

**REPORT OF THE MEETING OF THE EAST OF
SCOTLAND BRANCH OF ATAXIA UK
LASSWADE HIGH SCHOOL CENTRE,
SATURDAY 17 SEPTEMBER 2011**
<http://www.ataxia-east-scotland.org.uk>



Present: Pete Dalby (Chairman), Ronnie Browne, Penny Gardner, Derek Main, Liz Dalby, John Reid, Tom & Doreen Vandeppear, Tina Thatcher and Frances Wright.

Apologies: None

1. Welcome and Minutes of last Meeting

Pete welcomed everyone to the meeting, especially Tina Thatcher, the Ataxia UK Branch Development Officer who came to talk to us.

2. Ataxia Awareness Day 25 September 2011

We planned to have a stall at the Gyle, but unfortunately after a lot of hard work from Pete, it was decided to cancel it. There was just too much red tape – we had to be there from 8am – 8pm with many forms to complete, street trading license required etc. Just too much hassle and paperwork.

3. Circulation Booster Machines for Loan

At the last meeting it was agreed that Tom & Doreen would get 2 circulation booster machines, using the Branch funds that are ring fenced in Scotland. The Circulation Booster machines cost £166.66 each, total £333.32. These are for loan to members who can try them out between meetings and decide if it's worth buying one themselves. Tom got them so the price was VAT free.

They will be on loan between meetings & returned for others to try. Booklets mentioning maintenance / cleanliness should be provided. The Pharmacist (Lloyds) is very interested to know how everyone gets on. Pete agreed to devise an extra instruction sheet and a feedback sheet. Those borrowing the machines need to sign a disclaimer.

4. Treasurer's Report

Frances reported that, since the May AGM, Mr & Mrs Smith had made their regular £10 donation each month, £40 total. Also, an anonymous donor made 4 payments of £15 = £60. Bank interest received was 64p! Tom & Doreen gave £30 at barge trip in August; £20 from Doreen & £10 from Mrs Moody whose sister died suddenly. Total received was £130.64. Frances said we can now pay in through RBS branches, which is much easier than having to go to the only HSBC branch in town.

Expenditure since May included paying for the registration fees for the 5 members who went to the conference in Glasgow on 2 July, £20 each, total £100 John, Maria, Pete, Liz & Frances got lost a few times and had a flat tyre but got there in time. Since then, we've been in touch with Ataxia Central Office to ask for transcript of meeting. The CD came but cannot be played – we'll be checking on this. There is also a written script, which will be edited, available later. Everyone reported that the Conference was very good.

Other expenditure was £14 for teas and coffees at the last meeting and £24 for stamps, total expenditure since May = £137.

The balance at the bank was £2920.74 yesterday (16th September).

Frances recommended that we make a £50 donation to Seagull Trust as thank you for putting on the (free) barge trips + teas and coffees. This was agreed. Tina Thatcher suggested submitting a little story for the Ataxian magazine with photos.

5. Tina Thatcher, Branch Development Manager of Ataxia UK

Tina handed everyone post-its and asked us to write down what we felt were the benefits of belonging to a branch. Answers included 'making and meeting friends' 'getting information about ataxia' 'sharing ideas' 'relaxing and having fun'. Clearly, there are many benefits – but how do we tell the others about it? The people who do not or cannot attend a meeting? We need to get more people to the meetings and/or involved and benefitting from their membership.

Why do people not come along? Maybe there's a reluctance to come the first time? Perhaps a lack of publicity – there's little on the radio or in the media. Look out for the Radio 4 appeal in October – though local radio stations may be better in Scotland.

We tend to email information – or send out written minutes – but we need to let people know that they can claim their travelling costs to get to meetings if the cost would otherwise mean they cannot attend (we allocate a small fund for this purpose). Penny said that she forwards Tina Thatcher's information to all branch members by email where relevant but no one ever responds. Branch committee members / honorary officers can claim travel expenses when representing the Branch or Ataxia UK at an event such as a neurological alliance meeting.

How did people find out about the Branch originally? Doreen and Tom found out through Professor Robert Will – who encouraged them to get in touch with Derek. Everyone agreed that it's nice to meet other people with

ataxia, no one is the same. Some folk might prefer not to have face to face meetings. Apparently there is nothing about Ataxia on notice boards in the hospital; they were there at the Western but were taken down.

How do we publicise the branch? No AUK funds are available for mass advertising, which is dreadfully expensive. They want everyone in the branches to do it on a more local basis. How can we get publicity for our branch? Local paper – local radio – Patsy Riggs at Ipswich & Dave Stobley at Ataxia South East are always getting their branches reported in local media - how do they do it? Evening News in Edinburgh? Metro?

Raising awareness is fundamental part of local branches. Tina suggested that we look at organising an awareness & publicity campaign. One in Leicester used posters on the back of buses. We should put together a campaign of our own. List where – we can get posters from Central Office size A4 or A3 – where do we want to go to? Posters or leaflets in local libraries, doctors' surgeries, neurologists? We could download the GP guidelines and send a hard copy with covering letters from the branch. The personal approach is much more effective than a blanket mailing ie call in and talk to someone about it, hand over the letter & leaflet. Wording could be 'Do you have any patients with ataxia? We enclose a copy of medical guidelines & please refer them to us.' Face to face approach is better, much more likely to get a positive response.

We need to reach all the people with Ataxia out there who don't know about us – how many are there?

Liz has late onset CA. She said that she came to the first meeting age 39 with her friend – pushed the door open and saw all the people in there – wanted to turn round & go home but her friend pushed her in and she's never looked back.

We could revive the idea of a contact list – everyone has to give permission to share contact details eg email, phone number. Branches & support groups who do that find that if someone is having a low day, they can phone someone in between meetings. One to one encouragement is so important.

We may be able to apply for external funding /grants to get people to meetings. From the mailing list identify people from areas further out who could meet if it was nearer. Perhaps move our venue occasionally so other people can come – or have less formal meetings in between our main ones. We could also host a joint event / get together with the Glasgow Branch – it's our turn to do this.

Fund raising can be on any scale - coffee mornings, home baking, home made jam, unwanted Christmas presents. Doreen's Quiz.

We need to give our Branch a focus – a plan for the year. We could set the amount of fundraising we want to achieve or a target figure – how are we going to do it? We need a fundraising organiser on the committee – it could be someone who doesn't come along that has these skills. We need to make plans for speakers, outings & events; allocating tasks and getting volunteers. We would be better motivated because there is a focus.

Some fund raisers send it straight to Central Office so the total may not be apparent. Do we have a representative on the local neurological alliance? Tina is a member of NeuroNet, an organisation in the West Midlands: one of its activities is training social workers, raising their awareness. In some areas people with ataxia volunteer to be 'guinea pigs' for trainee doctors - Derek & Liz both do this. Hospital staff can know nothing about it – maybe nurses need training too?

Ataxia UK have a 10 minute presentation, suitable for schools, colleges, and universities; talking about ataxia. The speaker, if not an ataxian, needs someone with ataxia to go along too. There a project for young people at the October conference in Leicester, making a film. Tina is hoping to encourage as many youngsters as possible to go along. Ronnie will speak to his daughter who works at Watson's – get it into the School magazine.

Action – Penny to pass on the presentation when received from Tina

Local free magazines newspapers – maybe we get some content into them? New fundraising pack – get hold of it. Might be on website. It has lots of ideas.

Tina's final advice – we need to make notes of ideas – talk about them – prioritising things ie what will we do in the next year? What will have the biggest impact?

6. Social Events and Fundraising

More ideas – people can sell things on EBay & donate to AUK.

Branch Officer's weekend is planned for April 2012 in Leicester University Friday – Sunday, it will be free. Travel costs can be claimed back. Share ideas, training, updates to branch guide. Please send a member as a delegate if no committee members can come. Details are to be notified end Jan/Feb.


Doreen agreed to be co-opted on to the on committee. We arranged to hold a committee meeting on 5 Nov at Doreen's, 2pm.

7. Dates of Next Meetings

Date of next Branch meeting is 19 Nov – we'll again have a meal afterwards but with a change of venue to the Polton Inn which is fully accessible (the toilets at the Laird and Dog Inn where we've been for the last few years are very awkward and inaccessible).

We discussed the Jan & March dates. These were agreed as 21 Jan & 24 March 2012.

YOUR BRANCH COMMITTEE

Chairman: Pete Dalby		info@ataxia-east-scotland.org.uk Please put 'for Pete Dalby' in the subject line.
Secretary and Vice-Chair: Penny Gardner		0131 332 5218 penny@ataxia-east-scotland.org.uk
Treasurer: Frances Wright		0131 467 9023 frances@ataxia-east-scotland.org.uk
Committee Member: John Reid		johnreid@ataxia-east-scotland.org.uk
Committee Member: Liz Dalby		liz@ataxia-east-scotland.org.uk
Social Events: Derek Main		0131 477 4371 derek@ataxia-east-scotland.org.uk

USEFUL WEB LINKS

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

www.ataxia.org.uk the Ataxia UK (AUK) 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

<http://www.vocal.org.uk> VOCAL

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

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, 9 Colinton Mains Terrace, Edinburgh EH13 9AT