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The Tourette Syndrome (UK) Association

Report of the Trustees and Financial Statements

1 April 2005 - 31 March 2006

LOOKING FORWARD

Company number: 261393 Charity number: 1003317



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Trustees

Dr Jeremy Stern
Susan Hayter
Roger Barons
David Broad
Kaye Dann
Margaret Filby
Roy Hillard
Cerith Owens

Chairman
Vice Chairman
Treasurer

Areasurer

Vice Chairman
Vice C

Chief Executive

Judith Kidd

Professional advisers

Barclays Bank Plc 102 St James Square Newport Isle of Wight PO30 1UP

CCLA
Investment Management Ltd
COIF Charity Funds
80 Cheapside
London EC2V 6DZ

Bates, Wells & Braithwaite, Solicitors 2-6 Cannon Street London EC4M 6YH

Anderson Strathern, Solicitors 1 Rutland Court Edinburgh EH3 8EY

The Kings Mill Partnership, Chartered Accountants and Registered Auditors 75 Park Lane Croydon CR9 1XS

Patrons

Mr Daniel Katz MBE Sir Jonathan Miller CBE Dr Oliver Sacks

Hon Medical Advisers

Dr Uttom Chowdury Prof Peter Hill Dr Geoffrey Kewley Prof Andrew Lees Dr Harry Nash Dr Hugh Rickards Prof Mary Robertson Prof Michael Trimble

ESSENTIALS

The Tourette Syndrome Association (TSA)

The TSA is the leading UK charity supporting people with TS. It provides information and the opportunity for contact with other people whose first hand experience of TS ensures that they understand how the condition affects everyday life. The TSA aims to help people living with TS both directly and by supporting professionals, especially teachers, who work with TS children and adults. It has around [400] members, but key services are not restricted to members and are available to the general public. The TSA is a registered charity number 1003317 and a company limited by guarantee number 2613993.

Tourette Syndrome

Tourette Syndrome - TS - is named after Dr George Gilles de la Tourette, the French neurologist who described it in 1825. The most obvious symptom of TS is tics, which are involuntary movements or sounds.

Tic types

Simple movement tics may involve blinking or head jerking, for example, while complex ones might involve jumping, touching other people or things, smelling, twirling, and sometimes hitting or biting oneself. Simple sound tics are often throat clearing, yelping, sniffing and tongue clicking, but complex ones may involve saying socially unacceptable words (coprolalia), and repeating a sound, word, or phrase just heard (echolalia). Attention deficit hyperactivity disorder and obsessive compulsive behaviours often occur together with TS, and make it even harder to deal with.

Variability

Tics can be so slight that they are hardly noticeable, or so severe that they can cause serious physical and social problems. Education can be badly disrupted.

Even within the same person, the tics vary in many ways:

- they wax and wane they get better and worse over time
- they change one tic stops and another starts
- they may be made worse by stress and anxiety
- they may be alleviated with relaxation or concentration on an absorbing task

These changes are completely unpredictable and the person with TS has no control over them.

Common feature

Tics are involuntary, It may be possible to hold them in for a time, but eventually they have to be let out.

Onset

TS usually starts in childhood, and in 30-40% of cases has disappeared completely by late adolescence. In many cases, however, severe tics persist into adult life.

Cause

Although TS is often inherited, we do not yet understand what goes wrong in the brains of people with TS to cause their tics. There are treatments, but they may have unacceptable side effects or be ineffective. There is no cure.

Statistics

- TS is believed to affect up to 1 in every 100 school children although only about 10% of them will have symptoms severe enough to require medical attention.
- Coprolatia (involuntary bad language) only affects about 10-15% of people with TS.
- TS is 3 to 4 times more common in males than in females.

Cover picture Brandon Lazarus with Tillie.

Objectives and Activities

Our aim this year has been to relocate the charity's headquarters from Scotland to London while maintaining and improving our services to people with TS.

The news that we were to benefit from Pete Bennett's Big Brother victory came several months after the end of the period covered by this report. The sum raised - around £400,000 - means that we will be in a position immediately to implement our plans to improve our services for people with TS. These will be fully reported next year.

Relocation

The location of a charity's headquarters is always a sensitive question, especially in membership organisations like the TSA. It raises issues of local pride - Why isn't the HQ where I live? - and cost - Where is the cheapest place to be?

After careful analysis London was found to be the best and most cost effective location, taking into account the availability of staff with the necessary skills and accessibility to MPs and opinion formers. We have selected an economical office in a shared building. The fact that the building has great character, as a former Royal Doulton factory and showroom, is a bonus.

Relocation inevitably has implications for people, too. The process of winding down operations in Scotland was begun, with a view to total closure by December 2006. A number of staff in Scotland sadly had to be made redundant, although the office there remains open and still provides our administration and acts as our mailing house.

At the same time, we had to build a new staff team in London, and started with the appointment of a new Chief Executive, Judith Kidd, in November 2005. We also appointed new contractors for IT and accountancy services and bought a new, fully-functional database.

Although relocation is itself a substantial programme of work, it is being accomplished while maintaining our current services and improving them wherever possible.

Current Services

One of the most valued services is the helpline, which offers parents (the usual callers) the chance to talk about TS to someone who understands. It is an 0845 number to minimise the cost to callers.

The majority came from friends and family - usually parents - of people with TS. About half the calls were from non-members. The usual reason for contacting the TSA was for information about TS, but for some people the call was an opportunity to talk to somebody who understands TS and its symptoms. We sent essential information about TS free of charge to all those who needed it - nearly 500 people.

In addition, we recruited 69 new members and distributed a further 122 full information packs. However, given the prevalence of TS, we need to reach many more people and that is a key objective for the future.

Thanks to Dr Hugh Rickards, for most of the year, we provided an opportunity to put questions directly to a neurologist with great experience of TS. This was a popular service.

Another valued service was Family Networking. This enables people with TS and families living with the condition to be meet other people in their area. Where we have a group, we put them in touch with leader. Meetings are informal, and take place wherever suits the group. The group leader might hold meetings at home, or (for example the Stevenage Group) in their local pub.

Where there is no group, we try to find suitable people close to the person who wants support, and give them the details of members who have offered to help in this way. Family Networking is a service that is restricted to members.

During the year, there were 7 groups in England. We worked successfully to raise awareness of TS in South Wales, and we now need to build on that to develop our network there. Similarly, relocation to England will not be at the expense of providing services north of the Border.

Service improvements

We also improved our services in a number of ways. The website had become badly out of date. We made it more topical, particularly with news of events being run by the TSA. More controversially, we also suspended the online Forum. At first sight, this seems like a reduction in service. In fact, we had we recognised that in its current form it presented unacceptable risks, particularly to the children who were using it. A number of users were also abusing the facility, and we will restore it when we are satisfied that we can do so without risk to users.

We overhauled our newsletter, introducing colour and making it more topical. We sent out the first of the new editions in March 2006 and we continue to send it our promptly every quarter. As we also use the newsletter to promote the TSA, it always includes basic information about TS and about our work.

Other work

A surge in calls followed the broadcast on 3 January 2006 of *Teenage Tourettes Camp*. This featured 5 British teenagers with TS who joined a summer camp in America which made special provision for TS. Not surprisingly, there was considerable enthusiasm among the members for similar provision for children with TS in the UK. We were unable to progress matters partly through lack of resources, and partly because, of the 5 teenagers who went out, one had to come home early. We will not run a camp ourselves until we are confident that we can give adequate support to all who attend.

Robert Key MP tabled an Early Day Motion about TS, signed by 97 MPs. It highlighted all our concerns, particularly the use of Ant First Newsletter in new format - March 2006 against children with TS, the national shortage of specialists for diagnosis and treatment, and the rejection of requests for statements of educational needs.

There continued to be a high level of press interest in TS, and press enquiries accounted for nearly 10% of calls to us. Where a report or feature seems likely to help people with TS we do our best to respond. Conversely, where the press are only interested in sensationalising TS, we do not.

Supporting activities

Our trustees undertake a considerable amount of the TSA's work themselves as volunteers, especially manning the TSA's helpline, and moderating the TSA's online Forum, raising funds themselves and supporting other volunteers.

During the year, it became apparent that the trustees needed to focus more on governance. A training day was arranged (held in April 2006) to help them do this. The Trustees met 3 times and were in frequent contact by e-mail.

Future trustee vacancies will be openly advertised. New trustees will be appointed by the board to serve until the next AGM, when they will be expected to stand for election as provided in the Memorandum and Articles. Normally 1/3 of the trustees are required to stand down in rotation each year, although they are eligible for re-election at the AGM. Induction training will be introduced for trustees and further training needs identified.

Major risks to which the TSA is exposed are kept under continual review and precautions taken accordingly. The Chief Executive reports on health and safety at each board meeting.

Donations and fundraising

We received quite exceptional support and generosity from our patron Mr Daniel Katz MBE during the year, without which we would have achieved very little. Most of our income comes from donations from Mr Katz and others and from fundraising efforts by members and volunteers. We fully accept the need to increase sources of funds, and we initiated the development of a business plan, which will enable us to develop and apply a fundraising strategy in future years.

Financial Review

Overall the TSA's financial position remains satisfactory. Although the TSA made a loss of £29,000, and drew on its reserves by £20,000, it retains sufficient reserves to carry it forward into 2006 and beyond. The principal reasons were the unexpected resignation of the fundraiser, together with additional costs such as redundancy payments due to relocation and the purchase of a new database.

That said, the TSA has to increase its income, both by diversifying its sources of funds and by redoubling its fundraising efforts. These have deliberately been put on hold pending the completion of the business plan. The TSA is also improving its financial control by developing the financial information available to trustees.

The TSA will revisit its reserves policy in 2006 to see whether there is scope safely to reduce them further, in order to maximise the resources available for

services. The investment policy and objectives are limited to placing the reserves in a high interest account which allows instant access.

Responsibilities of the Management Committee

Company law requires the Management Committee to prepare financial statements for each financial year which give a true and fair view of the state of the affairs of the charitable company as at the balance sheet date and of its incoming resources and application of resources, including income and expenditure, for the financial year. In preparing those financial statements, the Management Committee should follow best practice and:

- 1. Select suitable accounting policies and then apply them consistently;
- 2. Make judgements and estimates that are reasonable and prudent; and
- 3. Prepare the financial statements on the going concern basis unless it is inappropriate to assume that the company will continue on that basis

The Management Committee is responsible for maintaining proper accounting records which disclose with responsible accuracy at any time the financial statements comply with the Companies Act 1985. The Management Committee is also responsible for the safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Members of the Management Committee

Members of the Management Committee, who are directors for the purpose of company law and trustees for the purpose of charity, who served during the year and up to the date of this report are set out inside the back cover.

Auditors

The Kings Mill Partnership were appointed as the TSA's auditors during the year. In accordance with Section 385 of the Companies Act 1985, a resolution will be put to the forthcoming Annual General meeting that The Kings Mill Partnership be re-appointed for the ensuing year.

This report has been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities (issued in March 2005) and in accordance with the special provisions of Part VII of the Companies Act 1985 relating to small entities.

Approved by the trustees on 9 September 2006 and signed on their behalf

Dr Jeremy Stern, Chairman

9 September 2006

INDEPENDENT AUDITORS' REPORT to the MEMBERS of the TOURETTE SYNDROME (UK) ASSOCIATION

We have audited the financial statements for the period ended 31st March 2006, which comprise the Statement of Financial Activities, Balance Sheet and the related notes. These financial statements have been prepared under the historical cost convention and the accounting policies set out therein.

This report is made solely to the company's members, as a body, in accordance with Section 235 of the Companies Act 1985. Our audit work has been undertaken so that we might state to the 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 company and the company's members as a body, for our audit work, for this report, or for the opinions we have formed.

Respective responsibilities of Directors and Auditors

As described on page 5 the company's directors are responsible for the preparation of the financial statements. It is our responsibility to form an independent opinion on those statements, based on our audit, and to report our opinion to you.

Basis of opinion

We conducted our audit in accordance with Auditing Standards issued by the Auditing Practices Board. An audit includes examination, on a test basis, of evidence relevant to the amounts and disclosures in the financial statements. It also includes an assessment of the significant estimates and judgements made by the directors in the preparation of the financial statements, and of whether the accounting policies are appropriate to the company's circumstances, consistently applied and adequately disclosed.

We planned and performed our audit in order to obtain all the information and explanations which we considered necessary to provide us with sufficient evidence to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud, error or other irregularity. In forming our opinion we also evaluated the overall adequacy of the presentation of information in the financial statements.

Opinion

In our opinion, the financial statements give a true and fair view of the state of the charitable company's affairs as at 31st March 2006 and of its incoming resources and application of resources, including its income and expenditure, in the period then ended and have been properly prepared in accordance with the Companies Act 1985.

The Kings Mill Partnership Chartered Accountants Registered Auditors 75 Park Lane, Croydon CR9 1XS

9 September 2006

TOURETTE SYNDROME (UK) ASSOCIATION Statement of Financial Activities (including Income & Expenditure Account) for the year ended 31 March 2006

Notes	Total Funds 2006 £	Total Funds 2005 £
Incoming Resources	L.	Σ.
Incoming resources from charitable activities		
Subscriptions & general donations	80,735	76,585
Information packs and publications	2,136 2,449	1,142
Just giving.com Medical research	2,449	203
CAF	3,467	203
Gift Aid	7,863	_
Concert Wales	1,678	-
Legacies		
Incoming resources from generated funds:		
Bank Interest	898	731
Other incoming resources	3,086	15,157
Total incoming resources	102,312	93,818
Resources expended Charitable activities		
Services to beneficiaries	53,119	39,643
Information packs and publications	16,614	12,717
Medical research	7,700	-
CAF	-	3,857
Gift Aid	582	3,961 2,606
Just giving.com Management & administration	43,652	32,478
Managonone a administration	40,002	02,470
Governance costs	10,004	1,042
Total resources expended 2	131,671	96,304
Net (outgoing) resources for the year / Net (expenditure) for the year	(29,359)	(2,486)
Total funds brought forward 1 April 2005	106,955	109,441
Total funds carried forward 31 March 2006 3 There are no recognised gains and lesses other than those in the statement of	77,596	106,955

There are no recognised gains and losses other than those in the statement of financial activities. Therefore no statement of total recognised gains and losses has been prepared. All the above amounts relate to continuing activities. All figures for 2005 have been re-stated in accordance with SORP 2005.

TOURETTE SYNDROME (UK) ASSOCIATION Balance Sheet As at 31 March 2006

	Notes	20	006	2005	
			£		£
Fixed Assets Tangible assets	5	_	5,834	_	8,443
Current Assets Stock W-I-P Other Debtors Cash at bank	6	9,807 - 5,937 69,776 85,520	_	1,020 18,593 2,908 81,563 104,084	
Liabilities Creditors: amounts due falling within one year Net current assets	7	(13,758)	71,762	(5,572)	98,512
Total assets less current liabilities		=	77,596	_	106,955
Funds Unrestricted funds	8	~	77,596	_	106,955

These financial statements have been prepared in accordance with the special provisions of Part VII of the Companies Act 1985 relating to small companies and were approved by the trustees on 9 September 2006.

Signed

Chairman

TOURETTE SYNDROME (UK) ASSOCIATION

Notes to the financial statements

For the year ended 31 March 2006

1 Accounting policies

The following accounting policies have been used consistently in dealing with items which are considered material in relation to the financial statements.

a) Basis of preparation of accounts

The financial statements have been prepared under the historical cost convention and comply with Companies Act 1985. The financial statements have been prepared in accordance with Statement of Recommended Practice (SORP), "Accounting and Reporting by Charities: Statement of recommended practice" published in March 2005 and applicable accounting standards. Where appropriate comparative figures have been restated.

b) Fund accounting

Unrestricted funds are available for use at the discretion of the Trustees in furtherance of the charitable objectives of Tourette Syndrome (UK) Association.

Restricted income funds are funds subject to specific restrictions imposed by donors or by the purpose of the appeal. The purpose and use of the restricted funds is set out in the notes to the financial statements.

c) Incoming resources

All income is accounted for as soon as TSA has entitlement to the income and there is certainty of receipt and the amount is quantifiable.

d) Members subscriptions and events & conferences

Subscriptions and events are accounted for in the year to which they apply. Subscription income received during the year that relates to subsequent financial accounting period is carried forward as a creditor in the balance sheet and shown as subscriptions received in advance.

e) Resources expended

All expenditure is accounted for on an accruals basis and has been listed under headings that aggregate all the costs related to that activity. Where costs cannot be directly attributed they allocated to activities on a basis consistent with the use of resources.

Overheads and salaries are allocated between expense headings on the basis of time spent.

Governance costs are those incurred in connection with the management of TSA's organisational administration and compliance with the constitutional and statutory requirements.

f) Fixed assets

Depreciation is charged on tangible fixed assets at 25% of cost *per annum*, so as to write them off over their expected useful lives.

TOURETTE SYNDROME (UK) ASSOCIATION Notes to the financial statements For the year ended 31 March 2006

2 Resources expended

1 1

a)	Analysis of total resources expended	Staff costs	Support costs	Other direct costs	Total 2006	Total 2005
	Unrestricted funds	£	£	£	£	£
	Charitable activities					
	Services to beneficiaries	12,272	40,979	-	53,701	50,047
	Information packs and publications	10,284	6,330		16,614	12,717
	Medical research	· -	· -	7,700	7,700	3,857
	Management & administration	33,101	10,551	-	43,652	32,478
	Governance	812	352	8,840	10,004	1,042
	Total unrestricted resources					
	expended	56,919	58,212	16,540	131,671	96,304
	Total resources expended	56,919	58,212	16,540	131,671	
	Total resources expended 2005	<u>55,570</u>	40,047	687	96,304	
b)	Analysis of support costs					
,		Premises	Other expenses	Travel	Total 2006	Total 2005
		£	£	£	£	£
	Services to beneficiaries	4,108	25,574	11,297	40,919	29,188
	Information Packs & Guidance	3,521	2,497	312	6,330	3,032
	Management & Administration	5,868	4,162	521	10,551	7,579
	Governance	196	139	17	352	348
	Total Support Costs	13,693	32,372	12,147	58,212	40,047
c)	Analysis of governance costs					
	Legal and professional fees				4,036	
	Accountancy charges				3,630	687
	Audit fees				1,175	-
	Apportionment of staff and support costs				1,164	355
	Total governance costs			_	10,004	1,042

TOURETTE SYNDROME (UK) ASSOCIATION

Notes to the financial statements

For the year ended 31 March 2006

3 Net incoming/(outgoing) resources

a) These are stated after charging:

These are stated after charging .	2006 £	2005 £	
Auditors' remuneration	1,175	-	
Depreciation	2,540	2,378	
Operating Leases - land & buildings	-		

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4 Trustees and employee information

a) Trustee information

Remuneration was paid to an associate of a trustee during the year (2005: £960). Expenses of £3504 for travel were paid to 6 trustees during the year. (2005: £Nil)

b) Employee information

Employee costs during the year were :	2006 £	2005 £
Salaries Social Security Other staff costs	47,775 8,126 -	47,337 8,233
	55,901	55,570

The number of employees whose emoluments amounted to over £60,000 during the year was nil (2005: £nil)

	2006	2005
The average number of full and part time employees		
during the year was:	6	7

TOURETTE SYNDROME (UK) ASSOCIATION

Notes to the financial statements

For the year ended 31 March 2006

5 Tangible fixed assets

5 Tangible fixed assets			Fixtures & fittings	Total
			£	£
Cost			40.450	40.450
At 1 April 2005 Additions			10,159	10,159
Additions			10,159	10,159
Depreciation				
At 1 April 2005			1,785	1,785
Charge for the year			2,540	2,540 4,325
Net book value			4,325	4,323
At 31 March 2006			5,834	5,834
At 31 March 2005				-
The above fixed assets are used to support all of TSA's activities				
6 Debtors				
			2006	2005
			£	£
Other debtors			2,684	_
Prepayments and accrued income			3,253	2,908
			5,937	22,521
			3,937	22,321
7 Creditors :				
Amounts falling due within one year			£	£
			~	~
Trade Creditors			8,512	1,737
Other Creditors			3,021	-
Social security and other taxes			2,113	3,401
Accruals and deferred income			112	434
			13,758	5,572
8 Total funds				
	0	Net	Obit-bla	Ologina
	Opening balance	incoming resources	Charitable expenditure	Closing balance
	£	£	£	£
Unrectricted apparel				
Unrestricted - general Restricted	106,955	102,311	131,670	77,596
	106,955	102,311	131,670	77,596
		······································		

9 Leasing commitments

At 31st March 2006, the company had annual commitments of £5,446 (2005: £5,446) under a non-cancellable lease on its Dunfermline office which expires within two to five years.

Tourette Syndrome (UK) Association

Administration 020 7793 2357

Helpline 0845 458 1252

Website

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Registered Office

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