

**REPORT OF THE MEETING OF THE EAST OF SCOTLAND
BRANCH OF ATAXIA UK
LASSWADE HIGH SCHOOL CENTRE,
SATURDAY 4 NOVEMBER 2006**
<http://www.ataxia-east-scotland.org.uk>

Present: Liz & Pete Dalby, Penny Gardner, Andy Hogg, Derek Main (Chairman), John Reid, Gillian Scott (speaker from Genetic Interest Group), Jim Shepherd, Vicky Shepherd & Alan Mearns.

Apologies: Andrea Bothwell, Ronnie Browne, Anne Green, Liz Griffiths, John Hunter, and Frances Wright.

1. Welcome and Introduction

Derek Main welcomed everyone and started with the usual introductions: Derek has idiopathic CA since 18 months old, and he will be 50 next Monday, he has been associated with Ataxia UK (AUK) for 10 years or so. (Idiopathic means that the doctors don't know its origin). In the past Derek has been a Trustee of Ataxia UK and is now Chairman of the Branch.

John Reid from Hawick has Friedreich's Ataxia (FA) - he broke his legs 18 months ago whilst driving his horse and had to spend 8 weeks in hospital – but he's in a wheelchair already so made no difference. He does horse riding and fell off many times before being diagnosed.

Liz has Cerebellar Ataxia (CA), she's a Branch committee member and was trustee of AUK, she used to go down to London in her wheelchair, Pete dropped her off at Edinburgh airport, and she used the Gatwick Express & taxi. She also went to a meeting in Amsterdam with Euro Ataxia and does voluntary work in a charity shop for kidney research. Pete is married to Liz, was former Branch Chairman and has been involved with the branch for quite a few years

Penny is the Branch Secretary and Tina Thatcher is the Branch support officer with Ataxia UK.

Alan, Vicky's boyfriend, has come with her from Aberdeen to find out more and what they can do to help her Dad. Vicky is Jim's eldest daughter, she lives with her dad and they all muck in together. Jim Shepard from Aberdeen has just been diagnosed with CA, needs information and wants to see what he can do to help as well.

Gillian Scott is works for genetic interest group charity based in Edinburgh, she covers all of Scotland and hopes in time to get more staff & have more activity. She is a genetic counsellor and worked in Guys for a while.

2. Report of last meeting and matters arising

The report of the meeting held on 9 September 2006 was approved.

3. Gillian Scott on Genetic Counselling & the Genetic Interest Group

Gillian works for the Genetic Interest Group (GIG) and AUK is one of its funding bodies. There have been some recent developments in Scotland. GIG has been in existence for only 15 years, and was put together by 7 individuals who noted that lots of different genetic condition charity support groups existed and decided they would have a stronger voice by working together. Another aim of the group is to raise awareness of genetic conditions. Most GPs and many neurologists don't understand, so it is difficult to get pressure for improved services but though such conditions are rare, when people stand together there are very many of them and they have a stronger voice.

GIG influences patient voice & patient experience. Can help with decisions being made, eg by catching a politician at the right moment. It brings decision makers into contact with those experiencing the conditions, families etc. It is not a support group, but is able to deal with policy issues. Can issue press reports, help give some balance. GIG is trying to get patient voice into measurement of quality of service. There has been some success with this in England, but not yet in Scotland. Assessing quality of genetic provision eg access (stairs) can be slow but results are coming. GIG can also put different charity support groups in touch with other, so they can learn from each other eg in fund raising. Small number of staff UK wide (only 13) who speak to industry and government, for example on the Human Tissue Bill. GIG also has representation on many different committees. It produces many publications and can provide information or refer them to the right person. It also sets up workshops & questionnaires to gather information and present to politicians.

The website address for GIG is <http://www.gig.org> Increases in staffing are planned – 15 more genetic counsellors in Glasgow, 3 or 4 in Edinburgh, 1 in Aberdeen and 1 in Dundee. There will be improvements in education for GPs and neurologists, computer networks, laboratory planning. Gillian brought along a questionnaire to gather views of people directly and will put her PowerPoint file on website. We will put a link to questionnaire & GIG on the Branch website.

4. Treasurer's Report

Frances sent her apologies and Penny presented the report on her behalf.

Income (since last meeting 9th Sept)

Mr & Mrs Smith's regular monthly standing order of £10, a £20.00 subscription / donation from John Hunter, John Reid brought £10 from a

collecting can, £1 from the sale of Susan's Stories, a £10 subscription / donation from Winnie Walmsley, £16.80 from Derek Main's collecting cans at the Station Bar and a £25 subscription / donation from Ian McPheat
Total £82.80

Richard Thomson is still collecting money from his sponsored run so will let us know when he has a total (he hoped to be at the Branch meeting)

Expenditure

Branch expenses were: Cost of teas / coffees at Branch meeting £10;
Frances: sympathy / thank you cards over year bought on behalf of group, £8 and Penny copying reports of meetings, £31.50.

Total £49.50

Present bank balance will be (once the above is taken into account) + any interest approx £1150.00

Message from Frances: "Have a good meeting + I will get the updated copy of it from the website".

5. Mark White

It is with great sadness that we report that Mark White passed away on Friday 29th September, aged 37. He gained a BA Honours in Business Studies at Abertay University Dundee and worked in the assessors department of Tayside Regional Council and then for Allied Dunbar until his deteriorating health forced him into early retirement.

Away from work, he was involved with the training programme of the Advocacy Group, Dundee and was an active member of Headway and Ataxia Scotland as well as a volunteer with the Dundee Disabled Children's Group. He recently joined us on the Falkirk Wheel trip, travelling from Dundee. Our thoughts are with his family and friends.

6. Branch Christmas Meal

This had to be cancelled due to lack of support. We had not made a booking so no costs were incurred.

7. Secretary's Report – Branch Website News

The Branch website (<http://www.ataxia-east-scotland.org.uk>) has now had nearly 800 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. Penny has added a **ClustrMap** to the site which shows where in the world our users live – so far it includes people from North America, South America, Iceland, Turkey and Australia!

Due to the volume of spam being generated, all mail links are being removed from the website, apart from the two that link to the secretary: penny@ataxia-east-scotland.org.uk and info@ataxia-east-scotland.org.uk . The other links are disguised eg DerekATataxia-east-scotland.org.uk so if you type this in, replacing AT with the @symbol, it will work.

8. AOCB

There is a TV programme on BBC1 on Wednesday 8th November "One Life" featuring Kirsty Maddox who has Ataxia. Penny is recording this if anyone would like to borrow the DVD.

9. Dates of Next Meetings

The next Branch meetings will be held at Lasswade on 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 and Jack Blaik of Edinburgh City Council has agreed to talk to us again about the Direct Payments Scheme.

YOUR COMMITTEE

Chairman	Derek Main	0131 477 4371
	derek@ataxia-east-scotland.org.uk	
Secretary and Vice-Chair	Penny Gardner	0131 332 5218
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Treasurer	Frances Wright	0131 555 5665
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Committee Member	Liz Dalby	
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ADDRESS FOR MAILING:

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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

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