

**REPORT OF THE MEETING OF THE EAST OF SCOTLAND
BRANCH OF ATAXIA UK
LASSWADE HIGH SCHOOL CENTRE,
SATURDAY 9 SEPTEMBER 2006
<http://www.ataxia-east-scotland.org.uk>**

Present: Liz & Pete Dalby, Penny Gardner, Mary Gilhooley, John Hunter, Derek Main (Chairman), John Reid, Tina Thatcher and Frances Wright.

Apologies: Ronnie Browne, Anne Green, Andy & Fay Hogg, Alastair Macdougall, Susan McPheat, Jane Morrison, Lesley & Andy Pringle, Jim, Essa and Lynn Quin, Jim Shepherd, Alan Smith, Peter Smeaton, Eileen Steele and Richard & Anne-Marie Thomson

1. Welcome, Introduction and Report of AGM

Derek Main welcomed everyone and started with the usual introduction: Derek has CA; John Hunter has SCA2 and has had an eventful year: his cousin and brother also have SCA2; John Reid from Hawick has FA and sadly lost his brother recently; Frances is the Branch Treasurer; Pete is married to Liz who has CA – Liz says ‘you just get on with life’; Mary, Liz’s friend, has come to give a talk on healing therapies which might be helpful; Penny is the Branch Secretary and Tina Thatcher is the Branch support officer with Ataxia UK.

2. Minutes of last meeting (the AGM) and matters arising

The minutes of the AGM held on 6 May 2006 were approved.

3. Mary Gilhooley on Reflexology

Mary explained the theory of reflexology: all the nerves of the body end in the feet with 10 energy zones running up the body from big toe to thumb etc. Theory that ailments can be traced to emotional upsets in life. Blocked energy can manifest in ailments, eg kidneys & eyes are in same zone, so it is common for both to be affected. A pressing action on nerve ends in the feet gives all organs a ‘massage’ and unblocks the blockages. Liz is a good example, coming to Mary for 8 years because the hospital said she’d soon be in a wheelchair – that was 8 years ago and she is still not using a wheelchair. Liz also had Reynaud’s syndrome with purple hands and feet, she has seen a definite improvement in these too.

Reflexology can be effective in many ailments, eg, Mary started work on a client in 1996; a year before that he’d been told he had 2 years to go before losing his right leg, due to a lower leg artery taken to bypass an aneurism. 10 months later he didn’t turn up to his appointment and rang Mary on the Saturday morning in distress – on the Thursday his lower leg had gone

completely cold, the doctor sent him in to hospital, then they sent him home saying nothing more hospital could do, amputation the next step. He went to Mary and she worked on him, at first his lower leg & foot stone cold – 2 appointments a week. By the 4th session there was an improvement, soles of feet were pink, 5 weeks after he was cured and is still OK, he goes to Mary once a month. She wonders how many people have lost their legs because they have not had treatment? You can often see what's wrong by looking at the feet. On one occasion, Liz's foot was sore when Mary touched it in the left 'face' area – Mary asked if she'd been to the dentist – the next day she was up the whole night with toothache, which turned out to be a massive abscess. Mary only charges what people can afford, she enjoys doing it and being able to help people.

Tina then volunteered to be a guinea pig – and we all watched while she tried not to fall asleep. Mary gave a running commentary as she went and emphasised that you must tell your therapist when you feel discomfort, because she relies on this feedback. Anything affecting the brain is felt on the opposite side of the foot. Tina definitely felt the benefit of the session and we all thanked Mary for coming along.

4. Treasurer's Report

Frances reported that the bank balance at the last statement date (end of August) was approximately £1,200.

Since May, there has not been a lot going on. Mr and Mrs Smith, who have been making a regular monthly donation, transferred the standing order to the new bank. Penny received an email from the Quin family, who are also going to set up a standing order. John Reid's mum sent a £200 donation in memory of his brother Brian, who sadly passed away in June. Frances raised £60 sponsorship from her 50 miles walk along the West Highland Way in May/June. Andrea's friend Janice & Rebecca Livingston and their dog Ziggy did the Great Scottish Walk in June and raised £100. Other fundraising included £1 from the sale of 'Susan's Stories', contents of two collecting cans from Derek (Station Bar, London Road, not yet counted). Finally, John Hunter made a £20 donation. Income total between May and September was £391 + £20 + money from cans.

Expenses: we donated £500 + £178 (collecting cans money) to Head Office in May. Frances had a terrible job getting an acknowledgement of the money sent to Head Office: finally after many calls a letter was received at the end of June & our donation was printed in the Ataxian magazine. Teas coffees at Lasswade cost £12 and cards & posters from HO cost £13.50. We made a donation to the Seagull Trust (who provide the free barge trip) of £40. We had booked a minibus for this trip but it had no ramp so no charge, saved the Branch £120! Everyone managed to get there by

sharing cars and vans. A wee snack in coffee bar afterwards brought the total to £38.20 including petrol costs. Penny claimed £33 copying and postage costs, £45 website fees (6 months). In total £880 outgoing since the last meeting.

5. Falkirk Wheel Trip

Frances reported that the trip had been a great success, although not everyone managed to attend. 7 people went (would have been 9 but 2 people got the day wrong). We had booked a minibus with wheelchair access for everyone to travel from Meadowbank but when it turned up on the morning, one of the ramps wasn't working so everyone took their own cars / vans and we saved the cost of the hire! Sailed up the Union Canal taking 1hr 15 minutes, tea & chocolate biscuits on the way, landed at the boat house, the weather was lively and hot. At the end the drivers got a lift down and brought the cars up, then everyone sat in a glass roofed coffee shop. It would be nice to go again (it costs £8pp normally). The Seagull Trust has a leaflet to book their 6 berth holiday boat the Marion Seagull, cruising the lowland canals of Scotland including the Falkirk Wheel www.seagulltrust.org.uk if anyone is interested.

6. Secretary's Report – Branch Website News

The Branch website (<http://www.ataxia-east-scotland.org.uk>) has now had nearly 700 visitors. If you have ideas for any other content pages or useful links on our site, please let Penny know: info@ataxia-east-scotland.org.uk. The website costs us about £80 annually in web hosting and domain fees, which we think is good value for money.

7. Tina Thatcher, Branch Support and Development Officer

Tina's role is to visit Branches and groups and to help set up Branches and Groups. Lottery money has been awarded for this role. She has been going round the branches listening to their problems & issues: one problem identified is that the Branch support pack can be confusing with too much information, especially for new members – Tina is aiming to develop a simpler, shorter document, with help of several Branch chairs; this will be launched at the November conference in Birmingham. It will be a condensed Branch guide document, without going into too many details. It will contain the main basic standards for operating branches. Tina will help Branch committees go through them and if a Branch wants to do more than the basics, fine. There are a few rules in there but that's a very small part of it. She is hoping it will be received well. She is also developing a guide for support groups, which are different from branches, much simpler.

Another comment that has arisen in Tina's talks with Branches is in relation to communication, with feelings of isolation from Head Office. In the past there has not been enough time or staff to maintain the effort needed to

look after the network. This is Tina's role, so all this should now improve. She has been sending us lots of emails with useful information and Penny has been forwarding them on right away. Also when a Branch sends her their newsletter, she forwards it on to everyone else. This helps people in branches to get ideas, remember someone from conference, all this helps to build bridges. It's a slow process, with only Tina to look after whole of UK and Northern Ireland – but the number of Branches & support groups is growing. She is very passionate about it – feeling that it's very important that Ataxia UK serves more people with Ataxia on a local basis. John Reid asked: 'How many Branches?' 11 now, plus about 7 support groups with the East Sussex & West Kent and South Wales branches being the most recent new branches and Ipswich being a new support group. Also Inverness is soon to have a support group. These new groups would benefit from help and support from other branches.

Tina is also looking into setting up a buddy system – where a new Branch chair can contact the committee of a longer established branch for sharing experiences. Also, some branches are setting up support groups eg in Leicester – satellite organisations, getting their support from the Branch. It's all very exciting.

Tina's background is in the voluntary sector; her past roles have included working with black & ethnic groups, disabled people, asylum seekers etc. She was attracted to the job because of its development role.

There is an access fund to help people attend the conference if they can't afford it. Tina is trying to find out how many members are on each mailing list. Eg if a branch member dies or moves Ataxia UK may not know about it – we must communicate the information, a two way thing.

Tina is main point of contact for branches and she is in constant communication with Head Office. Also she encourages people to volunteer for different tasks – although sometimes these have to be done at Head Office and there's not a lot of space there. Another issue that's been raised: a lot of Branches don't have enough able bodied people to help with events.

Pete asked the question about our research conference, in 2004 there were 3 regional conferences, Ataxia UK said they were trying it out to see how successful – but we never had feedback on this. It would have been nice to have had a formal evaluation from Ataxia UK on how successful / cost effective it all was.

Branch chairs would like to meet on a regular basis – even just an event arranged as part of the AGM. Perhaps a newsletter could be produced from

these meetings. On the Friday at the Birmingham AGM there will be a Branch committee meeting - the very first one - chaired & organised by Tina.

8. AOCB

8.1 Scottish Helpline for older people has taken over 16,000 enquiries in its first 2 years of operation. Helpline number is 0845 125 9732 and they also produce a bulletin. Email list contact enquiries@acscot.org.uk This will be added to the branch website.

8.2 Age concern older people's week is from 23 to 30 September 2006 – there are posters, flyers and a booklet available.

8.3 Derek brought along press articles on **stem cell therapy injections** – An MS sufferer paid £12,000 for treatment in Netherlands but benefits were short lived, she was back in her wheelchair in 2 months. Patients have been warned of the dangers of expensive, untested stem-cell 'wonder cures' – the extravagant claims do not stand up to scientific scrutiny. However, the therapies still have future potential, but only after a rigorous series of tests and clinical trials which might take many years.

8.4 Branch Christmas Meal 2006 – does anyone want to organise this? Derek suggested holding it at Lasswade again, we had a Christmas meal here 2 years ago and it was excellent and good value. They will give us a cost for the date. Or maybe Seagull trust would do Christmas meals? Frances agreed to investigate this. People should pay a non-refundable deposit. Possible dates are Saturday 2nd or Sunday 3rd December – maybe a lunchtime rather than an evening event. Please respond to Derek on the tear off slip at the end of this report.

8.5 Ataxia UK AGM will be held at Birmingham 10 – 12 November 2006.

8.6 Computer Help? For many people with a disability, their computer is an essential rather than a luxury. It would be good to get computer experts willing to volunteer to help with problems – Penny agreed to add something to the Branch website, asking for volunteers.

8.7 Alastair Macdougall

Alastair, the Chief Executive of Ataxia UK has resigned (personal reasons)

9. Dates of Next Meetings

The next Branch meetings will be held at Lasswade on Saturday 4 November 2006 and Saturday 20 January 2007 from 1.30pm to 4pm. Dates for the March and May (AGM) 2007 meetings have not yet been

decided. The January meeting will be a Burns event of haggis neeps & tatties, no speaker yet in November or January – any ideas?

YOUR COMMITTEE

Chairman	Derek Main	0131 477 4371 derek@ataxia-east-scotland.org.uk
Secretary and Vice-Chair	Penny Gardner	0131 332 5218 penny@ataxia-east-scotland.org.uk
Treasurer	Frances Wright	0131 555 5665 frances@ataxia-east-scotland.org.uk
Committee Member	John Reid	johnreid@ataxia-east-scotland.org.uk
Committee Member	Liz Dalby	
Email committee Member	Susan McPheat	

ADDRESS FOR MAILING:

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Penny Gardner, Branch Secretary
3 Craigleith Gardens
Edinburgh EH4 3JW

USEFUL WEB LINKS

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

www.ataxia-east-scotland.org.uk: our Branch website

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

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

enquiries@acscot.org.uk Scottish Helpline for Older People

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 penny@ataxia-east-scotland.org.uk

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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

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BRANCH CHRISTMAS MEAL

Would you be interested in joining us for a Christmas lunch on Saturday 2nd or Sunday 3rd December? This may be at Lasswade. If we make a booking, there will be a deposit payable to secure your place.

If so, please complete this form: Saturday 2nd? Sunday 3rd?

Name _____ Telephone No. _____

Address _____

E Mail address _____

Please post to the Secretary, Penny Gardner, at 3 Craigleith Gardens, Edinburgh EH4 3JW or e mail penny@ataxia-east-scotland.org.uk