

**REPORT OF THE MEETING OF THE EDINBURGH AND LOTHIANS
BRANCH OF THE ATAXIA GROUP
LASSWADE HIGH SCHOOL CENTRE,
SATURDAY 12 NOVEMBER 2005**
<http://www.ataxia-east-scotland.org.uk>

Present: Sheree & James Allan, Derek Main (Chairman), Pete & Liz Dalby, Penny Gardner, Lesley and Andy Pringle, Jim, Essa and Lynn Quin, John Reid, Eileen Steele, Richard, Anne-Marie and Selina Thomson & Frances Wright

Apologies: Rhona Brankin, Faye and Andrew Hogg, Jane & Davie Morrison & Alan Smith

1. Welcome and Minutes of last Meeting

Everyone introduced themselves. The report of the meeting held on 3 September 2005 was approved. Derek reported the sad news that Isobel Brockie passed away recently; Branch members extend their sympathy to George and family. Derek also announced his recent retirement from his job at the Scottish Executive, as he can't run up and down the stairs any more. Rhona Brankin, MSP, would have been speaking but was ill and sends her apologies.

2. IAAD International Ataxia Awareness Day, 25 September 2005

Ataxia UK's chief executive, Alastair Macdougall, came up from London to address the Scottish Executive on 27 September, where he showed the GMTV Graham and Polly programme. He is willing to go anywhere to speak to people / organisations about Ataxia. We may get one or two new members from the meeting.

3. Secretary's Report – Branch Website News

We have been getting good feedback on the Branch website (<http://www.ataxia-east-scotland.org.uk>). There is now a link from the Ataxia UK website and we have our own small section on there too. 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 There's a link on the main Ataxia UK website (<http://www.ataxia.org.uk>) to the excellent GMTV programme on Graham and Polly 'Living with Ataxia'. Penny will post up the minutes of the Glasgow Branch meetings if she can get an electronic copy of them.

We can have up to 500 email addresses for branch members, so if you would like one, please contact: penny@ataxia-east-scotland.org.uk. Your email address will be yourname@ataxia-east-scotland.org.uk. Any emails will be forwarded to your private email address, which will not be published on the website.

4. Treasurer's Report

Frances reported that it has been quiet since the last meeting in September. Derek's brother David and friends ran the Edinburgh marathon, splitting the proceeds between our branch and the Sick Kids Hospital: our second instalment is £165.50 making £393 in total. £30 came from membership subs, £37 from Anne-Marie's knitting plus the Smiths are still making their regular £10 monthly regular donation. Two full cans were brought along: one from the Braid Hills Hotel (Derek) and one by Sheree and James; the amounts will be reported at the next meeting. There were various expenses as usual for copying and postages. The bank balance including interest is £222.25. Frances reported that the CAF (Charities Aid Foundation) Bank allows deposits to be made through HSBC, so an agreement has been made by the Committee to transfer the Branch account there. There's quite a bit of paperwork to be done for this.

5. Social Events: BBQ and Boat Trip

The BBQ was a great success, with 15 people attending. Even the sun came to join us at the end of the afternoon! Unfortunately, the boat trip at the Falkirk Wheel had to be cancelled as some people were unable to come and we fell below the minimum number. We hope to get another chance for this trip next year, probably April.

6. Branch Christmas Lunch Sunday 4 December 2005

2005 is the 10th anniversary of the Branch, and the 40th anniversary of Ataxia UK. The Royal Terrace Hotel, Edinburgh is booked at a cost of £14.95 for a 4 course lunch: £5 per person deposit required as soon as possible. Frances brought the menu for people to see.

7. Report from Ataxia Conference and AGM 7 – 9 Oct in Birmingham.

This celebrated the Ruby anniversary of Ataxia UK (40 years). Lesley & Andy Pringle attended and reported that they enjoyed it very much. The following are 'edited highlights' from Andy and Lesley; a full report will be published in the Ataxian Magazine.

According to Ernie Heath, £410,000 is currently committed to research, with £3 million having been contributed over 40 years.

Barry Hunt and Julie Greenfield gave a research update, covering the two medical conferences. There's a new genetic test for FA (Friedreich's Ataxia) and a number of SCA's (spino-cerebellar ataxias) and it's now believed that there are about 25 SCA's. The SCA mouse model was discussed, and there's also a lot of research currently into associated conditions eg Huntingdon's Chorea and Parkinson's.

Drug therapies were discussed including CoQ10, MitoQ10 trials in Australia and the USA, and gene therapies. There's been a trial of Idebenone (synthetic CoQ10). Some experiments have been too small to be classified as clinical trials, but have yielded useful results.

The question and answer sessions at the conference were particularly interesting: exercise is a good thing to do, regardless of your condition, increased quality of diet has resulted in a general reduction in degenerative diseases. Branch members discussed cheaper sources of CoQ10, eg the internet – webvitamins.co.uk was mentioned - and whether you can get it prescribed (Liz gets hers through the Western General). Katie Henderson of Ataxia UK sources hers from the USA, but there could be tax implications. What doses of CoQ10 are taken daily? Lesley takes 400mg (having dropped back from 600mg), at night to avoid bad indigestion. Liz is on 600mg. Some US trials have suggested 1500mg. Apparently there is no danger of overdose – but the tablets can be very expensive.

Another question at the conference asked if neurological disorders such as FA and CA affect bone strength. They don't, but inactivity does affect it.

Another symptom can be 'emotional incontinence' eg giggling fits; Lesley said that she's prone to these and is glad to know there's a reason.

A conference member explained that her son is 'living with' ataxia, not letting it stand in his way – he has just completed a sky dive.

How do we get the ataxia message across? Suggestions included leaving your copy of the magazine in your GP's office after you've read it, sending posters to GPs (Ataxia UK set to do this in 2006). Graham Fickling spoke about Branch activities and what they are for: social support being the most important, followed by fundraising.

Andy also recommended a technology aids brochure: www.inclusive.co.uk. Also, anyone using a pc can take advantage of Windows accessibility options through the control panel.

Finally, Andy reported that they travelled to the conference with BA, who were brilliant. The hotel was very good, but not adapted enough to meet their needs.

8. AOCB – Speakers at future meetings

Derek will get Rhona Brankin MSP to come and speak at our January meeting instead. The topic will be 'What can your MSP do for disabled people?' We will also have our usual haggis, neeps and tatties in celebration of Robert Burns' anniversary. Peter Smeaton has offered to

Speak again at our March meeting, and can continue his humorous account of working as a vet with ataxia.

Other suggestions for speakers were Professor Robert Will (possibly September 2006?), representatives from the Disabled Living Centre at the Astley Ainslie and Liz's friend Mary who practices Reiki.

13. Dates of Next Meetings

The next Branch meeting, will be held at Lasswade on 21 January 2006 (Burns supper), 11 March 2006, 6 May 2006 (AGM).

YOUR COMMITTEE

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If you would like to be removed from the mailing list, please write, phone or email. If writing, please PRINT your name or just return the letter marked 'gone away'.

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

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