

**REPORT OF THE MEETING OF THE EAST OF
SCOTLAND BRANCH OF ATAXIA UK
LASSWADE HIGH SCHOOL CENTRE,
SATURDAY 14 NOVEMBER 2009**



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

Present: Derek Main (Chairman), Rhona Brankin, Tony & Mary Callow, Liz & Pete Dalby, Penny Gardner, John Reid, Richard & Anne-Marie Thomson, Tom & Doreen Vandeppear, Chris & Fiona Wragg, and Frances Wright,

Apologies: Andrea Bothwell, Ronnie Browne, George Foulkes, Anne Green, John Hunter, Susan McPheat, Jim Shepherd.

1. Welcome and Minutes of last Meeting

Derek welcomed everyone, especially the four new members, Tony & Mary and Chris & Fiona. We all made introductions and everyone explained their connection to ataxia. Tony is from Falkirk and has cerebellar atrophy and Fiona's Mum has CA. Tom has had spinal CA for 15 years, Derek has had CA for 53 years, Liz has CA (SCA8) and John has FA.

2. Chairman's Remarks

Derek commented on the good facilities offered by Lasswade; they are always very friendly and helpful. He then explained to the new members how the Branch runs & what we do with money that comes in etc. He then introduced our speaker, Rhona Brankin who is the MSP for Midlothian.

3. Speaker: Rhona Brankin

Rhona promised to spend no more than 1 hour talking about politics! She is very interested in and concerned about children's life chances. She used to be a teacher in Primary & Secondary and spent time as a support teacher. She identified barriers to learning, including learning disabilities, physical impairments, difficulty in accessing education. She has lectured in education in Aberdeen & Dundee and believes everyone should have the best education; unfortunately many have not. She went into politics to try & do something about it. Acquisition of language & literacy skills is vitally important – far too many children are leaving school without going into education, employment or training. Too many have no opportunities opened up to them. Not all but many; the educational system has let them down. They come into nursery or school with poor communication. They need targeted help with these skills; otherwise they will always be at a disadvantage. Though we have in Scotland a good reputation for teaching, other countries are catching up with us.

Literacy: Scotland is still doing OK, but by the time they reach P5 if the gap isn't addressed it continues to widen all through the rest of their school

lives. Many leave who have not reached functional literacy. Ability to learn is OK but the skills are missing, for example in literacy and numeracy. These are everyday skills which we all need to function in society. Rhona set up a working group including Professor Tommy McKay, to work in West Dunbartonshire (a very mixed area) to enable functional literacy over a 10 year period. They achieved it – everyone signed up to it, the schools and the parents. Literacy was the key thing and 97% achieved it. A literacy commission has been set up by the Scottish Parliament which will be reporting at the end of December – they plan to make Scotland the first country in world to eradicate illiteracy. The Government MUST sign up to it.

Schemes to support parents are available. Get them involved in the literacy programme with support for their own literacy. The West Dunbartonshire programme didn't cost a lot, it was about setting priorities. Class sizes can have an impact, especially on younger kids, but a good teacher is the most important. Having a specialist literacy teacher is the most important factor. The current government doesn't ring fence the money. Can inspectors make literacy levels a priority?

Frances asked if Rhona's duties have changed? She is now involved with additional support for learning and the legislation for disabled parking about how it will be implemented; she can send an update.

Tom & Doreen said they have a taxi card and hoped to use it while on holiday. It normally costs £22 to the airport but with the taxi card they charged £25 Bluebird at Gilmerton added £3 on then took £3 off so no saving was made and they cancelled the booking. Made arrangement with City Cabs for the 3.30am pickup – it was much more helpful as the driver brought the car into their drive. Bluebird turned up in spite of cancellation 2 days before. At the airport they were charged £10 because Tom needed assistance and had to go to the counter. Globespan charged £20 extra for assistance.

Rhona said that she could arrange another visit to the Scot Parliament in the New Year. We all thanked her for an interesting and informative talk.

4. Treasurer's Report

Since the September meeting, income has been the usual Standing Orders from the Smiths and Jim S's daughter, totalling £20 pm. Tom & Doreen brought along donations from their friends of £50 & £20

Expenses were £12 for teas & coffees at the September meeting. The balance at the bank is currently £818.96. Head Office has sent a thank you letter for the £2,000K donation in October, which included Andrea Bothwell's £1,000 birthday donation.

5. General Discussion

There followed a general discussion on diagnoses, symptoms and treatments:

Tony said that his diagnosis in 2006 of cerebellar atrophy didn't mean anything (it just describes the symptoms of ataxia). His mother died of MS but that could have been ataxia. His Neurologist has now retired; he receives no after care, and has been told there is nothing he can do. Finally he was referred to Falkirk Royal to see physiotherapists and occupational therapists and was given an information pack which gave a contact number for Ataxia UK, from there learned about the Branch. He thinks it's brilliant and is not alone any more. When he rang AUK they gave him Derek's number.

Tom has been attending Edinburgh University seeing Dave & Jon (who told us about their research in 2008); it's been excellent. Jon is going to the Ataxia conference in Germany. Doreen contacted Professor Will who saw Tom and confirmed that he does have spino-cerebellar ataxia. He found out that Tom's files in archives at the Western General from his first visits 15 years ago have since been destroyed. They were shocked. At the time they said nothing could be done so don't go back. Tom is spending 3 hours at a time at Moray House, has discovered that using a walker is the worst thing possible, walking poles are much better.

There is a new specialist unit in Sheffield dealing solely with ataxia.

Fiona's mum age 74 has just been diagnosed with ataxia. GP referred her to a neurologist in Glasgow where she had tests including a lumbar puncture and SCA6 was diagnosed. She was told: "We can't do anything; come back if you feel worse". Fiona's Dad is the carer. They were not told about any aids, counselling or support. Fiona's Mum is not ready to go to a meeting yet.

5. Social Events

Meal tonight (14 November) at the Laird & Dog in Lasswade will follow on from the meeting.

6. Dates of Next Meetings

The next Branch meetings will be held on Saturday January 23, Saturday 13 March and Saturday 8 May 2010 (the AGM) at Lasswade.

YOUR BRANCH COMMITTEE

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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

www.simr.org.uk/pages/news/index.html seriously ill for medical research

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

ADDRESS FOR MAILING:

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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.