REPORT OF THE MEETING OF THE EAST OF SCOTLAND BRANCH OF ATAXIA UK LASSWADE HIGH SCHOOL CENTRE, SATURDAY 22 SEPTEMBER 2007

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

Present: Derek Main (Chairman) Ronnie Browne, Sheree & Michael Allan, Penny Gardner, John Hunter, Nikki Joule (Ataxia UK Focus Group Facilitator), Sue Millman (Ataxia UK Chief Executive), Jim Shepherd, Peter Smeaton, & Frances Wright

Apologies: Andrea Bothwell, Rhona Liz & Pete Dalby, Liz Griffin, Faye & Andrew Hogg, Anne Green, Janice Heath, Jessie & James Quin, John Reid (horse riding), Alan Smith, Laura Stewart (Ataxia UK). Richard & Anne-Marie Thomson and family (in Florida).

1. Welcome and Minutes of last Meeting

Derek welcomed everyone especially the two guests from Ataxia UK (AUK): Sue Millman who has been Chief Executive for three months, Nikki Joule who would be running the focus group discussion and Ronnie Browne who described himself as our 'aging patron'. Derek explained that he has has CA for 49 years, having been diagnosed at 14 months. The report of the Annual General Meeting held on 12 May 2007 was approved. Pete and Liz were unable to attend but sent the news that Pete is doing well, recovering slowly from his illness.

2. Treasurer's Report

Frances reported the changes since the May AGM:

Income included sales of goods: 15 ties for £75, members' subscriptions £40, the usual standing orders from Claire Shepherd and the Smiths (£10 per month each), a £40 donation from Mr & Mrs Quin and a cheque from the 154th Scout Guild of £250, Penny's miscellaneous collecting cans £60 and bank interest to the end of August £15.38. The bank balance at 21 September 2007 was £1,400.81.

Expenses were teas and coffees at the May meeting £7.20, copying charges and postages £84 and we made a donation to Head Office of £1000. The Bradford support group are also interested in using CAF Bank and information would be sent to them.

Derek said that a substantial donation would be coming from the local Masonic group shortly, in excess of £1,000 – to be used in Scotland for social events, so this will be ring fenced in the accounts. One possible use would be for members' expenses coming to the Scottish Parliament visit in November. Sue Millman said we could also use it to enable members to attend events. Other suggestions were for attending Ataxia UK events eg the children's event at Alton Towers in March 2008.

3. Ataxia UK – Sue Millman and Nikki Joule

Nikki Joule said that AUK would pay for the cost of refreshments at this meeting and would also reimburse members' travelling expenses. Forms for this were handed round. Sue asked if we would be interested in a mini Ataxia UK conference in Scotland and the consensus was 'yes'.

Sue also informed us that AUK is abandoning its members subscriptions scheme and will be asking for donations from members instead. We told her how good Tina Thatcher (our Branch Support Officer) has been at keeping us informed about AUK and Branch matters. In general, communication with AUK staff has much improved. When Tina started AUK had 10 branches and 2 support groups; we now have 26 in all, 12 branches and 14 support groups, with a few more in the pipeline too. Hopefully some of the support groups will convert to branches in due course. All are asked to encourage their members to become members of AUK as well.

Sue Millman explained that the number of research projects funded has increased from 10 to 22. There have been a few breakthroughs but it is a slow process and will be many years before therapies can be developed. Stem cell research is still uncertain and apparent results may be due to a placebo effect. AUK received a legacy of £700,000 which has helped the funds. She asked how much AUK should prioritise research v care activities? For example, care includes the help line and specialist staff member for benefit problems, who already has a waiting list. People when first diagnosed may have more interest in research but later on they might feel that care activities are more important.

Awareness in very important as very few people have heard of Ataxia. How do we ensure a campaign is successful - about 10,000 adults in the UK have it. International awareness day on 25 September 2008 will include a competition with 10,000 balloons being released across the UK. The 2008 conference will be the second weekend in October at Stanstead (a much better venue than we had in 2007).

4. Focus Group Discussion

This will be reported briefly as members were having a frank discussion about their problems and experiences with diagnosis and the medical support after diagnosis for people with Ataxia. AUK knows anecdotally that it's a problem area but needs to research and report it formally before it can be used to push for better services. The research report will be totally anonymous and we'll be given a copy when it is published (a summary in May 2008 and the full report later in the year). This fits in well with AUK's plans as the Corporate Report runs out in May 2008 and a new one will be needed.

Nikki used to work for a neurological alliance and this was the first time she encountered Ataxia and AUK. Since then she has worked a lot with people with ataxia. Everyone explained briefly what type of Ataxia they have and how long ago they were diagnosed.

Members' experiences discussed included initial diagnosis and the treatment received from hospital doctors, nurses and GPs. Some people were informed in a sensitive manner, others received a blunt diagnosis with little or no support offered. Some members said there was a family history of ataxia, often not realised until they had it themselves – eg finally understanding why mother or granddad had used a wheelchair and had speech problems. Others found family members took a 'head in the sand' approach to their diagnosis.

Day to day problems included being thought of as drunk, finding out about and getting access to helpful drugs and physiotherapy, Insurance for travel can be difficult to obtain (BA insurance recommended here as OK so long as you disclose your condition, also SAGA insurance). All members have regular appointments with a neurologist – keeping fit can mean fewer visits are needed – or people can be signed off with an 'open door' policy if they need to go back, Maybe in these cases there should be an automatic recall after a number of years? It can be useful to be referred to a geneticist, speech counselling, physiotherapist but often you have to ask for this. Sometimes an operation might be suggested as a solution to problems.

Nikki explained that is an information resource for health professionals and the Brain and Spine Foundation has an information access toolkit on their website (http://www.brainandspine.org.uk/helpline/index.html). There is a new Ataxia centre at Sheffield Hallam hospital where the clinic has everything you need: neurologist, speech therapy, physiotherapist and a specialist nurse in Ataxia (3 days per week). AUK wants national cover by Ataxia centres – there's accommodation and office space in Glasgow but no staff available or funded yet.

Finally Nikki asked people to think about these questions: "What was it like when you were diagnosed – could you understand what you were being told?" and "What is an acceptable time to wait for a diagnosis?". 2 – 3 years seems to be the average but 6 months would be the ideal.

Following these focus group discussions and report, AUK intends to prepare guideline for medical professionals to address the issues and problems.

5. Social Events

We are planning a Branch meal out at the Laird and Dog in Lasswade on Saturday 17 November, immediately following the Branch meeting. What other activities would members like to attend?

Sue's suggestion of a Scottish mini conference was discussed and Stirling University suggested as a central location - maybe a Saturday afternoon / Sunday morning in 2008.

6. AOCB

- We were informed of the sad loss of Ernie Heath, past Chairman of AUK, who was diagnosed with Motor Neurone disease in January and passed away in April. Our thoughts are with Wendy and his family (Ernie was Wendy's carer).

- Penny needs to write two articles for the Ataxian magazine: one on hints and tips for preparing Branch newsletters and the other on using wikis for sharing information and getting a fast and free online presence on the Web.

- Derek tendered his apologies for the November meeting as he will be attending his Scout group's 50th anniversary annual dinner.

- Another member had received incapacity form IB50 but as he receives higher rate care and mobility allowance does not need to complete this form. The form was sent to everyone receiving DLA (Disabled Living Allowance) and if he had filled it in he may have lost his benefit!

7. Dates of Next Meetings

The next Branch meetings will be held on Saturday 17 November 2007 and Saturday 26 January 2008 at Lasswade. We are planning to have a meal immediately after the November meeting, at 4.30pm.

BRANCH MAILING ADDRESS

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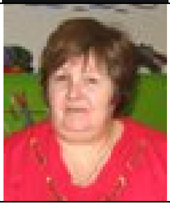
Committee Member: Liz Dalby		Email committee Member: Susan McPheat	

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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

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.brainandspine.org.uk/helpline/index.html Brain and Spine Foundation online Helpline.

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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