	0
	Fundraising and prize draw expenses		0	0	0	0	16438
	Grants awarded/(recovered)		0	0	0	7500	0
	Apportioned support costs		-95880	28882	34357	7061	25581
	<b>Total</b>		<b>0</b>	<b>136,440</b>	<b>147,011</b>	<b>33,500</b>	<b>110,635</b>
				<b>2020</b>	<b>2019</b>		
				<b>£</b>	<b>£</b>		
	Support costs include governance costs of			7,188	5,556		
	Grants awarded included						
	To individuals			0	0		
	To organisations			13,385	7,500		

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2020

6	Staff costs	2020	2019
		£	£
	Salaries and wages	122,619	238,245
	Social security costs	9,250	19,587
	Pension contributions	5589	14,154
		<b>137,458</b>	<b>271,986</b>
	Staff employed under service contracts	0	0
	Other employment and training costs	784	280
	Total employment and training costs	<b>138,242</b>	<b>272,266</b>

The average number of employees during the year was 3.8 (2018: 8.8) of whom 2 were full-time. The full-time equivalent was 3.2 (2018: 6.1), No employee earned more than £60,000 during the year (2019: nil). The total of employee benefits paid to key management personnel was £19,875 (2019: £60,093).

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 March 2019, the Society owed £635 (2018: £nil) to these pension schemes.

### 7 Trustees' remuneration and expenses

The trustees received no remuneration for their services (2019: nil). Two trustees (2019: two) were reimbursed for travel expenses and other costs totaling £2,657 (2018: £1,281).

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2020

<b>8</b>	<b>Non-current assets</b>		
	Office equipment and fixtures		
			£
	Cost at 1 April 2019		22317
	Additions		0
	<b>Cost at 31 March 2020</b>		<b>22317</b>
	Depreciation at 1 April 2019		18588
	Charge for the year		2583
	<b>Depreciation at 31 March 2020</b>		<b>21171</b>
	Net book value at 1 April 2019		3730
	<b>Net book value at 31 March 2020</b>		<b>1147</b>
	<b>Investment in subsidiary</b>		
	Investment in Dystonia UK Ltd		1
<b>9</b>	<b>Debtors</b>		
		<b>2020</b>	<b>2019</b>
		£	£
	Prepayments	4980	10,913
	Other debtors and accrued income	0	11,163
		<b>4,980</b>	<b>22,076</b>
<b>10</b>	<b>Cash at bank and in hand</b>		
		<b>2020</b>	<b>2019</b>
		£	£
	Bank investment accounts	95999	95,854
	Other bank and building society accounts	118880	161,055
	Petty cash and groups	2816	2,861
		<b>217,695</b>	<b>259,770</b>
<b>11</b>	<b>Creditors: Amounts falling due within one year</b>		
		<b>2020</b>	<b>2019</b>
		£	£
	Taxation and social security costs	3555	10,400
	Other creditors	13785	19,525
	Accruals	9550	8,010
		<b>26,890</b>	<b>37,935</b>
<b>12</b>	<b>Commitments under operating leases</b>		
		<b>2020</b>	<b>2019</b>
		£	£
		54900	31,110

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2020

13	Analysis of net assets between funds				
		Restricted	Designated	General	Total
		funds	funds	funds	funds
		£	£	£	£
	Fixed assets	0	0	1,147	1,147
	Current assets	57,255	0	165,420	222,675
	Creditors	-13,385	0	-13,505	-26,890
		<b>43,870</b>	<b>0</b>	<b>153,061</b>	<b>196,931</b>

### 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.

15	Activity on restricted funds					
		Opening	Income	Transfers	Expenditure	Closing
		balance				balance
		£	£	£	£	£
	Awareness and best practice	8,000	0	0	-5,000	3,000
	Information and support	19,307	29,113	-3,818	-18,831	25,770
	Research	26,771	2,285	0	-13,956	15,100
		<b>54,078</b>	<b>31,398</b>	<b>-3,818</b>	<b>-37,787</b>	<b>43,870</b>

### 16 Related party transactions

The Chair is a governor of Queen Alexandra College (a registered charity). The Society paid QAC £1,089 in respect of the hire of a conference facilities and catering for its General Meeting in October 2019. The Chair was not involved in the negotiation of the contract and the decision to use the facility was taken by the board.