

Company Registration Number: 3309777  
Charity Registration Numbers: 1062595 and SC042127

## **THE DYSTONIA SOCIETY**

**A company limited by guarantee**  
**Financial Statements**  
**31 March 2017**



# THE DYSTONIA SOCIETY

## Financial Statements for the year ended 31 March 2017

<b>Contents</b>	<b>Page</b>
Reference and administrative information	1
Report of the trustees	2 - 9
Independent examiner's report	10-11
Statement of financial activities	12
Balance sheet	13
Statement of cash flows	14
Notes to the financial statements	15 - 21



# THE DYSTONIA SOCIETY

## Financial Statements for the year ended 31 March 2017

### Reference and administrative information

#### Royal Patron

HRH Princess Alexandra

#### Patron

Fiona Ross OBE

#### Trustees and Directors

Joanna Atkin	Chair	
Christopher Bradshaw	Honorary Treasurer	
Nirmaljit Gill	Vice Chair	Retired 27 May 2017
Penny Ritchie Calder MBE		
Peter Meager		
James Wishart		
Daniel Berry		
Andy Young		
Daniel Brett Schneider		Appointed 10 November 2016
Christine Chapman		Retired 9 February 2017
Alec Sandison		Retired 18 September 2016

#### Secretary

Jane Seaton ACA

#### Chief Executive

Guy Parckar

#### Medical Advisers

Prof. Tom Warner  
Dr. Mark Edwards  
Dr. Marie-Helene Marion  
Dr. Kathryn Peall

#### Registered Office

89 Albert Embankment  
London  
SE1 7TP

#### Independent Examiner

Moore Stephens LLP  
150 Aldersgate Street  
London  
EC1A 4AB

#### Bankers

CAF Bank  
Kings Hill  
West Malling  
Kent ME19 4TA

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

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2017 (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 2017 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

Looking back over the past year there has been a huge amount of activity across the Society and some very notable successes, including national broadcast media coverage and direct engagement on a major new clinical guideline that could improve recognition and referral for anyone with dystonia. In particular through our support services and information we continue to provide an invaluable service to thousands of people with dystonia, supporting them when they need us, whether through our helpline, providing up-to-date information or connecting people through local groups.

This has, however, been delivered against an immensely challenging backdrop in terms of the long-term funding of the organisation, culminating with a decision to both relocate to a smaller office, and reduce staff hours across the team to ensure our sustainability. Thanks both to the incredible way that our staff team responded to these challenges, and to the notification late in the year of a very substantial legacy left to the Society, we now have the opportunity to develop a sustainable financial strategy for maintaining our services.

We remain very concerned about the ongoing challenge of a decline in trust and statutory funding for the Society. This has represented a major source of income for the Society over many years, but the loss of several larger grants and a general slowdown in trust funding has had a significant impact on the Society and ultimately drove the decision to reduce expenditure significantly through relocation and reduced staff hours. The legacy for which we received notification late in the year appears as a debtor in these accounts, and will be received during the current year. The decision to make immediate significant expenditure reductions was driven by the need to maintain sufficient cash reserves until the legacy is paid.

Reduced hours across the staff team have of course resulted in reduced capacity for our activity, although we have worked very carefully to minimise the impact on our members, and to ensure that all of our key support services continue. The reduction in hours came into effect at the very end of the financial year, so will make more impact in the current year, as we work to manage within our current resources. We can report however back positively on our achievements in the past year, while sounding a note of caution that much more needs to be done to identify more long-term, sustainable funding opportunities to continue all of the Society's work.

#### **We said that in 2016/17 we would...**

...Update and enhance our website and online social media presence to reach more people with dystonia;

#### **Raising Awareness**

- Over the past year we have been working hard to raise awareness and understanding of dystonia, and the impact that the condition can have. We have continued to use our online presence to reach people, including through our website,

## Report of the Trustees for the year ended 31 March 2017 (incorporating the Directors' Report)

...Secure media coverage to raise public awareness of dystonia;

...Raise awareness of dystonia with medical professionals through targeted engagement with them and their representative bodies.

which for the first time received more than 1 million visitors in the past year. We have also been working on redesigning the website to make it easier to navigate and use, and will be launching a new site in the coming year. We have continued to be supported brilliantly by Google Ad Grants, which we use to target people searching for symptoms of dystonia to helpful information and advice on our website.

- Our annual awareness week continues to provide an opportunity to build awareness and to achieve positive media coverage around dystonia, with activity taking place across the country, led by people with dystonia, but we also work year-round to secure media coverage. This year we helped to develop an excellent piece on dystonia on Channel 5 news, featuring one of our members and our chief executive. As well as appearing on prime time news, the video clip was viewed thousands of times online.
- We again worked closely with the British Neurotoxin Network, the network for botulinum toxin injectors in the UK, presenting at their annual conference, and supporting developing work with physiotherapists working in the field.

...Ensure dystonia is well-represented in the forthcoming NICE guideline on diagnosing neurological conditions;

...Renew and republish our 'best practice' guidance to help drive improved, more consistent dystonia services;

...Use expertise and experience to defend dystonia services across the UK, including botulinum toxin clinics.

### Delivering best practice

- Ensuring that the best possible treatment options are available for members all across the UK remains a key objective, particularly in light of financial challenges within the NHS.
- This year we have been very directly involved with the developing NICE guidance (which applies to England only) on neurological conditions, with our chief executive being part of the committee helping to develop and inform the guideline. This work has been ongoing over the course of the year, with a draft guideline due to go out for formal consultation in the coming year. As a tool to assist those in primary care identify when they should refer to neurological services this should help drive better awareness and understanding among GPs, helping in turn to drive down diagnosis times.
- Our limited resources have meant that we have not yet undertaken a full review of our *Guide to Best Practice*, but it continues to be used widely. Meanwhile, we are developing a plan to secure the funding to allow us to undertake a much fuller review of the guidance. Alongside this we continue to periodically review all our materials and leaflets to ensure that they follow current best practice and the latest information.
- Over the past year we have been required to step in to defend or improve several services, working successfully with our members to ensure that clinics remain viable, or at the very least are opened up again as swiftly as possible when problems have occurred. We aim to do this as quickly as possible, ideally working with trusts or commissioners to support the reinstatement of services. Over the past year there has not been any systemic threat to services, but there have been several instances where specific issues have caused backlogs or even temporary closures. We continue to monitor for these using the intelligence we gain from our network of members and our connections with key medical professionals, to identify and respond to issues as they arise.

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2017 (incorporating the Directors' Report)

...Offer a high-quality, responsive helpline for anyone in the UK affected by dystonia;  
...Offer in-depth, personalised advocacy support for those affected by dystonia, helping them get the support they need through, for example, welfare benefits, employment or the NHS;  
...Provide self-management support, empowering people with dystonia to manage their own condition more effectively.

### Supporting individuals

- Our helpline has continued to provide an invaluable service thousands of people with dystonia over the course of the year. The support ranges from simply sending out leaflets and information to dealing with incredibly complex and challenging calls from people who require significant ongoing support. We continue to monitor the service intensively through user feedback, and continue to receive exceptionally positive responses - over the past year all responses from the sampling came back to say that the service had either been helpful or very helpful. We also assess the type of outcomes people report and have seen an uplift over the course of the year in people reporting a better understanding of their condition, or feeling less isolated thanks to the call.
- Alongside the helpline we have continued to offer more in-depth advocacy support, guiding people through more complex challenges, such as securing the right welfare support, or facing discrimination in the workplace. In particular, with major changes coming into effect in the disability benefit system there has continued to be very strong interest in this sort of support. While reductions in staff hours have impacted on our capacity significantly, we have still managed to increase the number of advocacy letters sent over the course of the year, and continue to see a very high success rate, particularly within the benefits system. The impact of expenditure reductions will be very carefully monitored in the coming year, as there will continue to be significant pressure on the service. Securing additional funding to allow the further development of this service will be a key focus in the year ahead.
- We have continued to deliver a range of self-management support, through both a bespoke series of workshops targeted at supporting and empowering people with dystonia to manage their condition as effectively as possible, and through 'telephone self-management' delivered through our helpline. We have delivered the workshops at locations across England and Scotland, which receive exceptionally positive feedback, and have also worked to build the self-management approach into all our helpline activity, helping us to ensure that this work is sustainable in the longer-term. While some of the funding for this activity has now drawn to a close, we will continue to deliver support in the coming year, including a series of new workshops, and piloting a new programme targeted at supporting carers.

...Continue to support peer-to-peer support groups for people with dystonia across the UK;  
...Offer Living With Dystonia days and other opportunities to bring people with dystonia together with key medical professionals;

### Linking people affected by dystonia

- The Society supports nearly 40 local groups across the UK – the majority are locally or regionally focused, but some operate more widely and focus on a specific type of dystonia. For many people with the condition attending a local group meeting may be the first time that they have ever met another person with dystonia, and the ability to talk and share information and ideas is absolutely invaluable for many. The groups are led by local volunteers but supported, depending on their needs, by the Society's staff team. Over the course of the last year there were more than 200 individual group meetings, bringing hundreds of individuals together to share their experiences.



# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2017 (incorporating the Directors' Report)

...Provide online resources, information and social media to allow people with dystonia to come together and share information and advice.

- Working with our local groups we also look to deliver larger 'Living With Dystonia' events, where we bring together people with dystonia and medical professionals, along with other information (such as demonstrations of relaxation techniques), that can help people with the management of their condition. In the light of funding constraints we pursued a policy of holding major events only when we had secure funding in place. We did however hold very well-attended events in Newcastle and Edinburgh this year, as well as supporting several other large group meetings with medical professional and other attendees.
- Through our online forum, Facebook, Twitter and other online resources we continue to support the sharing of information and ideas. In the coming year as well as launching a new website we will also launch a new online forum, offering more opportunities to help people to come together share tips and information safely and securely.

...Support the successful research proposal into real-time ultrasound muscle mapping of botulinum toxin injections;

...Partner with other research bodies to help deliver research into dystonia;

...Work with researchers to provide potential volunteers for appropriate research programmes, and ensure delivery of existing supported research (such as our previous seed grant winners, and our planned 'brain bank' project).

### Supporting research into dystonia

- Last year saw us award a significant 'seed grant' to a research project in Manchester, looking at how real-time ultrasound muscle mapping could help improve the efficacy of botulinum toxin injections. The project is focusing on cervical dystonia and as with all our seed grant projects we hope it can develop from a small grant into a larger project that could offer tangible benefits to people with dystonia across the UK.
- As well as supporting this project, we have continued to work with recipients of previous grants to support their ongoing work, as many of the projects that we fund deliver over the course of several years. Wherever necessary this includes working with our members to identify potential participants in research, for which we generally find there is significant interest –we have been able to connect researchers in Manchester, Coventry and Dundee, for example, with people with dystonia to support their work. We have also continued to direct people to the brain bank project in Queen Square in London, where we have members who wish to register to donate their brain to help improve the ability of researchers to better understand dystonia.
- We were also able to develop a new partnership with the organisation Fight For Sight, who agreed to match-fund a small grant programme with us into blepharospasm (dystonia which affects muscles in and around the eyelids). Unfortunately this grant was eventually not awarded, as no applicant was considered to meet the essential requirements, but it will be re-run in the coming year, with the match-funding providing a new way to help to supplement our ability to fund research.

## Plans for Future Periods

In the year ahead we will have a strong focus on maintaining existing income, and seeking new sources of income, alongside continuing to manage our expenditure prudently and effectively. Having had to reduce our staff capacity in 2016/17, we will have to be particularly targeted and focused in 2017/18, ensuring that we are delivering the maximum possible benefit for all of our members and anyone with dystonia in the UK. This will mean continuing to focus on high-quality services and support, as well as reviewing and enhancing our fundraising capacity, and looking at new ways of supporting anyone who needs us. Overall our key aim for the year ahead is to maintain our current range of services, but the response time across those services may be impacted by our reduced

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2017 (incorporating the Directors' Report)

resources. Launching a new website and online forum should help make it easier to access our services, and both easier and more appealing for people to support or fund our work. In particular, we will do this by

### **Raising awareness**

- Securing regional and national media coverage to raise awareness and understanding of dystonia;
- Continuing to run our Dystonia Awareness Week, and seek any other opportunities to increase the recognition of the condition;
- Launching a new website, making it easier for people to access information and to support the Society if they want to do so.

### **Delivering best practice**

- Working with NICE on their proposed guideline on the recognition and referral of neurological conditions – providing the opportunity for people with dystonia to input in and feedback on proposals;
- Continuing to review and manage all our information resources, ensuring we are providing up-to-date information that can be used by health professionals or individuals;
- Working with our members and health professionals to defend (and improve) health provision for people with dystonia across the UK

### **Supporting individuals**

- Maintaining a high-quality, responsive helpline service, supporting people with dystonia, and their friends, family, carers and interested medical or other professionals;
- Delivering in-depth advocacy support to ensure that people with dystonia are treated fairly and can access the benefits or other support that they need.

### **Linking people affected by dystonia**

- Continuing to support our local groups across the UK, providing a peer-to-peer network across as wide an area as possible;
- Creating a new online forum and maintain an active social media presence, offering new ways for people with dystonia to connect and safely share information;
- Where funding can be secured, or suitable partnerships agreed, supporting high-quality local or national events bringing people with dystonia together and raising awareness and understanding of the condition.

### **Supporting research into dystonia**

- Continuing to support the delivery of our range of funded research projects, including previous 'seed grant' recipients;
- Working with partner organisations to deliver new research funding opportunities;
- Reviewing current research developments and seek any funding opportunities to deliver additional research projects.

## **Financial Review**

Income increased from £465,049 in 2015/16 to £672,711 in 2016/17. The Society received notification of a substantial legacy late in the year. Until that time, we were forecasting a decrease in our funding from grant programmes, our principal income stream, and had already taken steps to reduce expenditure immediately, and to set a recovery budget for 2017/18. Expenditure fell as a result of the ending of specific grant funded projects, and cuts in overhead costs, from £697,529 in 2015/16 to £654,558 in 2016/17. As a result of those cost reductions, and following receipt of the legacy, the Society generated a small surplus of £18,153 for the year. While this is an improvement on the £232,480 deficit reported in 2015/16, the trustees remain concerned that, on balance, the Society is too dependent on unpredictable legacy income.

# **THE DYSTONIA SOCIETY**

## **Report of the Trustees for the year ended 31 March 2017 (incorporating the Directors' Report)**

### **Reserves**

#### **Unrestricted funds**

The trustees feel it is prudent to maintain the Society's general unrestricted reserves at a level sufficient to cover existing commitments (e.g. property rental and staffing costs) and to reflect the relatively low number of assured annual donors, and the opportunities and challenges set by substantial but infrequent legacies. The trustees also aim to set an upper target level of not more than 60% of annual operating costs based on the current year's figures.

Legacy income can vary significantly from year to year and may be subject to restrictions. Legacy income, and the corresponding reserves, may be designated to fund deficit budgets. In this way, legacy income enables us to sustain a higher base level of activity than would otherwise be possible.

The level of unrestricted reserves, excluding designated funds, is reviewed each year when setting the budget. The balance at 31 March 2017 represented 23% of the total expenditure for that year compared to 20% in 2015/16.

Total unrestricted reserves at 31 March 2017 would be sufficient to support the planned activities of the Society uninterrupted for 5 months in 2017/18 assuming no further income was received. This compares to 3 months budgeted expenditure at 31 March 2016.

#### **Restricted funds**

Certain grants and donations received by the Society are given in respect of particular projects or initiatives. Funds held in respect of these activities at the period end are carried forward for future expenditure on these projects or initiatives. The accounts for the year ended 31 March 2017 show a balance of £65,364 in respect of restricted funds. The figure at 31 March 2016 was £113,944. Details of the makeup of restricted funds are given in note 15. These funds are represented by cash held in bank accounts and creditors for grants agreed but not yet paid.

### **Investment Policy**

In order to avoid the risks of market and currency fluctuations, the trustees believe the Society should not invest in equities. 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 particular 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 by a secret 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 a maximum of three terms. A trustee may be appointed by the Board if a vacancy becomes available during the financial year and this trustee would then stand for re-election at the year end. The maximum number of trustees is twelve.

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2017 (incorporating the Directors' Report)

New trustees are given a programme of induction. Training is available when required and relevant.

During the year three trustees retired and one was appointed.

The trustees are advised by a number of specific sub-committees made up of trustees and volunteers co-opted by the trustees for their expertise. The sub-committees are supported by members of staff who work in the relevant area. These include the Finance and General Purposes Committee, the Support Services Committee, the Research Committee, the Communications and Fundraising Committee and other task-specific groups. The committees meet between two and four times per annum. In addition, working groups are set up to address other specific policy issues as they arise (e.g. constitutional changes). Decisions of the trustees are implemented by the Chief Executive and the 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 believe that implementation of agreed actions and procedures will significantly reduce the probability and the impact of these risks.

The most recent review identified the following key risks, and mitigations in place.

### Governance

Board performance is supported by robust recruitment processes, skills audits, and provision of appropriate information to Trustees. Mechanisms are in place to ensure that the Society is aware of, and compliant with relevant legislation.

### Small staff team

Robust recruitment, appraisal and general staff management processes are in place.

### Income insufficient to cover costs

Annual budgets are prepared, and performance in all areas, particularly fundraising initiatives, is closely monitored. Prudent forecasts of variable income streams, particularly legacies and larger grants, are incorporated in the annual budget to ensure that the income is used effectively, but reserves are designated to ensure that activity can be sustained if income is, in the short term, lower than planned. Projects dependent on specific funding applications are not started until all the funding has been secured.

### Public benefit

The trustees have referred to the guidance contained in the Charity Commission's general 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 activities.

## 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 (United Kingdom Generally Accepted Accounting Practice).

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 United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable law). 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

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2017 (incorporating the Directors' Report)

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; and
- 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 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 examiner is aware of that information.

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

### Small company exemption

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

### Thanks

We are very grateful indeed to the Society's volunteers, patrons, donors and fundraisers, to the charitable Trusts which have given grant funding, and to doctors and other healthcare professionals who have attended meetings through the course of the year, donating their time and expertise. Their presence, especially at regional events, is hugely appreciated by our members, many of whom feel that their condition is not always understood or taken seriously enough.

The Rt. Hon. Lord Macdonald of Tradeston CBE retired as a patron in 2016. We would like to take this opportunity to thank him for his generous involvement with the Society over many years.

### Approval

This report was approved by the Board of Trustees on 14 September 2017 and signed on its behalf by

Joanna Atkin

Chair of Trustees

# THE DYSTONIA SOCIETY

## Independent examiner's report to the members of the Dystonia Society

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**

## **Independent examiner's report to the members of the Dystonia Society**

### **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.

**Philip Clark**

Chartered Accountant

25 October 2017

Moore Stephens LLP

150 Aldersgate Street  
London  
EC1A 4AB

# THE DYSTONIA SOCIETY

## Statement of financial activities for the year ended 31 March 2017

		Restricted	Designated	Unrestricted		Restricted	Designated	Unrestricted	
	Notes	Restricted funds	Unrestricted funds	2017 Total		Restricted funds	Unrestricted funds	2016 Total	
			Designated funds	General funds			Designated funds	General funds	
		£	£	£	£	£	£	£	£
<b>Income from</b>									
Donations and subscriptions		9,111	-	200,336	209,447	7,519	-	185,844	193,363
Grants		165,990	-	34,429	200,419	134,075	-	46,140	180,215
Legacies and in memoriam gifts		-	-	257,829	257,829	39,000	-	47,985	86,985
<b>Total donations, subscriptions, grants and legacies</b>	<b>3</b>	<b>175,101</b>	<b>-</b>	<b>492,594</b>	<b>667,695</b>	<b>180,594</b>	<b>-</b>	<b>279,969</b>	<b>460,563</b>
Other trading activities		-	-	4,598	4,598	-	-	3,771	3,771
Investments		-	-	418	418	-	-	715	715
<b>Total</b>		<b>175,101</b>	<b>-</b>	<b>497,610</b>	<b>672,711</b>	<b>180,594</b>	<b>-</b>	<b>284,455</b>	<b>465,049</b>
<b>Expenditure on</b>	<b>5</b>								
Raising funds		-	-	160,209	160,209	-	-	179,595	179,595
Charitable activities	<b>3</b>	<b>219,521</b>	<b>-</b>	<b>274,828</b>	<b>494,349</b>	<b>215,195</b>	<b>-</b>	<b>302,739</b>	<b>517,934</b>
<b>Total</b>		<b>219,521</b>	<b>-</b>	<b>435,037</b>	<b>654,558</b>	<b>215,195</b>	<b>-</b>	<b>482,334</b>	<b>697,529</b>
<b>Net income/(expenditure)</b>	<b>7</b>	<b>(44,420)</b>	<b>-</b>	<b>62,573</b>	<b>18,153</b>	<b>(34,601)</b>	<b>-</b>	<b>(197,879)</b>	<b>(232,480)</b>
Transfers between funds		(4,160)	53,000	(48,840)	-	(1,087)	(73,933)	75,020	-
<b>Net movement in funds</b>		<b>(48,580)</b>	<b>53,000</b>	<b>13,733</b>	<b>18,153</b>	<b>(35,688)</b>	<b>(73,933)</b>	<b>(122,859)</b>	<b>(232,480)</b>
<b>Reconciliation of funds</b>									
Total funds brought forward		113,944	56,000	138,860	308,804	149,632	129,933	261,719	541,284
<b>Total funds carried forward</b>	<b>14</b>	<b>65,364</b>	<b>109,000</b>	<b>152,593</b>	<b>326,957</b>	<b>113,944</b>	<b>56,000</b>	<b>138,860</b>	<b>308,804</b>

All the above results are derived from continuing activities. The notes on pages 15 to 21 form part of these financial statements.



# THE DYSTONIA SOCIETY

## Balance sheet at 31 March 2017

	Notes	31 March 2017 £	31 March 2016 £
<b>Fixed assets</b>			
Tangible assets	8	<u>3,144</u>	<u>4,192</u>
<b>Current assets</b>			
Debtors	9	293,257	50,949
Cash invested at bank and in hand	10	<u>92,303</u>	<u>328,074</u>
		<u>385,560</u>	<u>379,023</u>
<b>Creditors: amounts falling due within one year</b>	11	<u>(61,747)</u>	<u>(74,411)</u>
Net current assets		<u>323,813</u>	<u>304,612</u>
<b>Net assets</b>		<u>326,957</u>	<u>308,804</u>
<b>Represented by</b>			
Unrestricted funds			
General funds		152,593	138,860
Designated funds	15	<u>109,000</u>	<u>56,000</u>
Total unrestricted funds		<u>261,593</u>	<u>194,860</u>
Restricted funds	15	<u>65,364</u>	<u>113,944</u>
<b>Total funds</b>	13	<u>326,957</u>	<u>308,804</u>

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

The Trustees acknowledge their responsibilities for

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

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

Approved and authorised for issue by the Trustees on 14 Sept 2017 and signed on their behalf by

Joanna Atkin (Trustee)

Chris Bradshaw (Trustee)

Company Registration Number: 3309777

The notes on pages 15 to 21 form part of these financial statements.

# THE DYSTONIA SOCIETY

## Statement of cash flows for the year ended 31 March 2017

	2017	2016
	£	£
Net income/(expenditure) as per the statement of financial activities	<b>18,153</b>	(232,480)
Adjustments for		
Depreciation charges	<b>1,048</b>	1,048
Interest from investments	<b>(418)</b>	(715)
(Increase)/decrease in debtors	<b>(242,308)</b>	(11,898)
Increase/(decrease) in creditors	<b>(12,664)</b>	(7,941)
Net cash used in operating activities	<b>(236,189)</b>	(251,986)
Cash flows from investing activities		
Interest from investments	<b>418</b>	715
Purchase of equipment	-	(5,240)
Net cash provided by/(used in) investing activities	<b>418</b>	(4,525)
Net decrease in cash and cash equivalents	<b>(235,771)</b>	(256,511)
Cash and cash equivalents at the beginning of the year	<b>328,074</b>	584,585
Cash and cash equivalents at the end of the year	<b>92,303</b>	328,074

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2017

### 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.

Expenditure on charitable activities comprises services supplied identifiable as wholly or mainly in support of the Society's objectives in five streams of work, and are allocated to the particular stream where the costs relate directly to the activities within that work stream. Support costs are re-allocated to each of the charitable activities (and to the associated restricted funds) on the basis of staff salary costs.

Costs of raising funds relate to expenditure incurred in persuading 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 2017

### e) Tangible fixed assets

Items of equipment are capitalised if their cost exceeds £1,000 and if they have an expected useful life in excess of 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. Further details of these funds are shown in note 15.

Designated funds are unrestricted funds earmarked by the trustees for particular purposes. Unrestricted funds are donations and other incoming resources receivable or generated for charitable purposes, in line with the objects of the Society.

### 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.

## 3 Analysis of income and expenditure by charitable activity

	2017		2016	
	Income	Expenditure	Income	Expenditure
	£	£	£	£
Awareness	86,588	143,847	74,500	160,246
Best Practice	-	18,455	10,450	13,144
Support for individuals	60,316	185,544	48,309	300,326
Linking	19,244	95,344	8,335	43,437
Research	8,953	51,159	39,000	781
	<u>175,101</u>	<u>494,349</u>	<u>180,594</u>	<u>517,934</u>

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

## 4 Net incoming resources

	2017	2016
	£	£
<b>Net incoming resources are stated after charging</b>		
Operating lease – land and buildings	<b>33,900</b>	29,590
Auditor's remuneration	<b>(256)</b>	7,700
Independent examiner's fees	<b>3,600</b>	-

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2017

5	Total resources expended	Support	Raising	Best	Support for	Linking	Research	Fundraising	2017 Total
		costs	awareness	practice	individuals				
		£	£	£	£	£	£	£	£
	Employment and training	84,479	24,379	10,824	106,471	50,630	2,774	84,778	364,335
	Premises and facilities	76,205	-	-	-	-	-	-	76,205
	Printing, telecoms, internet and post	21,179	102,127	-	-	50	-	-	123,356
	Independent examination and accountancy	5,044	-	-	-	-	-	-	5,044
	Conferences, meetings and travel	3,647	628	196	4,890	1,867	957	187	12,372
	Direct project costs	-	-	-	954	8,017	-	1,800	10,771
	Fundraising and prize draw expenses	-	-	-	-	-	-	15,874	15,874
	Grants awarded	-	-	-	1,079	-	45,522	-	46,601
↪	Apportioned support costs	(190,554)	16,713	7,435	72,150	34,780	1,906	57,570	-
	<b>Total</b>	<b>-</b>	<b>143,847</b>	<b>18,455</b>	<b>185,544</b>	<b>95,344</b>	<b>51,159</b>	<b>160,209</b>	<b>654,558</b>
									<b>2016 Total</b>
	Employment and training	100,246	35,836	-	165,840	20,006	-	83,858	405,786
	Premises and facilities	80,324	-	-	20	60	-	-	80,404
	Printing, telecoms, internet and post	22,285	98,198	-	1,898	584	-	140	123,105
	Audit and accountancy	7,700	-	-	-	-	-	-	7,700
	Conferences, meetings and travel	5,771	382	292	14,892	8,302	781	230	30,650
	Direct project costs	-	250	12,852	660	205	-	14,376	28,343
	Fundraising and prize draw expenses	-	-	-	-	-	-	21,132	21,132
	Grants awarded	-	-	-	409	-	-	-	409
	Apportioned support costs	(216,326)	25,580	-	116,607	14,280	-	59,859	-
	<b>Total</b>	<b>-</b>	<b>160,246</b>	<b>13,144</b>	<b>300,326</b>	<b>43,437</b>	<b>781</b>	<b>179,595</b>	<b>697,529</b>

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2017

### 5 Total resources expended (continued)

	2017	2016
	£	£
Support costs include governance costs of	<b>18,614</b>	<b>25,099</b>
Grants awarded included in total resources expended		
To individuals	<b>1,079</b>	409
To organisations	<b>45,522</b>	-
	<b>46,601</b>	<b>409</b>

### 6 Staff costs

	2017	2016
	£	£
Salaries and wages	<b>311,952</b>	328,584
Social Security costs	<b>28,158</b>	28,250
Pension contributions	<b>20,076</b>	22,974
	<b>360,186</b>	379,808
Other employment and training costs	<b>4,149</b>	25,978
Total employment and training costs	<b>364,335</b>	405,786

The average number of employees during the year was 14 (2016: 14 employees) of whom 5 were full time. The full time equivalent was 9.9 (2016: 10.14).

No employee earned more than £60,000 during the year (2016: nil). The total of employee benefits paid to key management personnel was £47,700 (2016:£56,503).

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 2017 the Society owed £1,801 (2016: £1,617) to these pension schemes.

### 7 Trustees' remuneration and expenses

The trustees received no remuneration for their services (2016: £nil). Five trustees (2016: five) were reimbursed for travel expenses, postage, stationery, telephone and other costs totalling £1,102 (2016: £2,228).

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2017

### 8 Tangible fixed assets

	Office equipment and fixtures £
<b>Cost</b>	
At 1 April 2016	17,717
Additions	-
<b>At 31 March 2017</b>	<b>17,717</b>
<b>Depreciation</b>	
At 1 April 2016	13,525
Charge for the year	1,048
<b>At 31 March 2017</b>	<b>14,573</b>
<b>Net book value</b>	
<b>At 31 March 2017</b>	<b>3,144</b>
<b>At 31 March 2016</b>	<b>4,192</b>

### 9 Debtors

	2017 £	2016 £
Income tax recoverable	3,767	11,500
Other debtors and accrued income	250,488	3,854
Prepayments	39,002	35,595
	<b>293,257</b>	<b>50,949</b>

### 10 Cash at bank and in hand

	2017 £	2016 £
Bank investment accounts	50,953	293,647
Other bank and building society accounts	39,920	33,420
Petty cash	1,430	1,007
	<b>92,303</b>	<b>328,074</b>

### 11 Creditors: amounts falling due within one year

	2017 £	2016 £
Taxation and social security costs	5,329	8,375
Other creditors	49,718	7,002
Accruals	6,700	59,034
	<b>61,747</b>	<b>74,411</b>

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2017

### 12 Commitments under operating leases

At 31 March 2017 the Society had annual commitments under non-cancellable operating leases

	2017 £	2016 £
Operating leases for land and buildings which expire in between two and five years	<b>44,404</b>	49,333
The Society's office lease was surrendered on 23 May 2017. On that date a new lease was signed which, if in place at 31 March 2017, would have resulted in a figure of £18,301 being disclosed above.		

### 13 Analysis of net assets between funds

	Restricted funds £	Designated funds £	General funds £	Total funds £
Fixed assets	-	-	3,144	<b>3,144</b>
Current assets	110,155	109,000	166,405	<b>385,560</b>
Creditors: amounts falling due within one year	(44,791)	-	(16,956)	<b>(61,747)</b>
	<b>65,364</b>	<b>109,000</b>	<b>152,593</b>	<b>326,957</b>

### 14 Contingent assets

At 31 March 2017 the charity had been notified of three legacies involving significant uncertainty as to the amount and timing of any payment.

	2017 £	2016 £
Estimated fair value at 31 March	<b>100,000</b>	49,000

### 15 Designated and restricted funds

#### Designated funds

To protect the Society's planned activities, the Trustees designated £56,000 at 31 March 2016. This amount was equal to budgeted legacy income in 2016/17. Unrestricted legacy funding received in 2016/17 was significantly below the budgeted amount, and this amount was released to general funds at 31 March 2017 to cover the shortfall in income..

The Society's Trustees have approved a deficit budget for 2017/18, to utilise legacy funds notified prior to 31 March 2017, and expected to be received in the course of the year. Funds equal to the forecast deficit of £109,000 were transferred to designated funds at 31 March 2017, to reflect this commitment.



# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2017

### 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** - to promote the awareness of dystonia especially amongst those without a diagnosis. Funds were held at 31 March 2017 for a planned Essay Competition.
- **Best practice**— 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.
- **Support for individuals**  
**Helpline** – to provide information and emotional support to people affected by dystonia.  
**Welfare grants** – to fund future grants in accordance with the Society's guidelines.  
**Conferences and *Living with Dystonia* days** – to run events enabling people with dystonia to meet, learn about dystonia and try therapies. Funds were held at 31 March 2017 for a *Living with Dystonia* day in East Sussex.
- **Linking** – to fund awareness and welfare initiatives at a local level and encourage the participation of volunteers.
- **Research** – to support research projects relating to understanding, treating and living with dystonia.
- **Specific national and regional funding** is held within the above funds as appropriate.

### Activity on restricted funds

	Opening balance	Income	Transfers	Expenditure	Closing balance
	£	£	£	£	£
Awareness	6,000	86,588	-	(86,588)	6,000
Best Practice	-	-	273	(273)	-
Support for individuals	10,000	60,316	3,640	(63,956)	10,000
Linking	31,217	19,244	(8,346)	(17,545)	24,570
Research	66,727	8,953	273	(51,159)	24,794
	<b>113,944</b>	<b>175,101</b>	<b>(4,160)</b>	<b>(219,521)</b>	<b>65,364</b>

Transfers are from groups which have decided to allocate funds raised locally to other funds of the Society, including unrestricted funds.

### 16 Related party transactions

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