

**EAST OF SCOTLAND BRANCH OF ATAXIA UK
ANNUAL GENERAL MEETING HELD AT LASSWADE
HIGH SCHOOL CENTRE ON SATURDAY 14 MAY 2005**

Present: Liz & Pete Dalby, Penny Gardner, John Hunter, Derek Main (Chairman), Sheree Logan & James Allan, Peter Smeaton, Alan Smith and Frances Wright.

Apologies: Andrea Bothwell, our Patron Ronnie Browne, Richard and Anne-Marie Thomson, Andy Hogg, Alastair Macdougall (Ataxia UK) and John Reid

NEW! BRANCH WEBSITE: www.ataxia-east-scotland.org.uk

Date of next meeting: Saturday 3 September 2005

Branch BBQ – Saturday 24 September?

Falkirk Wheel Trip – Sunday 2 October?

1. Introductions

First of all, Derek let everyone know that John Reid has had a bad accident whilst out riding in his horse and trap and is in Borders General Hospital. The members send him their very best wishes for a speedy recovery.

Everyone then introduced themselves: Derek has had CA for 46 years, John Hunter from Selkirk has SCA2 CA and is active in sports, both as a coach and a participant, Liz Dalby is on the committee and has SCA8 CA and Sheree and James have a 12 year old son with FA. Pete is Liz's husband so lives with CA and Alan Smith from Kirkcaldy has CA. Alan was pleased to be attending his first meeting for over a year since he has at last got Direct Payments through enabling him to get transport provided – obtaining this proved to be a long process! Peter Smeaton has had CA since 1959 and thought originally that it resulted from the use of OPs (organo-phosphates) in his veterinary practice but friends have since said that they could see it his gait at the age of 21. Frances has been Treasurer for 10 years and has many friends with CA, likewise Penny who has been Branch Secretary for 10 years.

2. Reports of Meetings

The report of last year's AGM (Saturday 8 May 2004) was approved. The report of the Meeting on 19 March 2005 was also approved. Derek reminded members that he has collecting cans, wheelchair stickers and car stickers, just contact him on CelticDerek@blueyonder.co.uk or telephone **0131 477 4371**.

3. Chairman's Report

Derek explained that he took over from Pete Dalby as Chairman last September and thanked Pete for all the work he has done for the Branch, taking over and holding the reins so well and especially the successful organisation of the Ataxia Research Conference in July 2004.

At present we have Derek as Chairman, Penny as Secretary and Frances as Treasurer. Liz is a committee member, John Reid as webmaster and committee member and not forgetting Susan McPheat as an emailing committee member. Everyone has intimated their desire to carry on in post, although a vacancy does exist for Vice Chair. If anyone from the floor wishes to volunteer as a committee member or stand for any of the existing posts, they may do so.

Derek advised members that John Reid has had an accident, he fell from his horse and carriage last week and has had an operation. He is in Borders General Hospital and has been visited by Pete and Liz. We will send him a get well card and gift on behalf of the Branch.

In the past few months we have had a mixed turn out at meetings – in fact pretty poor – which Derek hopes and trusts will change. He was hoping to have introduced and welcomed Ataxia UK's Chief Executive, Alastair Macdougall, who was going to address us but due to other commitments in London sent his apologies for today and hopes to visit us later in the year.

In the past few meetings we have had Dr John Womersley from Glasgow Health Board (November 2004) speaking on entitlements to Direct Payments and the best way to apply for them, a traditional Burns' supper with music playing and a rather interesting talk from John Hunter and John Reid on their sporting achievements. At our March meeting this year we were extremely pleased to have Professor Robert Will, Director of the CJD surveillance unit talk to us about the ataxic effects of CJD.

This is now **your** AGM and the committee is keen to hear any ideas for speakers for 2005 and 2006 onwards. We already have plans to get another speaker on Direct Payments – I hope this is of interest to members, as the speaker planned for 3 September is Jack Blaik, City of Edinburgh's Direct Payments Team Leader, and he can offer advice on what can and cannot be claimed for (general advice not specific cases). Other suggestions for topics are very welcome.

Derek is waiting to hear from Edinburgh Council regarding the Assembly Rooms to see if the annual charities hypermarket is going ahead and if so, when. If we do take a stall we will need volunteers to help us run the stall (but do we have enough to sell?).

Two events are planned for this summer / autumn: a barge trip and a BBQ, dates to be settled later on and we hope to have a good turn out for both. As well as our official business at this AGM, we are fortunate to have Peter Smeaton with us, who will talk about stem cell research.

5. Treasurer's report

Frances reported that she and Penny got the books balanced very quickly this year and that the accounts had been sent on to Head Office. Alastair Macdougall had acknowledged their safe arrival, plus the other information required which had been requested. The summary of the accounts to 31 March 2005 is attached as an appendix to this report. Acceptance of the accounts was approved by Pete Dalby and seconded by John Hunter.

The bank balance fell by nearly £4,000 this year due to a £2,000 donation to Ataxia UK and the £2,228 Branch costs of last July's conference. The total Branch contribution to the research conference was actually £2,603, as we paid a deposit the previous year as well. £1,500 of the conference costs were met from earmarked funds from the Bank of Scotland (now HBOS) and the remainder from our own fundraising over several years.

Current balance at the bank is £390.66, plus £140 from last year's walk recently deposited and not included in the total. £30 members' subscriptions, donations and regular standing orders will bring the total back to over £500. Ian McPheat also made a £20 donation and some money is due from aluminium cans from LEEP.

A payment of £293 has been made for Great Scottish Walk registration: we will gain publicity by this by inclusion on the website, but will not have as many participants in this as last year. We are still members of SDEF (Scottish Disability Equality Forum) which costs £5 pa and recent stamps and photocopying have cost £77.78.

At the moment, our Branch bank account is held with Bank of Scotland, but the service received from them has not been satisfactory. We are looking into changing to the CAF (Charities Aid Foundation Bank) but this may cause difficulties if totally reliant on the internet – in terms of Frances' access and paying in cash from collection tins etc.

6. Election of Committee

The existing committee members were re-elected, unopposed. Derek proposed Penny for the role of Vice Chair, which was accepted and agreed (conducting Branch meetings in the event of Derek's absence). Committee members for 2005/2006 are:

Chairman

Derek Main

Secretary and Vice-Chair

Penny Gardner

Treasurer	Frances Wright
Web Master and Committee Member	John Reid
Committee Member	Liz Dalby
Email committee Member	Susan McPheat

Derek thanked everyone for their contributions to the Branch.

7. Peter Smeaton's Talk

Peter is a former vet from Saltaire, Yorkshire, and a member of the Bradford self-help Ataxia group. He was wearing his Glasgow graduation tie for our benefit.

Peter opened by saying that he admires people who can think and speak at the same time – it's a 'poor do' when you can't stand up and give a vote of thanks. Personally, he is better when sitting down! He finds he gets stuck for words, as when saying grace at dinner.

This is the second time Peter has spoken (since acting as best man when young), the other being at the last meeting of the Bradford group, which was a bit like the 'inmates taking over the asylum' – very chaotic and noisy! He thought no one had heard a thing he he'd said, but afterwards, the group members said it was 'the best speech they'd ever been to'. He lives near the heritage village of Saltaire (similar to Lanark) where all the streets are named after Titus Salt's family and make up a complete alphabet: Albert Road etc. His talk will be based on 3 things for every letter – but he is not planning to go any further than M this time!

A – Albert Road

Peter said that until recently he was 'invisibly disabled' and 'came out' with his **ataxia** at the Bradford group meeting this year. He maintained that he could do everything except hurry; when working as a vet he used to refer things so that people didn't know and was good at getting on the phone. The race goes not to the clever, strong or swift, but to the person who can **adapt**.

Peter used to have a partner but got his own surgery so he could adapt it to suit himself. His nurse had been with him from school (age 18) and his secretary was his sister. The local Leonard Cheshire homes meant that MS (multiple sclerosis) was in people's vocabulary and people thought he had that, or back trouble was good to blame for a while. Some people like to go to the 'poorly vet' – someone who has suffered himself.

Now his ataxia is more visible, people can recognise and understand – he'd made notes for the speech but cannot read his own writing! Since 'coming out' his outlook on life has changed, he should have done it sooner.

Acting: in a way we all act a bit before we 'come out'. There are parallels with people who cannot read and manage to cover it up – W Somerset Maugham's story 'The Verger' is an inspiring story of overcoming obstacles, and discovering that they can even be an advantage. Peter managed to work all right in his own environment but it was not so easy being on call, not knowing the people, strangers, could be hard. As you age, you become a better actor and a good lateral thinker.

B – Baker Street

With ataxia, the message pathways to the **brain** and back and reflex level are not good. We can't suppress or reinforce, diminish or augment. Consider the budgie – very still, not like us. People who train **budgies** (and other animals) are very still, not like us. Our muscle recruitment is not even.

C – Caroline Street

The numbers in this street go up one side and down the other – confusing visitors.

The **cerebellum** is one eighth of the total brain weight. Is there a verb 'to cerebrate'? – Yes (showing brain activity). When the cerebellum is defective, gait, balance and speech are affected. In cerebellar function there is no compensation by other parts of the brain, only adaption, therefore learning takes place.

Christopher Reeve had an upper neck injury, Michael J Fox and Terry Thomas had Parkinson's disease. David Nixon and Don Revie had Motor Neurone Disease (MND). Footballers have a six fold risk of MND – should heading balls be banned?

D – Daisy Place

Peter's veterinary practice was small animals, **dogs** and cats – a 'moggie mender' as Ken **Dodd** put it – and he was able to put the dogs and cats between him and the client, by leaning on the table. Ken Dodd commended a stuffed cat which is clean and quiet about the house.

E – Edward Street

Exercise, muscle volume – use it or lose it. Get breathless, with active or passive, aerobic or unaerobic exercise, even in the bath. Charles Atlas pioneered the technique of dynamic tension isometrics. It is best to exercise on alternate days – but only to the point of pain and not through it. No pain, no gain – no gain, little point. Genetics play a part again.

F – Fanny Street

Feet – thinking on, therefore we're better sitting. Peter enquired of his Dad about Granddad, he said he was fleet – there's no answer to this! **Falls** can

lead to **fractures** – but it's better to falter rather than founder – should we wear protective gear? No lateral thinking, or you'll certainly fall – we seem to know when we're going off at a tangent!

People with **Friedreich's Ataxia** have to contend with heart problems and often diabetes and many other problems.

G – George Street

Grog – Tony Eden said 'if you have one, you might as well have 6' – with ataxia, people think you are drunk anyway! We only walk if we are lucky, and not in a straight line – this with loss of timbre makes us look and sound drunk. Peter has been breathalysed twice whilst sober.

H to Z

These will have to wait for another occasion! In conclusion, Peter said that with the current improved state of knowledge it would have been easier to have 'come out' about his condition. He feels that he turned it to his advantage during his professional life by being more caring and thorough and taking more time with longer appointments. The issue of stem cell research will be covered when he reaches 'S'!

8. Social Events

The date was agreed for the **Falkirk Wheel trip** with the Seagull Trust as Saturday 2 July, but had to be changed later due to the G8 march in Edinburgh. It will now be on **2nd October**. There is only one boat available, so the maximum number is twelve, including six wheelchairs and there must be two helpers. We would leave Edinburgh about 12.00 with a minibus, arrive 1pm, boat trip takes 2 hours, back by about 4pm. See the separate sheet to contact Frances and register for a place on this trip.

Penny is wanting to know who might be interested in a **BBQ at Almondell Country Park on Saturday 24 September**. Pete Dalby and James Allan offered to do the cooking. We hope members will tell us their suggestions for other **social events**, possibly including one or more joint events with the West of Scotland branch.

11. Date of Next Meeting

The next Branch meeting is set for **Saturday 3 September** at Lasswade. We usually have meetings in November, January, March and May as well. If anyone has ideas for **future speakers**, please let us know. If anyone is willing to help out on the **committee**, please let Derek know.

Branch Contacts are:

Derek Main (Chairman) 0131 477 4371 CelticDerek@blueyonder.co.uk
or **Penny Gardner (Secretary) on pennyjgardner@btinternet.com**

**EAST OF SCOTLAND BRANCH OF ATAXIA UK
FINANCIAL STATEMENTS FOR THE YEAR TO 31ST MARCH 2005**

INCOME	£	£	£
Donations - general	160.00		
Sale of goods	0.00		
Bank interest	41.00		
Social income	0.00		
Members voluntary subs	<u>115.00</u>	316.00	
Fundraising:			
General			
Individuals	171.16		
Great Scottish Walk	507.50		
Collecting tins	121.36		
Sale of cans	<u>44.73</u>	<u>844.75</u>	<u>1,160.75</u>
EXPENDITURE			
Postages & office supplies		185.98	
General Expenses		28.00	
Subs to organisations		0.00	
Meetings		52.40	
Travel expenses		2.20	
Welfare		315.00	
Great Scottish Walk Registration 2005		293.75	
Net cost of research conference, 3 July 2004		2,228.00	
Sundries			
social expenses		<u>0.00</u>	<u>3,105.33</u>
Deficit of expenditure over income			-1,944.58
Sent to HQ			<u>-2,000.00</u>
Decrease in bank balance			-3,944.58
Bank b/f			<u>4,335.24</u>
Bank c/f			<u><u>390.66</u></u>
Balance as per bank statement 31 March 2004			390.66
less unrepresented cheques			-
Bank balance c/f at 31 March 2005			<u><u>390.66</u></u>

USEFUL WEB LINKS

If there are any suggested additions to this list please let us know

www.ataxia-east-scotland.co.uk : our Branch Website

www.ohbother.co.uk: by an Ataxian and full of very useful information.

www.bbc.co.uk/ouch for an inside view on disability news.

www.evoc.org.uk: for local disability information in Edinburgh.

www.digg.org.uk: Glasgow's online resource for disability information.

www.matchinghouses.com: re: accessible holiday house swaps.

www.ataxia.org.uk the Ataxia UK website, has many good links.

www.skill.org.uk information & advice for disabled students

E MAILED REPORTS

If you would prefer an e mail instead of a hard copy, please let us know your e mail address:

Name _____ Telephone No. (optional) _____

E Mail address _____

Please post to the Secretary, Penny Gardner, at 3 Craigleith Gardens, Edinburgh EH4 3JW or e mail pennyjgardner@btinternet.com

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MEMBERS VOLUNTARY SUBSCRIPTIONS.

Please send a contribution if you can - £5 per household is suggested,

Please send a cheque, payable to East of Scotland Branch of Ataxia UK to: Frances Wright, Flat 8, 25 Queen Charlotte Street, Edinburgh EH6 6AX

BRANCH BARBECUE

We will be making a small charge to cover the cost of hiring the site and food costs: £3 per adult, £1 per child under 10.

If you are interested in the Branch barbecue on **SATURDAY 24 SEPTEMBER 2005**, please complete the form below and send to:

Frances Wright, Flat 8, 25 Queen Charlotte Street, Edinburgh EH6 6AX

I am interested in the Branch Barbecue on 24 September:

Name _____ Telephone No. _____

Address _____

Number of Adults _____ @ £3 per person

Number of Children _____ @ £1 per person (babies free)

BARGE TRIP

These trips are free, but we usually make a donation to the Seagull Trust so a small contribution would be appreciated on the day. If the day doesn't suit you, you are under no obligation and if more than 12 people apply we may arrange a repeat visit later in the year.

If you are interested in a boat trip to the Falkirk wheel on **SUNDAY 2 OCTOBER 2005**, please complete the form below and send to:

Frances Wright, Flat 8, 25 Queen Charlotte Street, Edinburgh EH6 6AX

I am interested in the boat trip to the Falkirk Wheel on 2 October:

Name(s) _____ Telephone No. _____

Address _____

Number of People _____ including number of wheelchairs _____