

**REPORT OF THE MEETING OF THE EAST OF SCOTLAND
BRANCH OF ATAXIA UK
LASSWADE HIGH SCHOOL CENTRE,
SATURDAY 21 JANUARY 2006**
<http://www.ataxia-east-scotland.org.uk>

Present: Rhona Brankin, Derek Main (Chairman), Penny Gardner, John Reid & Frances Wright

Apologies: Ronnie Browne, Pete & Liz Dalby, Eileen Gordon, John Hunter, Lesley and Andy Pringle, Jim, Essa and Lynn Quin, Peter Smeaton, Alan Smith and Anna & John Thomson.

1. Welcome and Minutes of last Meeting

The report of the meeting held on 21 November 2005 was approved – Penny apologised for spelling Rhona Brankin's name incorrectly, and will change it on the Branch website. The very small turnout was unexpected, due mainly to illness, many apologies having been received.

2. Secretary's Report – Branch Website News

The Branch website (<http://www.ataxia-east-scotland.org.uk>) has now had over 300 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

3. Report on Branch Christmas Lunch, Sunday 4 December 2005

10 people attended the meal at the Royal Terrace Hotel, Edinburgh. As we had to pay in advance for the 15 places booked at a cost of £14.95 per person, a small loss was suffered. However, since the meal was unsatisfactory and the toilet facilities inadequate, Penny agreed to write a letter of complaint to the manager in the hope that some refund may be forthcoming.

4. Treasurer's Report

Frances reported on the income and expenditure since the last meeting in November. Derek's brother David sent through another £50, our share of £100 from a member of the relay team who has moved abroad, making £443 in total from this fundraising event. £5 came from membership subs, £37 from Anne-Marie's knitting plus the Smiths are still making their regular £10 monthly regular donation. The two full cans from the last meeting: one from the Braid Hills Hotel (Derek) and the one from Sheree and James, totalled £39.01. Expenses included £15.20 for teas at the November meeting, £60.06 stamps and copying, and £34.35 deficit on the Christmas lunch. The bank balance including interest at 23rd December was £1,129.83.

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. Rhona Brankin MSP: Talk

Rhona is the Member of the Scottish Parliament for Midlothian and explained that she would be talking about the different roles of MPs, MSPs and local government councillors in helping people with disability and other issues.

Your **MP** (Member of Parliament at Westminster) can give advice and information on the benefits system, tax, passports and compensation eg to people in former mining areas. Rhona shares an office with the local MP and most of the MP's enquiries relate to benefits. The House of Commons website has MP details: <http://www.parliament.uk/directories/directories.cfm>

Your **MSP** (Member of the Scottish Parliament) can help with health issues – but it's important to try to resolve these first through the **NHS Board Patient Liaison Officer** (contact details are on the Health Boards' websites). If the Health Board doesn't sort out your problem, then your MSP could write to the Chief Executive – eg if you are having to wait too long to see a neurologist, first make sure your doctor has made it clear that the referral is urgent, if still not resolved then your MSP could help.

For issues with council services, eg aids, appliances, social work, direct payments, ramps, personal care etc – first approach the council, then your local **councillor** and if that does not work then your own **MSP** may be able to help. You must always contact your own MSP - information on who this is can be obtained from the Scottish Parliament, telephone 0131 348 5901. or <http://www.scottish.parliament.uk/msp/index.htm>

In summary, problems with:

Tax, Benefits, passports → MP

Health Issues → GP → Health Board → MSP

Aids, appliances, social work → Council → Councillor → MSP
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Rhona then explained several key issues. A local authority assessment is the key to ascertain ones needs eg aids and adaptations. How does your pattern of services work in practice? Personal and nursing care and support in your own home should give the maximum amount of independence possible.

There is a massive variation in local authority attitudes to Direct Payments, and a need to get more information out to people. Councils should be encouraging people to apply but some are more user friendly than others (eg Falkirk Council's website is particularly bad – it's almost impossible to find the Social Work pages, let alone Direct Payments information!). Of course, not everyone wants to take responsibility for Direct Payments and some people prefer to be provided with services as before.

A recent NHS care report states that you should have access to the same quality of health care wherever you live. However, this does vary throughout Scotland eg orthopaedics, hearing aids etc are better / worse in some areas than others. The key thrust is the recognition that people have a variety of different needs and should be maintaining their health and avoiding having to go into hospital for acute problems. Direct Payments can help with this. A range of services, eg physiotherapy, access, showers etc are needed locally and make up the elements of the care package. Clinics need to get their waiting times reduced.

Neurological alliance work recognises that we need to get smarter at dealing with the range of conditions. People need access to the most appropriate / knowledgeable specialist for their condition, to get the most up to date treatments and to get tablets prescribed appropriately. Even among our Branch members there is variation in whether people have to pay for supplements or not. With rare conditions it's important that the health professionals drawing up the care packages eg nurses and care workers understand the neurological condition.

Wheelchairs have been a 'Cinderella' service up to now – there's a review of this service ongoing. Rhona also has information about additional support for learning; if anyone needs it she will be pleased to pass on information to the Branch committee. We also discussed access issues in education.

Finally, Rhona offered to arrange a visit to the Scottish Parliament for our members. If we know the names of those visiting in advance, she can arrange for all the local MSP's to be present to meet their constituents. Neurologists could be invited as well, eg Professor Robert Will, Dr Brian Pentland and Dr John Womersley. This could provide an opportunity for us to raise awareness of ataxia – and possibly gain publicity in the local / national press? The MS society organises such an annual event – we could ask to join with them or hold a separate event – the latter might be better for publicity purposes.

Rhona was thanked for her interesting and informative talk.

6. AOCB

A new guide for disabled drivers, called 'Get Motoring' has been published by RADAR, the disability rights campaigning organisation. It outlines the stages when considering buying or leasing a new car and explains the financing options. It is available directly from RADAR on 020 7250 3222 or via Disability Living Centres, shopmobility centres and Motability car dealerships in the UK.

7. Dates of Next Meetings

The next Branch meeting will be held at Lasswade on Saturday 11 March 2006 and the AGM is booked for Saturday 6 May 2006.

YOUR COMMITTEE

Chairman

Derek Main 0131 477 4371
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Secretary and Vice-Chair

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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.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