

**REPORT OF THE MEETING OF THE EAST OF  
SCOTLAND BRANCH OF ATAXIA UK  
LASSWADE HIGH SCHOOL CENTRE,  
SATURDAY 24 JANUARY 2009**



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

**Present:** Derek Main (Chairman), Ronnie Browne, Liz & Pete Dalby, Penny Gardner, John Reid, Jim Shepherd, Tom & Doreen Vandeppear & Frances Wright,

**Apologies:** Andrea Bothwell, Rhona Brankin, Anne Green, John Hunter, Richard & Anne-Marie Thomson, Andy Hogg,

### **1. Welcome and Minutes of last Meeting**

Derek welcomed everyone and we all made the usual introductions. The reports of the May AGM, and September and November 2008 meetings were approved. These are all on the Branch website and hard copies were posted out just before Christmas. Derek gave a special welcome to our Branch Patron, Ronnie Browne.

### **2. Chairman's Reports**

Derek thanked everyone for coming. He announced that reflexologist Susan McVicker is coming along after the tea break and the first aid suite downstairs is booked for one to one treatments, paid for by the Branch.

According to BBC website and news stem cell research has arrived at a critical stage in Southern General Hospital in Glasgow. But as Derek reminded us, many years ago when we had our speaker on the topic, it's an ongoing thing not the solution to everything – still in the very early stages and unproven. They are trying treatments on stroke victims at the moment. The next stage, in mid 2009, they will be looking for volunteers. Also Barak Obama signed yesterday to allow it to go the next level in the USA.

Derek was called as a volunteer by the ERI to go along for 3<sup>rd</sup> year medical students to tell them about problems that ataxians have – he's going on Monday 26 Jan. He feels that the more doctors know about the problems we have, the better. Anyone else wishing to volunteer, please notify Prof Will at the Western General on 0131 537 2115 / 536 2000.

### **3. Treasurer's Report**

Since 15 November, there has not been a lot of change. Income: Mrs Scott & husband sent a fund raising cheque of £430 from their Halloween party, and a donation of £211.30 from their Mum in law's funeral. Total £641.30. Also £20 from Mrs Scott in lieu of sending Christmas cards

Derek made a £10 donation. The collecting can money from the Nov meeting has now been counted: Tom and Doreen's wee box and the 2 cans from Lasswade contained £26.25. The quarterly bank interest was £10.21 – much better than we used to get from HBOS. Also the usual standing orders came in at the beginning of December and January from Jim Shepherd's daughter £10 and Mr & Mrs Smith £10. Anne-Marie Thomson has been knitting for fund raising, She could do with donations of wool, old quilts to unpick etc.

Expenses were £15 reflexology / massage charge for a member and expenses of £107.60 from Penny for copying and stamps.

The current balance at the bank is £1,988.07. Derek suggested sending £1,000 donation to Ataxia UK Head Office – this was agreed. If anyone wants to set up a direct debit for donations please contact Frances on 0131 467 9023.

#### **4. Haggis, Neeps and Tatties**

Frances read the last verse of Robert Burns' "Address to a Haggis" and we enjoyed Haggis Neeps and Tatties prepared by the catering staff at the Centre. Then Ronnie read part of "the Auld Farmer's New-Year Salutation to his Mare".

#### **5. Susan McVicker**

No one remembered to contact Susan to confirm her booking, so we'll need to organise it for the March meeting. Maybe a flyer with the meeting report for people to book a treatment.

#### **6. Social Events**

The Branch Christmas meal at the Laird and Dog on 15 November 2008 following the meeting was a great success. If anyone has other ideas for social events, please ring Derek on 0131 477 4371.

#### **7. Any Other Business**

Derek suggested a possible speaker from ERI at March meeting: Dr Bryan Allan. He will ask when he sees him next Monday. Dr Bryan is the Simulated Patient co-ordinator at the College of Medicine and Veterinary Medicine at University of Edinburgh - overseeing the examination for junior doctors. Doreen has an idea for a speaker from VOCAL in Johnston Terrace (Voice of Carers across Lothian). A nurse whilst dressing a wound suggested it.

We then discussed the problems with getting housing adaptations eg ramps and aids such as walkers. If you own your own house you have to

pay for whole cost. If you are disabled, it is important to apply for help before you are 60, because afterwards you can't get it.

The benefits of hydrotherapy were mentioned – being able to walk in water, The Astley Ainslie treats people one to one in their Special pool with a high temperature (NB you must be referred by your GP or physiotherapist). There is also believed to be a public one at Prestonpans .

### 8. Dates of Next Meetings

The next Branch meetings will be held on Saturday 14 March, Saturday 9 May (the AGM), Saturday 12 September and Saturday 14 November 2009 at Lasswade.

### YOUR BRANCH COMMITTEE

Chairman: Derek Main		0131 477 4371 <a href="mailto:derek@ataxia-east-scotland.org.uk">derek@ataxia-east-scotland.org.uk</a>
Secretary and Vice-Chair: Penny Gardner		0131 332 5218 <a href="mailto:penny@ataxia-east-scotland.org.uk">penny@ataxia-east-scotland.org.uk</a>
Treasurer: Frances Wright		0131 467 9023 <a href="mailto:frances@ataxia-east-scotland.org.uk">frances@ataxia-east-scotland.org.uk</a>
Committee Member: John Reid		<a href="mailto:johnreid@ataxia-east-scotland.org.uk">johnreid@ataxia-east-scotland.org.uk</a>
Committee Member: Liz Dalby		<a href="mailto:liz@ataxia-east-scotland.org.uk">liz@ataxia-east-scotland.org.uk</a>
Email committee Member: Susan McPheat		Contact through: <a href="mailto:susan@ataxia-east-scotland.org.uk">susan@ataxia-east-scotland.org.uk</a>

## USEFUL WEB LINKS

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

[www.ataxia-east-scotland.org.uk](http://www.ataxia-east-scotland.org.uk): our Branch website

[www.ataxia.org.uk](http://www.ataxia.org.uk) the Ataxia UK website, it has many good links.

[www.ohbother.co.uk](http://www.ohbother.co.uk): by an Ataxian and full of very useful information.

[www.bbc.co.uk/ouch](http://www.bbc.co.uk/ouch) for an inside view on disability news.

[www.evoc.org.uk](http://www.evoc.org.uk): for local disability information in Edinburgh.

[www.digg.org.uk](http://www.digg.org.uk): Glasgow's online resource for disability information.

[www.gig.org.uk](http://www.gig.org.uk) Genetic Interest Group

[www.matchinghouses.com](http://www.matchinghouses.com): re: accessible holiday house swaps.

[www.skill.org.uk](http://www.skill.org.uk) information & advice for disabled students

[www.simr.org.uk/pages/news/index.html](http://www.simr.org.uk/pages/news/index.html) seriously ill for medical research

## ADDRESS FOR MAILING:

East of Scotland Branch of Ataxia UK,  
Penny Gardner, Branch Secretary  
3 Craigleith Gardens  
Edinburgh EH4 3JW

## 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, 55 Carrick Knowe Road, Edinburgh EH12 7BN.