

**REPORT OF THE ANNUAL GENERAL MEETING OF
THE EAST OF SCOTLAND BRANCH OF ATAXIA UK
LASSWADE HIGH SCHOOL CENTRE,
SATURDAY 12 MAY 2007**



<http://www.ataxia-east-scotland.org.uk>

Present: Derek Main (Chairman) Liz Dalby, Penny Gardner, John Hunter, John Reid, Richard, Anne-Marie and Selina Thomson & Frances Wright

Apologies: Andrea Bothwell, Rhona Brankin, Ronnie Browne, Pete Dalby, Liz Griffin, James Harris, Faye & Andrew Hogg, Anne Green, Janice Heath, Eileen Meek, Nigel & Anne Molesworth, Jim Shepherd & family and Alan Smith.

1. Welcome and Minutes of last Meeting

Derek welcomed everyone and said that the usual introductions were not needed this time as we all knew each other. This is our 12th AGM since becoming a Branch and the report of the meeting held on 17 March 2007 was approved.

2. Chairman's Report on the Year

We have had a fairly busy year but have not had as many Social Events as in the past. This we will have to/endeavour to change in the future. I feel that we should ALL make endeavours to find sites for collecting cans, and make strides to increase our membership by sending out a flyer to Doctors Surgeries across Scotland - and to other places you can think of? I would like to pay tribute to Pete Dalby, our past Chairman who has been taken ill recently. But will give the floor to his wife Liz later, to update us on his condition.

Following our last AGM we had Mary Gilhooly speak to us in September 2006 on reflexology as a therapeutic treatment. We also had Tina Thatcher describe her new / old role as branch development officer. During Mary's talk Tina was pleased to take part in a demonstration of reflexology.

On 17 August 2006 we had a very successful trip to the "Falkirk Wheel". Our next Branch meeting was in November 2006, and we had Gillian Scott from The Genetic Interest Group talk to us on Genetic Counselling.

Our January 2007 meeting was addressed by Jack Blaik from Edinburgh's Social Work Department on Direct Payments and The Independent Living Fund. This talk was very useful, and a number of our members were able to take Jack's points on board and gain help from him. At the Meeting on 17 March one of our members Peter Smeaton addressed us (narrated by Penny) on his experiences of Ataxia over the years.

On 28 April we had a very successful joint meeting with the West of Scotland Branch at The Alona Hotel in Strathclyde Country Park, where we met our sister branch, and partook of High Tea with them. We hope to reciprocate their hospitality at a later date.

3. Treasurer's Report

Frances passed round copies of the 2006/07 accounts (attached), which were balanced with Penny in early April and sent to Head Office. We decided to send £1,000 to the research effort as that leaves us plenty for operating. Since 17 March Frances has paid in £349.17 made up of:

£74.42 from collecting cans, £10 donation from Janice Heath, £200 Mrs Campbell, Isobel Haddow's daughter (funeral) £19.75 profit on sale of an antique vase from Peter Wardlaw (Andrea's friend), £10 from Winnie Walmsley, £5 membership from Patrick Knox, £20 from Andy & Faye Hogg, £5 from Peter Smeaton & £5 from Jim Shepherd. In addition, Mr & Mrs Smith & the Shepherds have set up standing orders of £10 per month.

Money out: our £5 annual subscription to Disability Forum.

New balance 30 April = £1,643.34 (not including the £349.17).

Thanks to everyone for fund raising, donations, sale of goods etc. We keep the outgoings as low as possible – most of the expenses are copying charges, postages and the website. **Committee Decision:** Agreed to send £1,000 to Head Office of Ataxia UK.

4. Election of Branch Officers

The existing committee were re-elected, unopposed. These are:

Derek Main (Chairman), Frances Wright (Treasurer), Penny Gardner (Secretary & Vice Chair), John Reid and Liz Dalby (Ordinary Committee Members) and Susan McPheat (email committee member),

5. Social Events

Possibilities were discussed including Blair Drummond (but Anne-Marie not keen on this) and the Scottish Parliament. The latter could possibly take place in October 2007 and West of Scotland Branch members might want to come too. Rhona Brankin (MSP for Midlothian) is happy to organise a visit; she needs to know details of names and numbers). We need to check what day of the week does this need to be? Day time or evening?

6. Update on Pete Dalby

Liz explained that Pete took her to the shops and half an hour later her daughter rang, having found her Dad sitting on the step looking very grey. They rang for an ambulance which took him to hospital – and one hour after getting there he had a heart attack. They gave an immediate

angiogram and he had to lie flat for 24 hours, then came home the next day. He's taking gentle exercise, walking slowly and the main problem now is coping with the household tasks, Liz (who has CA) is finding it difficult to manage. Because Pete's condition is temporary the council won't give any extra help and they would have to pay full rate for it. Derek echoed everyone's thoughts; that we are pleased Pete's on the mend and wish him well.

7. More thoughts on Ataxia from Peter Smeaton – The Long Goodbye

'The Long Goodbye,' this soubriquet is often used in connection with Alzheimer's; however I have heard the blind broadcaster Peter White using the phrase when talking about slowly progressing forms of blindness. Peter was born blind so this does not apply to him but perhaps could be used for other long term conditions.

We with CA are frustrated when defeated by a task which once would have been straightforward. I started to alter a chicken coop for a trio of light Sussex bantams. I could measure and saw but nailing was a non-starter. A semi retired farmer tried with a big hammer, some round headed nails and little else. Then a retired joiner rescued me and the coop! He took it apart and power screwed it together, a nice job. Power fixing, being mainly cerebral would theoretically have been possible for me given the time. My cover of being an unhandy man has labelled me too well and the idea of me with power tools would alarm all and sundry, both far and wide.

This episode of the coop parodies but fortunately not parallels my working life which continued long after my first diagnosis. Working was feasible because I was using all my spare cerebellar capacity. I call this stage compensation and gradually it is followed by adaptation when the cerebrum has to deputise for the cerebellum. Fortunately, for me with CA, my Dad, a railwayman, had instilled in me good employment practice, "the labourer is worthy of his hire". This stood me in good stead, I valued, supported and developed my staff and they in turn reciprocated. I became expert at delegation, trading tasks and body language.

Regarding loss of coordination, the cerebrum cannot remedy this; we have to become exponents of triangulation which means having three points of contact with solid objects including the ground whenever possible.

CA is an esoteric condition. My number one son, a man of the cloth, supports me in this word usage. It means intelligible only to those who understand. So to be truly esoteric engage with information, always do what you can - it is better to wear out than rust. Hippocrates 400 BC said that the medical condition belonged to the patient and there is an obligation on the part of the doctor to make himself understood.

8. AOCB

- Derek brought along an article about **Chinese stem cell treatment**. It seems to have helped a Scottish man with Friedreich's Ataxia, but we believe UK neurologists are not convinced it offers long term benefits.
- Dr Julie Greenfield of Ataxia UK is on maternity leave and Laura Stewart (the **new Research Officer**) is at lstewart@ataxia.org.uk.
- Penny is setting up her own website and will be sharing the hosting with the Branch – thus halving the cost for both.
- John Reid suggested an '**articles for sale**' page on the website.
- Penny has suggested to Tina Thatcher that other UK Branches might like to try using '**Wikis**' for an easy, free, way to get some web pages and raise awareness. She has set up a practice wiki with PBwiki at <http://ataxiabranch.pbwiki.com> and the password is the name of our Branch liaison officer (lower case). Why not give it a try?
- The **Disability Rights** commission are having a meeting on Thursday 31 May on duties under the Disability Equality legislation and information sessions on the Disability Discrimination Act (DDA). People are encouraged to share problems they are having with hospitals eg steps and ramps. Anyone interested is invited to the free session at the Update Centre in Beaverhall road. Derek may go.
- We are planning a **meal at the Laird & Dog Hotel** in Lasswade on 17 November at 4.30pm. The cost is your choice of food & drink and prices are reasonable. A link to the menu is going on the website.
- Derek has been advised by Sheena, one of the Lasswade assistants, that the local **Masonic association** has been collecting to raise money and is looking for destination(s) for the proceeds. We may benefit from a considerable sum. One of their fundraisers is a dinner dance on 29 September, in Gorebridge.
- Is anyone else wanting a **collecting can**? Derek has them.
- The **Disabled Living Centre** <http://www.smart.scot.nhs.uk/> at the Astley Ainslie Hospital is holding a 'Safe Moving' seminar and an exhibition on 'Right or Wrong?' manual handling on Tuesday 3 July 10am – 4pm. Contact the DLC on 0131 537 9190 to book a place on the seminars (10.30 – 11.30 and 14.00 – 15.00).
- Richard, Anne-Marie and Serena brought along some super photos of their trip to **Graceland** last year.

6. Date of Next Meetings

The next Branch meetings will be held on Saturday 22 September 2007 and Saturday 17 November 2007 at Lasswade. We are planning to have a meal immediately after the November meeting, at 4.30pm.

Richard Thomson & family and Peter Smeaton tendered their apologies for the September meeting.

YOUR BRANCH 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
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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.gig.org.uk Genetic Interest Group

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

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

www.simr.org.uk/pages/news/index.html seriously ill for medical research

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