

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

**THE DYSTONIA SOCIETY**

**A company limited by guarantee  
Financial Statements  
31 March 2015**



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# THE DYSTONIA SOCIETY

## Financial Statements for the year ended 31 March 2015

### Reference and administrative information

#### Royal Patron

HRH Princess Alexandra

#### Patrons

The Rt. Hon. Lord Macdonald of Tradeston CBE  
Fiona Ross OBE

#### Trustees and Directors

Joanna Atkin	Chair
Roger Edmonds FCA	retired on completion of third term 31 March 2015
	Vice-chair (retired 31 March 2015)
	Honorary Treasurer (retired 31 March 2015)
Christopher Bradshaw	Appointed 12 February 2015
	Honorary Treasurer (appointed 1 April 2015)
Christine Chapman	
Nirmaljit Gill	
Penny Ritchie Calder MBE	
Alec Sandison	
Peter Meager	
Stephen Wishart	Appointed 4 September 2014
Daniel Berry	Appointed 4 September 2014
Philip Wilson	Appointed 4 September 2014
Andy Young	Appointed 12 February 2015

#### Secretary

Jane Seaton ACA

#### Auditor

Moore Stephens LLP  
Russell Square House  
10-12 Russell Square  
London  
WC1B 5LF

#### Chief Executive

Paul King (resigned 30 June 2015)  
Guy Parckar (appointed 8 July 2015)

#### Medical Advisers

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

#### Bankers

CAF Bank  
Kings Hill  
West Malling  
Kent ME19 4TA

#### Registered Office

89 Albert Embankment  
London  
SE1 7TP

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

# **THE DYSTONIA SOCIETY**

## **Report of the Trustees for the year ended 31 March 2015 (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 2015. 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 Activities**

The Society has focused on the following areas during the year

- Ensuring best possible treatment and support available to all affected by dystonia
- Empowering people with dystonia to manage all aspects of their condition
- Providing information and support
- Linking people affected by dystonia into a strong community
- Raising awareness of dystonia and the Society
- Seed-funding for research into dystonia

### **Ensuring best possible treatment and support available to all affected by dystonia**

#### **Defending botulinum toxin treatment availability**

The main treatment for dystonia, botulinum toxin injections, have to be delivered regularly (usually around each 12 weeks) by a medical professional injector to maintain continuity of relief. The Society therefore continually needs to support groups of patients where services are under threat due to funding withdrawal or non-availability of injectors. In the last year the Society

- Developed a library of evidence to enable injectors to defend funding of their services by demonstrating the proven clinical and cost effectiveness of treatments. This was presented to 80 professional injectors at their conference in September 2014 and has since been used in several areas to defend under-threat clinics.
- Provided successful group advocacy support where services were disrupted due to non-availability of an injector.
- Implemented a policy audit of Clinical Commissioning Groups (CCG) in order to identify both areas of best practice and CCGs without policies. We are now approaching all CCGs to promote best practice commissioning.

This area presents continuous challenges but the Society's work on defending treatments has been effective. The average gap between injections was 12.5 weeks (based on a 2015 online survey) down from 13.2 weeks in 2012 when this was last measured.

#### **Promoting best practice in treatment delivery**

The Society promoted best practice through circulating its updated 2014 best practice guide to more than 450 clinicians and received very positive feedback. In addition the Society presented at a series of medical conferences throughout the year. The results over the last year are

- 90% of poor responders to botulinum toxin have received at least one change to treatment to improve injection performance.
- However, there still needs to be more standardised use of important treatment adjustments such as use of EMG/ultrasound machines, immunity checking and second opinion. As a result of the Society raising this concern, the injector's umbrella body, the British Neurotoxin Network, is preparing a protocol on poor responders for publication.

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## **Report of the Trustees for the year ended 31 March 2015 (incorporating the Directors' Report)**

- The inconsistent use across the UK of in-patient services to deliver botulinum toxin injections has reduced.

### **Individual advocacy**

The Society provided individual advocacy in 117 cases where individuals needed support on issues such as treatment availability, employment and access to benefits. There was an ongoing 80% success rate in resolved cases but benefits cases in particular appear to be being resolved more slowly because of backlogs in the appeals processes. The demand for advocacy was lower than the previous year by 26% – due to reduction in the number of Employment Support Allowance cases and government delays in introducing Personal Independence Payments. But cases were increasingly complex and took longer to resolve, often involving intense emotional distress.

### **Empowering people with dystonia to manage all aspects of their condition**

#### **Self-management workshops**

Following the success of the pilot, the Society rolled out its self-management workshops nationally. The workshops focus on getting the best out of treatment, the emotions caused by dystonia, dealing with stress and coping with dystonia in everyday life. Feedback has been excellent with more than 95% reporting feeling better equipped to manage their dystonia at the end of sessions. Follow-up questionnaires were sent to participants with time lag of 4-17 months after the workshop. 92% of respondents reported maintaining at least one outcome with 60% saying they were now doing things differently and 40% saying there had been a change in their life. Changes included more effective treatment, improved mental health, reduced isolation and taking up volunteering.

#### **Telephone self-management**

The Society has been campaigning for an increased awareness of the holistic challenges caused by dystonia which include, in addition to the physical symptoms, high prevalence of non-motor symptoms such as anxiety / depression, pain, sleep difficulties and isolation. Despite this, referral to professional support for these issues remains disappointingly low. To address this, the Society is piloting a new telephone self-management programme that will help people with dystonia to identify key issues and support them in the process of obtaining the interventions they need to address these issues.

### **Providing information and support**

#### **Website**

The Society's website now receives nearly 470,000 visitors per year – an increase of 60% over the last year and 700% over the last 4 years. This has been achieved primarily through expanded content which has improved our search position and so attracts more visitors. Both UK and international visits continue to grow strongly.

#### **Helpline**

The Helpline service provided support to more than 1,000 people in the last year. Satisfaction levels on the helpline remain excellent with 99% reporting the service helpful and 86% very helpful. On the helpline 98% of callers reported achieving at least one outcome – with the service providing both information and emotional support. The levels of distress expressed by callers continued to be very high. 76% reported receiving new information while 67% reported an emotional benefit through it expressing their feelings and/or feeling less isolated.

#### **Leaflets and information**

The Society continues to develop new information and leaflets. New information developed includes coping with speech and swallowing difficulties, causes of dystonia in the brain and the side effects of

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## Report of the Trustees for the year ended 31 March 2015 (incorporating the Directors' Report)

eye injections. Our "Deep Brain Stimulation" leaflet has been updated to take account of new information. Several other leaflets have also been updated.

### Newsletter and e-newsletter

The Society sends a newsletter quarterly to 2,800 recipients talking about all aspects of dystonia. In addition, we provide a free monthly e-newsletter that is sent to any supporters who subscribe through our website. Circulation of our e-newsletter has risen to 2,500, up 40% year on year, and opening and click through rates remain high.

### Linking people affected by dystonia into a strong community

#### Events and peer support

The Society organised four *Living with Dystonia* events across the UK to enable those affected to obtain more information about dystonia and its treatment from medical professionals, share experiences and try out complementary therapies and other stress management techniques. The Society supports 38 of its own local groups, which are nearly all run by volunteers, and is affiliated with a further 4 local groups. In total, around 1,100 people were supported locally.

#### Online

Over the last year, the Dystonia Society's online forum was visited by 21,000 people, each on average reading around 7 pages. The forum has now received more than 3,600 posts. The Society's Facebook page now has 2,800 likes and the Society has 1,500 Twitter followers.

### Raising awareness of dystonia and the Society

#### Raising awareness using social media

Our recent social media awareness campaign reached nearly 9 million people thanks to the fantastic support of Stephen Fry, the TV personality, who has been involved with this for a second year.

#### Reaching people online

Since 2011 the Society has been running an initiative to reach people online by advertising to those who are researching symptoms such as "muscle spasms", "twisted neck" and "uncontrollable blinking". This year we reached 84,000 people through this outreach. In 2014/5, people have reported waiting 2.4 years from symptom onset to diagnosis down 35% since the project started.

#### Raising awareness among medical professionals

The Society continues to provide an online training module for medical professionals developed together with the British Medical Journal. In addition, in 2014/5 we ran our bi-annual essay prize on dystonia for medical students. The number of entries was high and the standard again excellent. Prizes were awarded to the winners in May 2015.

### Seed-funding for research into dystonia

The Society continued to be active in supporting research into dystonia.

#### Audit of childhood dystonia

The Society provided funding to the Evelina London Children's Hospital in 2011 to review its records to assess the impact of childhood dystonia and the results of therapies provided. This research has already resulted in several published papers. A further article, *Interventional studies in childhood dystonia do not address the concerns of children and their carers* was published in 2015 in the



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**European Journal of Paediatric Neurology.** The article reported that the main concerns raised by children affected by dystonia and their families were pain, problems with daily living activities, difficulties with hand use and seating. Despite this, most interventional studies used impairment scales to measure effectiveness rather than whether these important concerns of children and families had been addressed.

### Evaluation of outcomes following Deep Brain Stimulation (DBS)

In 2013 as part of a follow-up to the childhood dystonia audit mentioned above, the Society provided funding to the Evelina London Children's Hospital to reassess rating scales following DBS for dystonia. This project is in process and it is anticipated papers will be submitted for publication during 2015.

### Dystonia and mental health

In 2014, the Dystonia Society provided funding to Warwick Medical School to pilot test an intervention to help people with dystonia manage their mental health. The project is testing a 3-day residential course with the aim of helping people with dystonia and experiencing emotional problems to cope better with the condition. The pilot was completed in January 2015 and results will be available later in 2015, once follow-up interviews are complete.

### Hand therapy to treat focal hand dystonia

The Society provided funding to the National Hospital for Neurology and Neurosurgery for research into the use of hand therapy for the treatment of Focal Hand Dystonia. The completion of this research has been delayed due to illness. The final patient assessments are due to complete in mid-2015 with results expected by end 2015.

### Dystonia – the role of dopamine

In 2015, The Society awarded funding to Ninewells Hospital, Dundee, to apply recent advances in understanding the role of striatal dopamine in order to generate new insights into the basic biology of dystonia. The study will combine behavioural tasks with Functional Magnetic Resonance Imaging (fMRI).

### Research funds offered in 2015/16

The Society is holding £50,000 (in designated or restricted funds) to fund a new research project in 2015/16.

## Financial Review

Income decreased from £784,399 in 2013/14 to £707,144 in 2014/15. The fall was due to the ending of significant grant programmes, and a fall in legacy income. Expenditure fell only slightly, with activity levels in many areas continuing to increase. As a result, the Society reports a deficit of £17,967 for the year compared to a surplus of £53,223 in 2013/14.

## 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 take into account the relatively low number of assured annual donors.

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The level of reserves is reviewed each year when setting the budget and trustees aim for a level of not more than 60% of operating costs based on the current year's figures. The balance at 31 March 2015 represented 36% of the total expenditure for that year compared to 39% in 2013/14.

In a change from previous practice, from 2015/16 forward the Society will include a significant level of legacy income in its budgeting and strategic planning. In this way, the Society intends to make the best possible use of legacy income, to support sustained programmes of activity. Average annual legacy income over the past five years has been in excess of £100,000.

Despite the high average figure, legacy income can vary significantly from year to year. Therefore, to protect the Society's planned activities, the Trustees have at 31 March 2015 designated an amount equal to budgeted legacy income in 2015/16. This fund will be drawn upon only to the extent that actual legacy income in the coming year is lower than budget. Any balance remaining at the end of the year will be released back into unrestricted funds.

Unrestricted reserves excluding this amount and the balance of funds designated for research in 2013/14, would be sufficient to support the activities of the Society uninterrupted for 4.1 months in 2015/16 assuming no further funds are received. This compares to a level of reserves at 31 March 2014 that represented 5.4 months budgeted expenditure.

### 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 2015 show a balance of £149,632 in respect of restricted funds. The figure at 31 March 2014 was £221,640. Details of the makeup of restricted funds are given in note 16. These funds are represented by cash held in bank investment accounts.

### Investment Policy

In order to avoid the risks of market and currency fluctuations, the trustees believe the Society should not invest in equities but should gain, tax free, the maximum returns possible in money markets by using the Charities Aid Foundation's deposit facilities.

### Plans for Future Periods

During 2015/16 the Society will continue to promote the welfare of those suffering from dystonia by

- **Ensuring the best possible treatment and support is available to all affected by dystonia** through continuing to defend treatments and other support including advocacy as necessary; promoting increased treatment of less common types of dystonia such as voice, hand and mouth/tongue/jaw dystonias; promoting best practice particularly in relation to poor responders to botulinum toxin; and promoting improved referral for treatment of non-motor symptoms of dystonia.
- **Empowering people with dystonia to manage all aspects of their condition** by continuing its national roll-out of self-management workshops: supporting people with specific dystonia management goals through telephone self-management; and developing online videos of medical professionals providing guidance on managing dystonia.
- **Providing information and support** by maintaining our helpline; continuing to expand the range of information available online, in leaflets and newsletters; and commencing a project to support carers.
- **Raising awareness of dystonia and the Society** through outreach to those researching symptoms online and in treatment centres; raising awareness among medical professionals;

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## Report of the Trustees for the year ended 31 March 2015 (incorporating the Directors' Report)

and continuing to grow our presence on Facebook and Twitter, and take up of our e-newsletter.

- **Linking people affected by dystonia into a strong community** with a programme of Living with Dystonia events across UK; and by maintaining a strong network of volunteer-led local groups.
- **Seed-funding for research into dystonia** with funding for at least one new project in 2015/16.

### 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.

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

During the year one trustee retired at the end of his third term in accordance with the Articles of Association. Five new trustees have joined the Board.

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.

### 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.

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2015 (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 (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 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** published in March 2005
- 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 audit information of which the charitable company's auditor is unaware
- The trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditor 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.

### Auditor

On 1 May 2015 Chantrey Vellacott DFK LLP merged its business with Moore Stephens and a resolution proposing the appointment of Moore Stephens as auditor to the company was passed by the Board of Trustees on 10 September 2015.

### 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

## **THE DYSTONIA SOCIETY**

### **Report of the Trustees for the year ended 31 March 2015 (incorporating the Directors' Report)**

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 trustees particularly wish to express their thanks to Roger Edmonds, who retired as the Society's Honorary Treasurer on 31 March 2015, for the generous contribution of time and experience which he has brought to the management and governance of the Society.

#### **Approval**

This report was approved by the Board of Trustees on 10 September 2015 and signed on its behalf by

Joanna Atkin, Chair of Trustees

# **THE DYSTONIA SOCIETY**

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

We have audited the financial statements of The Dystonia Society for the year ended 31 March 2015 which comprise the Statement of Financial Activities, the Balance Sheet, and the related notes. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

This report is made solely to the company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006 and to the charity's trustees, as a body, in accordance with section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body and its trustees as a body, for our audit work, for this report, or for the opinion we have formed.

### **Respective responsibilities of trustees and auditor**

As explained more fully in the Statement of Trustees' Responsibilities, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view.

We have been appointed as auditor under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with regulations made under those Acts.

Our responsibility is to audit and express an opinion on the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's (APB's) Ethical Standards for Auditors.

### **Scope of the audit of the financial statements**

An audit involves obtaining evidence about the amounts and disclosures in the financial statements sufficient to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or error. This includes an assessment of: whether the accounting policies are appropriate to the charitable company's circumstances and have been consistently applied and adequately disclosed; the reasonableness of significant accounting estimates made by the trustees; and the overall presentation of the financial statements. In addition, we read all the financial and non-financial information in the Report of the Trustees (incorporating the Directors' Report) to identify material inconsistencies with the audited financial statements, and to identify any information that is apparently materially incorrect based on, or materially inconsistent with, the knowledge acquired by us in the course of performing the audit. If we become aware of any apparent material misstatements or inconsistencies we consider the implications for our report.

# **THE DYSTONIA SOCIETY**

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

### **Opinion on financial statements**

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2015 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

### **Opinion on other matter prescribed by the Companies Act 2006**

In our opinion the information given in the Report of the Trustees (incorporating the Directors' Report) for the financial year for which the financial statements are prepared is consistent with the financial statements.

### **Matters on which we are required to report by exception**

We have nothing to report in respect of the following matters where the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 (as amended) requires us to report to you if, in our opinion:

- the charitable company has not kept proper and adequate accounting records or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies' exemption in preparing the Report of the Trustees (incorporating the Directors' Report) and take advantage of the small companies exemption from the requirement to prepare a strategic report.

PHILIP CLARK (Senior statutory auditor)

for and on behalf of MOORE STEPHENS LLP  
Chartered Accountants and Statutory Auditor  
London

2 October 2015

MOORE STEPHENS LLP is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006

# THE DYSTONIA SOCIETY

## Statement of financial activities for the year ended 31 March 2015

	Notes	Restricted funds	Unrestricted funds		2015 Total	2014 Total
			Designated funds	General funds		
		£	£	£	£	£
<b>Incoming resources from generated funds:</b>						
<b>Voluntary income</b>						
Donations, grants and subscriptions		278,304	-	250,979	529,283	548,069
Legacies		12,495	-	159,550	172,045	230,531
		290,799	-	410,529	701,328	778,600
<b>Activities for generating funds</b>						
Sales of goods and literature		-	-	3,454	3,454	2,853
<b>Investment income</b>						
		-	-	2,362	2,362	2,946
<b>Total incoming resources</b>	<b>3</b>	<b>290,799</b>	<b>-</b>	<b>416,345</b>	<b>707,144</b>	<b>784,399</b>
<b>Resources expended</b>						
<b>Costs of generating voluntary income</b>						
		-	-	161,795	161,795	165,715
<b>Charitable activities</b>						
Raising awareness		126,722	-	16,219	142,941	143,699
Best practice in treatment and support		106,081	-	-	106,081	109,272
Support for individuals affected by dystonia		199,788	-	12,149	211,937	219,402
Linking people affected by dystonia		48,398	-	-	48,398	34,845
Research		1,743	29,762	-	31,505	38,310
		482,732	29,762	28,368	540,862	545,528
<b>Governance costs</b>						
		-	-	22,454	22,454	19,933
<b>Total resources expended</b>	<b>5</b>	<b>482,732</b>	<b>29,762</b>	<b>212,617</b>	<b>725,111</b>	<b>731,176</b>
<b>Net incoming/(outgoing) resources for the year</b>	<b>7</b>	<b>(191,933)</b>	<b>(29,762)</b>	<b>203,728</b>	<b>(17,967)</b>	<b>53,223</b>
Transfers		119,925	108,000	(227,925)	-	-
<b>Net movement in funds</b>		<b>(72,008)</b>	<b>78,238</b>	<b>(24,197)</b>	<b>(17,967)</b>	<b>53,223</b>
Funds at the start of the year		221,640	51,695	285,916	559,251	506,028
<b>Funds at the end of the year</b>	<b>14</b>	<b>149,632</b>	<b>129,933</b>	<b>261,719</b>	<b>541,284</b>	<b>559,251</b>

All of the above results are derived from continuing activities. There were no recognised gains or losses other than those stated above.

The notes on pages 14 to 21 form part of these financial statements.



# THE DYSTONIA SOCIETY

## Balance sheet at 31 March 2015

	Notes	31 March 2015	31 March 2014
		£	£
<b>Fixed assets</b>			
Tangible assets	8	-	-
Investments	9	-	25,000
		<u>-</u>	<u>25,000</u>
<b>Current assets</b>			
Debtors	10	39,051	131,822
Cash invested at bank and in hand	11	<u>584,585</u>	<u>463,769</u>
		623,636	595,591
<b>Creditors: amounts falling due within one year</b>	12	<u>(82,352)</u>	<u>(61,340)</u>
Net current assets		<u>541,284</u>	<u>534,251</u>
<b>Net assets</b>		<u>541,284</u>	<u>559,251</u>
<b>Represented by:</b>			
Unrestricted funds:			
General funds		261,719	285,916
Designated funds	15	<u>129,933</u>	<u>51,695</u>
Total unrestricted funds		391,652	337,611
Restricted funds	16	<u>149,632</u>	<u>221,640</u>
<b>Total funds</b>		<u>541,284</u>	<u>559,251</u>

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 10 September 2015 and signed on their behalf by

Joanna Atkin

Chris Bradshaw

(Trustee)

(Trustee)

Company Registration Number: 3309777

The notes on pages 14 to 21 form part of these financial statements.

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2015

### 1 Accounting policies

#### a) Basis of preparation of accounts

The accounts are prepared under the historical cost convention, in accordance with the Statement of Recommended Practice **Accounting and Reporting by Charities** published in March 2005, applicable accounting standards, the Companies Act 2006 and the Charities and Trustees Investment (Scotland) Act 2005. The accounts include the balances and transactions of 30 of the Society's support groups.

#### b) Cash flow

The Society has taken advantage of the exemption in Financial Reporting Standard No 1 (revised) from the requirement to produce a cash flow statement.

#### c) Incoming resources

Voluntary 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 generating voluntary income. 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.

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.

#### d) Capital grants

Grants for the purchase of fixed assets are credited to restricted funds when receivable.

Depreciation on the fixed assets purchased with such grants is charged against the restricted fund.

#### e) Resources expended

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.

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

#### f) Pension contributions

The Society makes contributions to defined contribution personal pension schemes held by employees. Contributions are charged to the Statement of Financial Activities in the year in which they are payable to the schemes.

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2015

**g) 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.

**h) 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.

**i) Fund accounting**

Restricted funds are to be used for specific purposes as stated by the donor. Expenditure which meets these criteria is allocated to the fund. Further details of these funds are shown in note 16.

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.

**j) Investments**

Investments are stated at open market value. Unrealised gains and losses are taken to the Statement of Financial Activities.

### **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 2015

### 3 Total incoming resources

	Restricted £	Unrestricted £	2015 £	2014 £
<b>Grants and donations</b>				
Raising awareness	73,729	-	73,729	84,636
Best practice in treatment and support	63,943	-	63,943	34,736
Support for individuals affected by dystonia	111,511	-	111,511	152,694
Linking people affected by dystonia	19,520	-	19,520	15,543
Research	9,601	-	9,601	4,953
	<b>278,304</b>	<b>-</b>	<b>278,304</b>	<b>292,562</b>
Not restricted	-	149,925	149,925	184,272
<b>Legacies</b>	12,495	159,550	172,045	230,531
<b>Subscriptions and regular giving</b>	-	101,054	101,054	71,235
<b>Sales of goods and literature</b>	-	3,454	3,454	2,853
<b>Investment income</b>	-	2,362	2,362	2,946
<b>Total</b>	<b>290,799</b>	<b>416,345</b>	<b>707,144</b>	<b>784,399</b>

	Restricted £	Unrestricted £	2015 £	2014 £
Grants receivable, included above				
Scottish Government Section 16B	5,000	-	5,000	20,000
Department of Health IESD Fund	34,794	-	34,794	33,946

### 4 Staff costs

	2015 £	2014 £
Staff costs during the year were as follows		
Salaries and wages	<b>338,893</b>	317,222
Social Security costs	<b>28,937</b>	28,985
Pension contributions	<b>24,947</b>	51,559
	<b>392,777</b>	<b>397,766</b>

The average number of employees during the year was 15 (2014: 14 employees) of whom five were full time. The full time equivalent was 10.67 (2014: 10.45). No employee earned more than £60,000 during the year (2014: nil).

The Society contributes to defined contribution personal pension schemes. The assets of these schemes are held separately from those of the Society in independently administered funds. At March 2015 the Society owed £2,270 (2014: £3,335) to these pension schemes.

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2015

### 5 Total resources expended

	Research	Raising awareness	Linking people affected by dystonia	Best practice in treatment and support	Support for individuals affected by dystonia	Generating Funds	Governance	Support costs	Total 2015	Total 2014
	£	£	£	£	£	£	£	£	£	£
Salaries and recruitment	1,380	37,000	19,512	58,373	136,302	87,690	4,044	51,520	<b>395,821</b>	402,648
Staff expenses and training	-	-	-	-	497	-	2,213	2,551	<b>5,261</b>	7,527
Direct costs	363	94,219	24,132	20,530	23,324	2,469	9,808	751	<b>175,596</b>	151,070
Grants awarded	29,762	-	-	-	1,160	-	-	-	<b>30,922</b>	36,649
Premises costs	-	-	-	-	214	-	-	50,505	<b>50,719</b>	53,106
Fundraising expenses	-	-	35	-	-	28,084	-	-	<b>28,119</b>	45,868
Administrative costs	-	-	-	-	-	-	-	34,310	<b>34,310</b>	29,313
Legal and professional	-	-	-	-	-	-	4,363	-	<b>4,363</b>	4,995
Apportioned support costs	-	11,722	4,719	27,178	50,440	43,552	2,026	(139,637)	-	-
	<b>31,505</b>	<b>142,941</b>	<b>48,398</b>	<b>106,081</b>	<b>211,937</b>	<b>161,795</b>	<b>22,454</b>	-	<b>725,111</b>	731,176

	2015	2014
	£	£
Grants awarded included above		
To individuals	<b>1,160</b>	649
To organisations	<b>29,762</b>	36,000
	<b>30,922</b>	36,649

During the year 3 grants were made to individuals (2014: 2 grants)

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2015

### 6 Trustees' remuneration and expenses

The trustees received no remuneration for their services (2014: £nil). Five trustees (2014: seven) were reimbursed for travel expenses, postage, stationery, telephone and other costs totalling £3,191 (2014: £2,281).

### 7 Net incoming resources

	2015 £	2014 £
Net incoming resources are stated after charging:		
Auditor's remuneration	6,300	6,300
Operating lease – land and buildings	28,827	28,827

### 8 Tangible fixed assets

	Office equipment £	Fixtures and fittings £	Total £
<b>Cost</b>			
At 1 April 2014	39,658	8,609	48,267
Disposals	(27,181)	(8,609)	(35,790)
<b>At 31 March 2015</b>	<b>12,477</b>	<b>-</b>	<b>12,477</b>
<b>Depreciation</b>			
At 1 April 2014	39,658	8,609	48,267
Disposals	(27,181)	(8,609)	(35,790)
<b>At 31 March 2015</b>	<b>12,477</b>	<b>-</b>	<b>12,477</b>
<b>Net book value</b>			
At 31 March 2014 and 31 March 2015	-	-	-

### 9 Investments

	2015 £	2014 £
Listed investments - UK Government Stocks		
Historic cost and carrying value	-	25,000

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2015

### 10 Debtors

	2015 £	2014 £
Income tax recoverable	12,300	11,559
Other debtors and accrued income	3,114	83,650
Prepayments	23,637	36,613
	<b>39,051</b>	<b>131,822</b>

### 11 Cash invested at bank and in hand

	2015 £	2014 £
Bank investment accounts	527,946	417,103
Other bank and building society accounts	56,471	46,058
Petty cash	168	608
	<b>584,585</b>	<b>463,769</b>

### 12 Creditors

	2015 £	2014 £
Taxation and social security costs	7,791	8,228
Other creditors	8,132	18,252
Accruals	66,429	34,860
	<b>82,352</b>	<b>61,340</b>

### 13 Commitments under operating leases

At 31 March 2015 the Society had annual commitments under non-cancellable operating leases as set out below

	2015 £	2014 £
Operating leases for land and buildings which expire in between two and five years	-	32,544

The Society's office lease expired on 23 May 2015 and at 31 March 2015, a renewal was under discussion but not agreed. The Society has now renewed for a five year term.

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2015

### 14 Analysis of net assets between funds

	Restricted funds £	Designated funds £	General funds £	Total funds £
Fixed assets	-	-	-	-
Current assets	149,632	179,659	294,345	<b>623,636</b>
Creditors: amounts falling due within one year	-	(49,726)	(32,626)	<b>(82,352)</b>
	<b>149,632</b>	<b>129,933</b>	<b>261,719</b>	<b>541,284</b>

### 15 Designated funds

There is a balance of £21,933 which is designated to provide funding for one or more new research projects, as outlined in the Report of the Trustees.

To protect the Society's planned activities, the Trustees have at 31 March 2015 designated £108,000, which is equal to budgeted legacy income in 2015/16.

### 16 Restricted funds

The Society holds balances on restricted funds which will be carried forward and used as follows:

- **Raising awareness** - to promote the awareness of dystonia especially amongst those without a diagnosis.
- **Best practice in treatment and support** – 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.
- **Department of Health Innovation, Excellence and Strategic Development Fund** – to develop a model of best practice and implement it to drive cost effective treatment.
- **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.
- **Scotland** – to support people with dystonia and work for improvements in services in Scotland.
- **Wales** – to support people with dystonia and work for improvements in services in Wales.
- **Self-management and telephone self-management** – to help people with dystonia to take control and actively manage their condition and treatment.
- **Young Dystonia initiatives** – to fund initiatives in support of young people and their families and carers.
- **Local activities** – England – to fund awareness and welfare initiatives at a local level.
- **Research** – to support research projects relating to understanding, treating and coping with dystonia.



# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2015

	1 April 2014 £	Incoming resources £	Outgoing resources £	Transfers £	31 March 2015 £
<b>Raising awareness</b>	<b>6,000</b>	<b>73,729</b>	<b>(126,722)</b>	<b>52,993</b>	<b>6,000</b>
<b>Best practice in treatment and support</b>					
Dept of Health IESD Fund	-	34,794	(34,794)	-	-
Trusts & Foundations	-	29,149	(67,170)	38,021	-
	<b>-</b>	<b>63,943</b>	<b>(101,964)</b>	<b>38,021</b>	<b>-</b>
<b>Support for individuals affected by dystonia</b>					
Helpline	-	58,941	(102,402)	43,461	-
Welfare grants	9,094	-	(1,160)	-	<b>7,934</b>
<b>Living with Dystonia</b> days and					
Conferences	-	3,500	(25,045)	41,545	<b>20,000</b>
Scotland – regional support	8,281	26,570	(42,768)	7,917	-
Wales – regional support	1,485	-	(13)	(1,472)	-
Self-management	41,389	2,500	(26,338)	-	<b>17,551</b>
Telephone self-management	-	20,000	(6,478)	3,978	<b>17,500</b>
Young Dystonia initiatives	3,624	-	-	-	<b>3,624</b>
	<b>63,873</b>	<b>111,511</b>	<b>(204,204)</b>	<b>95,429</b>	<b>66,609</b>
<b>Linking people affected by dystonia</b>					
Local activities	132,752	22,015	(19,179)	(103,351)	<b>32,237</b>
Branch and volunteer development	-	10,000	(28,920)	35,198	<b>16,278</b>
	<b>132,752</b>	<b>32,015</b>	<b>(48,099)</b>	<b>(68,153)</b>	<b>48,515</b>
<b>Research</b>	<b>19,015</b>	<b>9,601</b>	<b>(1,743)</b>	<b>1,635</b>	<b>28,508</b>
	<b>221,640</b>	<b>290,799</b>	<b>(482,732)</b>	<b>119,925</b>	<b>149,632</b>

Transfers are made from unrestricted funds to finance deficits on restricted funds.

As part of the trustees' commitment to a wide range of activities, the Society's unrestricted funds are made available to finance programmes which are not fully funded from external sources.

During the year, funds from a legacy received by a local group were re-directed, with the agreement of group members, to areas of the Society's work of particular relevance to the group and its local area.

Funds for regional support in Wales were transferred for use for a **Living with Dystonia** event in Cardiff.