

**THE DYSTONIA SOCIETY**

**Financial Statements for the year ended 31 March 2019**

**THE DYSTONIA SOCIETY**

**A company limited by guarantee**

**Financial Statements**

**31 March 2019**

# THE DYSTONIA SOCIETY

## Financial Statements for the year ended 31 March 2019

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# THE DYSTONIA SOCIETY

## Financial Statements for the year ended 31 March 2019

### Reference and administrative information

#### Royal Patron

HRH Princess Alexandra

#### Patron

Tully Kearney

#### Trustees and Directors

Fiona Ross OBE

Andy Young

Christopher Bradshaw

Peter Meager

James Wishart

Daniel Berry

Christina Gray

Penny Ritchie Calder MBE

Chair

Vice-chair

Treasurer

Resigned 9<sup>th</sup> May 2019

Resigned 12 April 2019

From 9<sup>th</sup> May 2019

#### Secretary

Roger Edmonds FCA

#### Independent Examiner

Michael Williams ACA

30 Retford Drive

Sutton Coldfield

B76 1DG

#### Chief Executive

Andrea West

#### 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 Hill

West Malling

Kent ME19 4TA

Bank of Scotland

14/16 Cockspur Street

London SW1Y 5BL

#### Registered Office

89 Albert Embankment

London

SE1 7TP

# **THE DYSTONIA SOCIETY**

## **Report of the Trustees for the year ended 31 March 2019 (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 2019 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**

As with many small charities, the last year has again been a challenging one for The Dystonia Society. A deficit of £132,896 was the result of reduced income of £166,946. Unrestricted funds reduced by £1,279. Legacies gifted to the Society enabled continued service delivery and strategic funding plans to be implemented.

To manage risk and meet the current and evolving needs of Society members and the patient community, in autumn 2018 the Board of Trustees embarked on a strategic review of all our activities to see how best we can continue to serve our members and others in the UK with dystonia. Much has changed since the Society was formed 35 years ago, and we are now in a world where information and communication are much more widely available through the internet and social media.

Consequently, we are moving away from having an isolated Head office culture to work more closely with the membership, involving them in fundraising, website, video diaries and many other projects.

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2019 (incorporating the Directors' Report)

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### **Strategic Review.**

#### **1. Helpline.**

There has been a significant decline in the number of calls – 2 or 3 a day – which did not justify the cost of continuing to run this dedicated service. The trustees therefore took the decision to close the helpline and make the whole team redundant.

#### **2. Staffing.**

Cutting costs was a major issue.

A total of 4 roles have been made redundant. The decision was based on reduced income and the drop in demand for services – 2 from the helpline, and 2 administrative staff.

2 members of staff have retired.

Andrea West, CEO, tendered her resignation in February.

#### **3. Membership Fees.**

These had remained unchanged for many years and were much lower than similar charities.

Despite the increase in fees, the majority of members renewed their subscriptions, demonstrating their commitment to the Society and its services.

### **2018/19.**

#### **Local Activity.**

Our network of around 30 local groups continues to be a valuable asset in terms of supporting individuals. These meet regularly, across the country. We also provide a network of 'virtual' online groups connecting those unable to attend face to face meetings.

We have also held several 'Living with Dystonia Days' across the country, to bring members and carers together.

#### **Online.**

Our website continues to be an essential database of information which has been accessed over 570,000 times in the past year.

#### **Newsletter.**

We produced 3 editions a year of our magazine, 'Dystonia Matters' which highlights medical developments and advice, patients' stories and fundraising opportunities.

Our e-newsletter reaches over 4000 people – across the world.

#### **Social Media.**

We continue to build and expand our presence on Facebook, Twitter and Instagram to inform and attempt to alleviate the isolation felt by many who are having to deal with dystonia.

#### **Raising Awareness.**

1. This year has seen us attend a number of professional conferences including the British Paediatric Neurology Association and the British Neurotoxin Network where we were able to raise the profile of the condition and the impact on those living with the diagnosis amongst professionals.

## **THE DYSTONIA SOCIETY**

### **Report of the Trustees for the year ended 31 March 2019 (incorporating the Directors' Report)**

2. In July we are co-hosting the Dystonia Europe Conference in London, bringing together clinicians, scientists drug companies and patients from all over Europe.

3. We established a 'Young Champions' programme to build a family network for young people who often feel isolated and marginalised by the condition.

4. A new patron, Tully Kearney, the Paralympic gold medal swimmer, and a new ambassador, Gemma-Louise Stevenson who is a sports journalist with SKY and the Financial Times, are helping us raise the profile. Both have dystonia.

5. We have also had a strong parliamentary advocacy presence in the Welsh Assembly for access to prompt appropriate treatment for Welsh patients.

6. We have also worked with other stakeholder organisations such as the Neurological Alliance to challenge moves to remove Botulinum Toxin treatment from the high cost drugs list, a move which would have put barriers in place for accessing treatment.

7. The Society responded to the Scottish Government's Consultation Document - National Action Plan on Neurological Conditions 2019-2024

8. Autumn 2018 saw us deliver another Parents and Carers of Children and Young People with Dystonia Conference. We brought together experts from across clinical and related disciplines to deliver a programme of interactive talks and networking opportunities to over 120 parents and carers. We also provided a comprehensive programme of care and activities for affected children and their siblings to enable parents and carers to take part.

9. An Essay Competition for medical students was held in 2018 – funded by Michael and AnnMarie Newbiggin. A high number of entries helped raise awareness of the condition among young medics.

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2019 (incorporating the Directors' Report)

### **Delivering Best Practice.**

Our members report their frustrations at accessing treatments and support, including pressure on NHS services resulting in delays and cancellations. Changes to disability benefits have resulted in individuals living with the condition being subjected to a lengthy and stressful application process. Some parents have also identified difficulties with educational placements.

This year we:

1. Provided over 150 advocacy letter templates to explain the impact of dystonia on individuals applying for Personal Independence Payment, going through an employment tribunal or trying to access the most appropriate educational support for their child.
2. Worked with other services to develop referral pathways for our service users to access organisations such as Citizen's Advice Bureau, IPSEA, ACAS, Disability Rights UK etc. to ensure that they have the necessary support and expertise.
3. Have secured funding to review and expand our condition specific materials and resources, which will be done with the expert input from the board of Medical Advisors and related professionals.
4. Have been invited to speak to represent the patient experience at a number of professional meetings, including those for clinicians, social care professionals, education and pharmaceutical and medical technology companies.
5. Implemented a review of the Good Practice Guide for Dystonia to develop a paediatric guide.

### **Research.**

This year a grant was awarded, in partnership with Fight for Sight, to study blepharospasm. We are funding researchers from Cardiff University to identify the symptoms associated with this - the involuntary tight closure of the eyelids, which can result in the sufferer being functionally blind. The Cardiff researchers, led by Dr Kathryn Peall, will investigate whether other non-movement symptoms such as changes to mood, sleep disturbances and difficulties processing information, are associated with the disorder, and whether these are linked to the severity of the muscle spasm

This year also saw the patent of the Pressop device by the team at the John Radcliffe Hospital in Oxford, for the management of blepharospasm. This device, which is mounted on a pair of spectacles, applies light pressure to the side of the temple, and is the outcome of previous research funding by the Society. This is an example of how meaningful placement of small research funds can impact on an individual's ability to manage symptoms on a daily basis.

Previous research funding at Manchester Metropolitan University and Professor Loram's team looking at mapping the neck muscles in cervical dystonia will be published this year and is an exciting springboard for further research.

The Society's contribution to these research projects has been funded from grants specifically restricted to research. Trustees will use similar grants in the future to promote research in consultation with our medical advisers.

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2019 (incorporating the Directors' Report)

### Future Plans.

The world has digitalised at an extraordinary rate and this changes the way non profit organisations are able to interact with the wider public.

#### 1. Website.

It is clear from our review that the majority of people want to find information online, therefore our website must be the 'go to' place about dystonia, providing information about medical services, treatments, support services and patients' view and experiences.

#### 2. Local Groups.

These will continue as members find interaction with others beneficial, but such meetings do not suit everyone and so we are planning to expand our network of 'virtual' groups where members can share their experiences and support each other.

#### 3. Staffing.

We are planning to recruit a Head of Operations & Development to oversee the administration of our organisation.

#### 4. Volunteers.

The Board of Trustees are all volunteers, and the majority have direct experience of the condition. Trustees will take on more individual management roles, and we have also involved our members, who have a diverse range of skills and experience, by creating volunteering opportunities.

#### 5. Fundraising.

The future of the Society depends on fundraising, and that has to be our immediate priority. Like other small charities we have suffered from the drop in donations and the strictures of grant giving bodies, in the current financial climate. So, it is our aim to identify new sources of income, aimed at specific projects, whilst being responsive to the needs of the community who rely on our services.

### Financial Review

Our financial position for the year ending 31<sup>st</sup> March 2019 was a deficit of £132,896 compared to a surplus of £53,580 in the previous year. Income was £294,690 (2018: £461,636). Reductions in income were experienced from donations and subscriptions £45,498, charitable trusts and foundations £53,603 and legacies and in memorium gifts of £67,081. Expenditure in 2018/19 was £427,586 (2017/18 £408,056).

The slightly higher level of expenditure includes the costs of the major Children's Conference (£10,566), essay prize (£3,000) and the blepharospasm research project (£7,500). This expenditure was met from restricted donations.

The Society has undergone restructuring of the staff team to meet the current service need, better align with our strategic plan and support increased funding for future service delivery. Restructuring costs of £39,275 were incurred in the last quarter of the year. This action will lead to cost savings of £102,000 in a full year.



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## Report of the Trustees for the year ended 31 March 2019 (incorporating the Directors' Report)

Community Fundraising by our supporters continues to be an important income stream for the Society. For example, our Facebook fundraising pages raised over £8,000, our annual raffle raised over £10,000 and community tea parties over £3,500.

We are rebuilding and establishing new relationships with funders, trusts and foundations to enable us to deliver our services.

Legacy income is extremely important to the Society, and we have benefitted from some substantial gifts in the past as well as the many in memoriam collections. During 2018/19, we received £228,678 in respect of legacies accrued as income in the previous year and a further £65,195 from additional bequests which are shown as current year income. These bequests have enabled us to maintain our reserves levels and offset the cost of restructuring. However, legacies by their very nature are a long-term income stream and the Society is developing a fundraising strategy that combines short, medium and long-term income opportunities that meet the changing environment and growing need.

### Plans for Future Periods

During 2019/20, the Society 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 significant 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.

In July 2019, in London, we plan to deliver the Dystonia Day Conference 2019 in partnership with Dystonia Europe. This international event brings together patients, professionals, companies and patient groups from across Europe to hear about new developments, current good practice and to network.

### Reserves

#### Unrestricted reserves

The trustees feel it is prudent to maintain the Society's general unrestricted reserves at a level sufficient to cover existing commitments such as property rental and staffing costs and to reflect the relative uncertainty of income from grant giving organisations or through legacies, and potential restrictions on the use of such income. The trustees have regard to both the accrued income and projected cash flow from these sources. The reserves policy is reviewed annually in conjunction with the trustees' review of the budget and financial plans.

The trustees may designate unrestricted reserves as part of their financial planning to fund deficit budgets or to meet specific project costs. At 31st March 2018, the trustees designated £100,000 for this purpose. However, given the challenges faced by the Society, the trustees do not consider it appropriate to set a further deficit budget and so have acted to reduce expenditure in line with income that is reasonably certain based on past experience. Any risk from a shortfall in income (after mitigating any loss) will be met from the general unrestricted reserves.

The level of unrestricted reserves, excluding designated funds, at 31<sup>st</sup> March 2018 represented 62% of total expenditure in that year (2017/18 54%).

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2019 (incorporating the Directors' Report)

### Restricted funds

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 31<sup>st</sup> March 2019, funds of £54,079 were carried forward (2018: £85,696).

### **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 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.

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. The trustees are advised by a Finance & General Purposes Committee which maintains oversight and scrutiny of activities between board meetings. In addition, working groups may be set up to address other specific policy or governance issues as they arise, such as appointment of senior staff or review of research proposals, and these may include volunteers and advisers co-opted by the trustees for their expertise and members of staff where appropriate. Decisions of the trustees are implemented by the Chief Executive and staff.

### **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 risks to be its ability to increase fundraising from corporate supporters and charitable trusts and to maintain its financial sustainability. The Society undertakes careful monitoring of its projected cash flows and levels of reserves so that it can meet its financial duties.

# **THE DYSTONIA SOCIETY**

## **Report of the Trustees for the year ended 31 March 2019 (incorporating the Directors' Report)**

### **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 2019 (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 2019 (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, many of whom feel that their condition is not always understood or taken seriously enough.

### **Approval**

This report was approved by the Board of Trustees on 24 July 2019 and signed on its behalf by

Fiona Ross OBE

Chair of Trustees

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2019 (incorporating the Directors' Report)

### *Independent Examiner's Report*

*I report on the accounts of The Dystonia Society for the year ended 31 March 2017 which comprise the Statement of Financial Activities, the Balance Sheet, the Statement of Cash Flows and the related notes.*

*This report is made solely to the Charity's Trustees, as a body, in accordance with Chapter 3 of Part 8 of the Charities Act 2011 ("the 2011 Act") and Section 44 of the Charities and Trustee Investment (Scotland) Act 2005 ("the 2005 Act"). My examination has been undertaken so that I might state to the Charity's Trustees those matters I am required to state to them in an independent examiner's report and for no other purpose. To the fullest extent permitted by law, I do not accept or assume responsibility to anyone other than the Charity and the Charity's Trustees as a body, for my examination, for this report, or for the opinions I have formed.*

#### **Respective responsibilities of Trustees and Examiner**

*The trustees (who are also the directors of the company for the purposes of company law) are responsible for the preparation of the accounts. The Trustees consider that an audit is not required for this year under section 144(2) of the 2011 Act and Regulation 10(1)(a) to (c) of the Charities Accounts (Scotland) Regulations 2006 ("2006 Accounts Regulations"), and that an independent examination is needed.*

*The charity's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of the Institute of Chartered Accountants in England and Wales (ICAEW).*

*Having satisfied myself that the charity is not subject to audit under company law and is eligible for independent examination, it is my responsibility to:*

- examine the accounts under section 145 of the 2011 Act and Section 44(1)(c) of the 2005 Act;*
- to follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act and Regulation 11 of the 2006 Accounts Regulations; and*
- to state whether particular matters have come to my attention.*

#### **Basis of Independent Examiner's report**

*My examination was carried out in accordance with the general Directions given by the Charity Commission and Regulation 11 of the 2006 Accounts Regulations. An examination includes a review of the accounting records kept by the Charity and a comparison of the accounts presented with those records. It also includes a consideration of any unusual items or disclosures in the accounts and seeking explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a "true and fair view" and the report is limited to those matters set out in the statement below.*

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2019 (incorporating the Directors' Report)

### *Independent Examiner's statement*

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

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

- to keep accounting records in accordance with section 386 of the Companies Act 2006, Section 44(1)(a) of the 2005 Act and Regulation 4 of the 2006 Accounts Regulations; and*
- to prepare accounts which accord with the accounting records, comply with the accounting requirements of section 396 of the Companies Act 2006 and with the methods and principles of the Statement of Recommended Practice: Accounting and Reporting by Charities, and Regulation 8 of the 2006 Regulations*

*have not been met; or*

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

**Michael Williams**

Chartered Accountant

1 August 2019

30 Retford Drive  
Sutton Coldfield  
Birmingham  
B76 1DG

# THE DYSTONIA SOCIETY

## Statement of financial activities for the year ended 31 March 2019

		Unrestricted funds				Unrestricted funds			
	Notes	Restricted funds	Designated funds	General funds	Total 2019	Restricted funds	Designated funds	General funds	Total 2018
		£	£	£	£	£	£	£	£
<b>Income from</b>									
Donations and subscriptions		6,010		186,540	192,550			238,048	238,048
Grants	15	18,250		10,436	28,686	53,474		28,815	82,289
Legacies and in memoriam gifts		2,868		69,281	72,149	21,000		118,230	139,230
<b>Total donations, subscriptions, grants and legacies</b>	<b>3</b>	<b>27,128</b>	<b>0</b>	<b>266,257</b>	<b>293,385</b>	<b>74,474</b>	<b>0</b>	<b>385,093</b>	<b>459,567</b>
Other trading activities				1,214	1,214			1,997	1,997
Investments				91	91			72	72
<b>Total income</b>		<b>27,128</b>	<b>0</b>	<b>267,562</b>	<b>294,690</b>	<b>74,474</b>	<b>0</b>	<b>387,162</b>	<b>461,636</b>
<b>Expenditure on</b>	<b>5</b>								
Raising funds				84,938	84,938			92,806	92,806
Charitable activities	3, 15	114,624		228,024	342,648	50,494		264,756	315,250
<b>Total expenditure</b>		<b>114,624</b>	<b>0</b>	<b>312,962</b>	<b>427,586</b>	<b>50,494</b>	<b>0</b>	<b>357,562</b>	<b>408,056</b>
<b>Net income/(expenditure)</b>	<b>7</b>	<b>-87,496</b>	<b>0</b>	<b>-45,400</b>	<b>-132,896</b>	<b>23,980</b>	<b>0</b>	<b>29,600</b>	<b>53,580</b>
Transfers between funds		55,879	-100,000	44,121	0	-3,648	-9,000	12,648	0
<b>Net movement in funds</b>		<b>-31,617</b>	<b>-100,000</b>	<b>-1,279</b>	<b>-132,896</b>	<b>20,332</b>	<b>-9,000</b>	<b>42,248</b>	<b>53,580</b>
<b>Reconciliation of funds</b>									
Total funds brought forward		85,696	100,000	194,841	380,537	65,364	109,000	152,593	326,957
<b>Total funds carried forward</b>	<b>14</b>	<b>54,079</b>	<b>0</b>	<b>193,562</b>	<b>247,641</b>	<b>85,696</b>	<b>100,000</b>	<b>194,841</b>	<b>380,537</b>



# THE DYSTONIA SOCIETY

## Balance sheet at 31 March 2019

	Notes	31 March 2019	31 March 2018
		£	£
<b>Fixed assets</b>			
Tangible fixed assets	8	3,729	6,313
<b>Current assets</b>			
Debtors	9	22,076	251,569
Cash at bank and in hand	10	259,770	163,264
		281,846	414,833
<b>Creditors: amounts falling due within one year</b>	11	-37,935	-40,610
<b>Net current assets</b>		243,911	374,223
<b>Net assets</b>		<b>247,640</b>	<b>380,536</b>
<b>Represented by</b>			
Unrestricted funds			
General funds		194,841	194,841
I&E 2018/19		-1,279	
Designated funds	15		100,000
<b>Total unrestricted funds</b>		<b>193,562</b>	<b>294,841</b>
Restricted funds	15	54,079	85,695
<b>Total funds</b>	13	<b>247,641</b>	<b>380,536</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.

Approved and authorised for issue by the Trustees on 24 July 2019 and signed on their behalf by

Fiona Ross (Trustee)

Chris Bradshaw (Trustee)

Company Registration Number: 3309777

The notes on pages 13 to 19 form part of these financial statements.

## THE DYSTONIA SOCIETY

### Statement of cash flows for the year ended 31 March 2019

	2019	2018
	£	£
<b>Net income/(expenditure) as per the statement of financial activities</b>	<b>-132,896</b>	<b>53,580</b>
Adjustments for		
Depreciation charges	2,583	1,432
Interest from investments	-91	-72
(Increase)/decrease in debtors	229,493	41,688
Increase/(decrease) in creditors	-2,675	-21,137
<b>Net cash used in operating activities</b>	<b>96,414</b>	<b>75,491</b>
<b>Cash flows from investing activities</b>		
Interest from investments	91	72
Purchase of equipment	0	-4,600
<b>Net cash provided by/(used in) investing activities</b>	<b>91</b>	<b>-4,528</b>
<b>Net increase/(decrease) in cash and cash equivalents</b>	<b>96,505</b>	<b>70,963</b>
Cash and cash equivalents at the beginning of the year	163,266	92,303
<b>Cash and cash equivalents at the end of the year</b>	<b>259,771</b>	<b>163,266</b>

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2019

### 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. From 2017/18, the Society has determined that it will not include the notional value associated with GoogleAds as income and expenditure as to do so gives a misleading representation of the income and expenditure of the Society.

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

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2019

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.

## **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 2019

<b>3</b>	<b>Analysis of income and expenditure by charitable activity</b>							
		<b>2019</b>		<b>2018</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	5,000	136,440	0	59,449			
	Support and information	18,260	147,011	48,473	222,821			
	Research	3,868	33,500	26,000	-29,429			
		<b>27,128</b>	<b>316,951</b>	<b>74,473</b>	<b>252,842</b>			
	Income is analysed according to restrictions imposed by donors and funders.							
<b>4</b>	<b>Net incoming resources</b>			<b>2019</b>	<b>2018</b>			
				<b>£</b>	<b>£</b>			
	Net incoming resources are stated after charging							
	Operating lease - land and buildings			25,961	28,926			
	Independent examiner's fees			1,800	1,800			
	Costs of office relocation			0	18,847			
<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>Total</b>
			<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>
	<b>2019</b>							
	Employment and training		34467	77472	92157	18940	68617	291651
	Premises and general overheads		51585	0	0	0	0	51585
	Printing and communications		3301	24609	3861	0	0	31770
	Independent examination and accountancy		2682	0	0	0	0	2682
	Conferences, meetings and travel		3845	0	0	0	0	3845
	Direct project costs		0	5477	16638	0	0	22115
	Fundraising and prize draw expenses		0	0	0	0	16438	16438
	Grants awarded/(recovered)		0	0	0	7500	0	7500
	Apportioned support costs		-95880	28882	34357	7061	25581	0
	<b>Total</b>		<b>0</b>	<b>136440</b>	<b>147011</b>	<b>33500</b>	<b>110635</b>	<b>427586</b>
	<b>2018</b>		<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>
	Employment and training		102,046	21,820	112,598	4,721	66,703	307,889
	Premises and general overheads		71,745	0	0	0	0	71,745
	Printing and communications		11,210	16,477	0	0	0	27,687
	Independent examination and accountancy		3,257	0	0	0	0	3,257
	Conferences, meetings and travel		4,330	737	704	0	0	5,770
	Direct project costs		0	0	4,172	0	0	4,172
	Fundraising and prize draw expenses		0	0	0	0	26,103	26,103
	Grants awarded/(recovered)		0	0	0	-38,567	0	-38,567
	Apportioned support costs		-192,588	20,415	105,348	4,417	62,408	0
	<b>Total</b>		<b>0</b>	<b>59,449</b>	<b>222,821</b>	<b>-29,429</b>	<b>155,214</b>	<b>408,056</b>
				<b>2019</b>	<b>2018</b>			
				<b>£</b>	<b>£</b>			
	Support costs include governance costs of			5,556	4,501			
	Grants awarded included							
	To individuals			0	0			
	To organisations			7,500	0			

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2019

6	Staff costs		
		2019	2018
		£	£
	Salaries and wages	238,245	224,959
	Social security costs	19,587	13,089
	Pension contributions	14,154	13,289
		<b>271,986</b>	<b>251,337</b>
	Staff employed under service contracts	0	43,050
	Other employment and training costs	280	9,130
	Total employment and training costs	<b>272,266</b>	<b>303,517</b>

The average number of employees during the year was 8.8 (2018: 11) of whom 1 was full-time. The full-time equivalent was 6.1 (2018: 5.9). No employee earned more than £60,000 during the year (2018: nil). The total of employee benefits paid to key management personnel was £60,093 (2018: £54,850).

During the year 5 employees received pay in lieu of notice totaling £20,198 and 4 received redundancy pay totaling £19,077.

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 £nil (2018: £1,688) to these pension schemes.

### 7 Trustees' remuneration and expenses

The trustees received no remuneration for their services (2018: nil). Two trustees (2018: three) were reimbursed for travel expenses and other costs totaling £1,281 (2018: £965).

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2019

<b>8</b>	<b>Tangible fixed assets</b>		
	Office equipment and fixtures		
			<b>£</b>
	Cost at 1 April 2018		22,317
	Additions		0
	<b>Cost at 31 March 2019</b>		<b>22,317</b>
	Depreciation at 1 April 2018		16,005
	Charge for year		2,583
	<b>Depreciation at 31 March 2019</b>		<b>18,588</b>
	Net book value at 1 April 2018		6,312
	<b>Net book value at 31 March 2019</b>		<b>3,729</b>

  

<b>9</b>	<b>Debtors</b>		
		<b>2019</b>	<b>2018</b>
		<b>£</b>	<b>£</b>
	Prepayments	10913	22,891
	Other debtors and accrued income	11163	228,678
		<b>22,076</b>	<b>251,569</b>

  

<b>10</b>	<b>Cash at bank and in hand</b>		
		<b>2019</b>	<b>2018</b>
		<b>£</b>	<b>£</b>
	Bank investment accounts	95854	91,360
	Other bank and building society accounts	161055	68,792
	Petty cash and groups	2861	3,112
		<b>259,770</b>	<b>163,264</b>

  

<b>11</b>	<b>Creditors: Amounts falling due within one year</b>		
		<b>2019</b>	<b>2018</b>
		<b>£</b>	<b>£</b>
	Taxation and social security costs	10400	7,515
	Other creditors	19525	26,284
	Accruals	8010	3,497
		<b>37,935</b>	<b>37,296</b>

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2019

<b>12</b>	<b>Commitments under operating leases</b>				
		<b>2019</b>	<b>2018</b>		
		<b>£</b>	<b>£</b>		
		14,640	36,112		

<b>13</b>	<b>Analysis of net assets between funds</b>				
		<b>Restricted</b>	<b>Designated</b>	<b>General</b>	<b>Total</b>
		<b>funds</b>	<b>funds</b>	<b>funds</b>	<b>funds</b>
		<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>
	Fixed assets	0	0	3,729	3,729
	Current assets	54,078	0	227,768	281,846
	Creditors	0	0	-37,935	-37,935
		<b>54,078</b>	<b>0</b>	<b>193,562</b>	<b>247,640</b>
<b>14</b>	<b>Contingent assets</b>				
		<b>2019</b>	<b>2018</b>		
		<b>£</b>	<b>£</b>		
		0	0		

### 15 Designated and restricted funds

#### Designated funds

The Society's trustees have approved a [breakeven] budget for 2019/20 and have not identified any other commitments for which they propose to designate funds. Consequently, no funds have been designated as at 31 March 2019 (2018: £100,000).

#### Restricted funds

As part of the trustees' commitment to a wide range of activities, programmes which are not fully resourced by external funding are supported using the Society's unrestricted funds.

The Society operated the following restricted funds during the year

- **Awareness and best practice** - to promote the awareness of dystonia including with medical practitioners, people concerned about possible symptoms of dystonia, and those involved in the care and support of patients and to ensure that people with dystonia are treated fairly and appropriately in relation to employment, treatment and benefits and that services are delivered with maximum possible effectiveness. Funds were held at 31 March 2019 for one further essay competition and for a project to update and improve the information resources available to members and users in both written form and on our website.
- **Information and support** – provide information and support to individuals through literature and our website, to run conferences and events enabling people to meet and learn about dystonia and its treatment, to provide information about sources of support such as benefits advice or



# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended

### 31 March 2019

mental health services, and to link people through local groups and social media networks to enable them to share experiences. Funds are held to support activities of individual groups.

- **Research** – to support research projects relating to understanding, treating and living with dystonia. Restricted funds held at 31<sup>st</sup> March 2019 are yet to be committed to a specific project.

Activity and balances on restricted funds are summarised below:

	Opening balance	Income	Transfers	Expenditure	Closing balance	Check
	£	£	£	£	£	
Awareness and best practice	6,000	5,000	0	3,000	8,000	8,000
Information and support	33,936	18,260	70,268	103,157	19,307	19,307
Research	45,759	3,868	-14,389	8,467	26,771	26,771
	<b>85,695</b>	<b>27,128</b>	<b>55,879</b>	<b>114,624</b>	<b>54,078</b>	<b>54,078</b>

#### 16 Related party transactions

The Charity has not entered into any related party transactions in the current or preceding periods that would require disclosure.