

**EAST OF SCOTLAND BRANCH OF ATAXIA UK
MEETING HELD AT LASSWADE HIGH SCHOOL CENTRE
ON SATURDAY 22 JANUARY 2005**

Present: Andrea Bothwell, Ronnie Browne, Liz & Pete Dalby, Penny Gardner, Andrew Hogg, John Hunter, Derek Main (Chairman), Isabel Purdie, John Reid, John & Anna Thomson and Frances Wright.

Apologies: Peter and Mary Case, Bob Greenhalgh, Alan Smith and Alison Wood

Introduction by Chairman

Derek welcomed everyone, especially **Ronnie Browne** as our Branch Patron. Ronnie stated that he is still happy to be our Patron: when we originally asked him he was high profile and could attract the Press. He's been retired for two years now and Pat, his wife, is not very well but sends her regards. We were also all very pleased that Andrea had been able to attend and John and Anna Thomson whom we had not seen for a long time.

Derek showed samples of a **new CA leaflet** produced by Ataxia UK. There will be more news on this at our Branch meeting but at first glance it seemed very useful and informative, however the size and style of the typeface are not easy to read and it is hoped that an accessible version would also be available.

Professor Robert Will of the Western General Hospital has agreed to speak at our next Branch meeting on March 19. He's a neurologist and plans to speak about the issue of Ataxia in CJD, which is his specialism. Although not directly related to FA and CA, it will be an interesting talk and Derek encouraged as many people as possible to attend.

Tragically, Jayne Fanshawe whom some of us met at the conference last July, has died. We plan to send a sympathy card to her Mum on behalf of the Branch. George Brockie had phoned to say that Isabel is not at all well and has had to move to a care home.

Website News

Pete Dalby had made a suggestion to Head Office that they include some information about Branches on the main **website**. This is now taking place and we have been contacted for basic information for them to include. Emails will go first to Head Office so they can be screened, then sent on to us. Eventually we will be given the facility to update information ourselves.

Some of the **web links** given in the last report were inaccurate, the corrected list is: www.obother.co.uk produced by an Ataxian and full of very useful information, www.bbc.co.uk/ouch for disability news and www.evoc.org.uk for local information. Glasgow has an online resource for disability information at www.digg.org.uk . Also information on accessible holiday house swaps: www.matchinghouses.com and not forgetting the Ataxia UK site: www.ataxia.org.uk

Derek has the list of **members' email addresses** and will pass this on to Penny so electronic versions can be sent where preferred.

Treasurer's report

Frances reported that we had made a donation of £2,000 to Ataxia UK and did eventually get a receipt for this after reminding them. This was too late to be included in the Ataxian magazine but we have been promised it will be in the next one. Teas and coffees at meetings cost £8.40.

Income included the regular standing order donation from Mr & Mrs Smith (friends of Richard and Anne-Marie), £45 in members' subscriptions and £42.12 from collecting tins. The bank balance stands at £1,065.50.

Members' Sporting Achievements

Two of our Branch members have won awards recently for their sporting achievements in the Borders. We offer them our sincere congratulations.

John Reid was given the James McLean Trust **Celebration of Sport 2004 Performance Award**, for his horseriding, curling and carriage driving. He was also able to take part in the Common Riding. There were two people nominated and the committee couldn't decide, so both got one.

John Hunter was given a slightly different award: The **Borders Sports Personality of the Year**. He has been encouraging people with disabilities to take exercise and talking about what we can do and what we can achieve. He's been taking an active part in curling at Kelso, training youngsters participating in wheelchair racing. He finds it gets you out, socialising, talking and meeting people with other disabilities.

John explained that using the **racing wheelchair** (which he raised funds to buy) is therapeutic, propelling with your hands is good exercise and keeps your hands going. Through Scottish disability sport he has been to Glasgow and met the Great Britain athletes for wheelchair training – by training harder he's improved his co-ordination. He entered the 2004 championships and got **2 Gold medals** – in the 100m and the 200m. In all he got 3 Gold medals and 3 Silver. The sport has given him mobility in his upper body and great self satisfaction.

John has also been to the **British Championships** in Birmingham, representing Scotland. He says “Have fun, enjoy yourself. The encouragement you get from everybody is out of this world”. It’s about what we CAN do, no need to compare to the ‘standy uppies’ – there’s tremendous support from the public, who see the person, not the disability.. John’s had good positive backing from everyone and likes to brag about it! He’s planning to take part in a 100m road race in October and has started some voluntary work, acting as Convenor of the Borders Disability Forum.

Intermission

There was then a break when everyone enjoyed a meal of haggis, neeps and tatties.

Fund Raising

Derek has a stock of **collecting cans** which can be placed in work, homes, shops, pubs etc. Please let him know if you would like one or more: 0131 477 4371.

The **Blackhall Framing Gallery** is making a donation to Head Office of £1 for every picture framed this year. Their son has Ataxia and wants to be an archaeologist.

Derek’s brother David is doing a **run in June** along with four other people, we’ll be sending out sponsor sheets and hope everyone can collect some cash. Even a small amount soon adds up.

We’ll be taking part again in the **Great Scottish Walk** in Edinburgh in June, last year we raised about £1,000 from this event, sponsor sheets will be available for these.

Derek plans to repeat his **mile walk on the treadmill** at the end of July / beginning of August and asked for others to some along and join him: Liz immediately offered to do the same. We could see if anyone from the West of Scotland Branch was interested and make it a joint event. If enough people take part it might attract some Press coverage. (continued over)

Social Events

Several possibilities were discussed:

A **Barge Trip at Ratho** in August (organized by the Seagull Trust), which is another possibility for a joint event with the West. Frances agreed to look into this and to contact Anne Mitchell. There could be a **BBQ** at Dalkeith Park or Almondell. These are usually popular family events. Penny will check this out and suggest possible dates.

We hope members will tell us their suggestions for **social events**, possibly a joint event with the Glasgow branch.

Other matters

Any member of Ataxia UK can apply for a '**Friends of Ataxia**' card, which explains the symptoms of Ataxia: ring Head Office on 0207 582 1444.

Head Office is looking for articles for the **Ataxian Magazine**. Frances, John Reid and John Hunter all agreed to write something.

Dates of Next Meetings

The next Branch meeting will be on **Saturday 19 March** and the AGM is set for **Saturday 14 May**, both at Lasswade. Professor Robert Will has kindly agreed to give a talk at the March meeting. We hope to get a good turnout at both. If anyone has ideas for **future speakers**, please let us know. If anyone is willing to help out on the **committee**, please let Derek know.

Branch Contacts are: Derek Main (Chairman) 0131 477 4371 or Penny Gardner (Secretary) on pennygardner@btinternet.com

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

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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 _____