

**REPORT OF THE MEETING OF THE EAST OF  
SCOTLAND BRANCH OF ATAXIA UK  
LASSWADE HIGH SCHOOL CENTRE,  
SATURDAY 26 JANUARY 2008**



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

**Present:** Derek Main (Chairman) Liz & Pete Dalby, Penny Gardner, Andy Hogg, John Hunter, John Reid, Jim Shepherd, Richard & Anne-Marie Thomson, Tom & Doreen Vandeppear & Frances Wright

**Apologies:** Andrea Bothwell, Rona Brankin, Ronnie Browne, George Foulkes MSP, Anne Green, Peter Smeaton, Alan Smith, Prof Will

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

Derek welcomed everyone especially the two new members, Tom & Doreen Vandeppear who live locally. Everyone introduced themselves and explained their type of Ataxia and / or connection to the Branch. The reports of the September and November 2007 meetings were approved.

### **2. Chairman's Remarks**

Derek mentioned the Ataxia UK collecting cans – eg the Lasswade one raises £20 - £30 every couple of months. Ideas for other locations are welcome as Derek has spare cans. Ataxia UK sent out home money boxes a while back Derek has asked them for another dozen, please let him know if you want one for collecting small change. Penny has been clearing out her loft and will return the stock of Ataxia sweat shirts (left over from our 2004 conference!) to Head Office.

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

Frances reported the changes since the 17 November meeting:

Income included the usual standing orders from Claire Shepherd and the Mr & Mrs Smith (£10 per month each), donation of £25 from Mr & Mrs Vandeppear and bank interest to 27 December £24.73. The bank balance at 24 January 2008 was £2648.81. Today there also a collecting can from Lasswade, still to be counted.

Expenses were teas and coffees at the November meeting £7.20, members' social expenses £270, photocopying £45 & stock of stamps £96 (postage costs going up in April 2008).

### **4. Ataxia UK conference 2008**

When Sue Millman visited she suggested a possible Ataxia UK conference in May 2008. Maybe this could be a joint event with the West of Scotland Branch in Stirling? This is now rather short notice and perhaps July would be more feasible? Please ring Derek on 0131 477 4371 with your thoughts.

## **5. General Discussion**

Physiotherapy was discussed and Derek said that the one at Western General is not much use, they do not know about ataxia. Liz has home visits from a neurological physiotherapist based at McLeod Street.

Access on flights, being charged for assistance etc was discussed, for example pre-booked assistance not turning up on the day.

Penny reported that a member from Tayside had phoned, was diagnosed 10 years ago and hasn't seen a neurologist since. Everyone agreed that there have been many changes over 10 years and everyone should be getting an annual check up – he should see his GP again and insist on this. Jim Shepherd agreed to phone and recommend his doctor (Dr Coleman Aberdeen Hospital) also Professor Will at DCN at the Western General Edinburgh is highly recommended by members. If people join Ataxia AK they can send you lots of useful leaflets. Derek said that 0131 537 2115 is the phone number for the reception at DCN (Western General). If the member doesn't have any success, maybe he could contact his MSP.

Scottish Support Groups Directory have asked if we want to be included in their listing – Penny agreed to add us to this.

Occasionally get emails from web directories wanting to add our website details. They do not look very useful, but it might be worth trying one to see if it generates any enquiries.

Stem cell research – Ataxia UK (and the medical profession in general) still advise people not to spend their money on it. There is no valid evidence of its long term benefits and no certainty about the safety of it either.

CoQ10 had amazing reports in the past but researchers are not even sure about that now. The drug is very expensive for the dosage needed by people with ataxia. Katie Henderson (AUK) buys it over the web and has details on her website: <http://www.obother.co.uk>.

Liz has found reflexology to be very helpful – she uses Mary Gilhooley in Gorebridge 0131 654 0246.

Penny has stock of ataxia T shirts (various sizes) that can be used for promoting ataxia at fundraising events.

## **6. Social Events**

Possible events in Summer 2008 could be barge trip, BBQ, meal out (maybe a meal at Laird & Dog in Lasswade after the May AGM?). Blair Drummond Safari Park was also suggested as a BBQ venue, although it

might be a problem all gathering to go there – and would involve the cost of a minibus or similar. Jim said there a lot of nice places at Aberdeen – but maybe that's a bit far for a day trip! Dalkeith Country Park is a nice venue, especially for kids. BBQ suggested for July – volunteer cooks are needed if we do this!

Another trip to the Falkirk Wheel was suggested. We could have a meal out, maybe hire a minibus & head north. Can hire handicabs, maybe through LCTS or social work.

## **7. Speakers at Meetings**

Ben Schogler will be speaking at the March meeting. He's a researcher at Edinburgh University who is an expert on ataxia and movement. He may bring his testing equipment with him. Professor Will may be able to talk at a future meeting.

Penny still needs to write the 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.

## **8. AOCB**

The report of the focus group meetings (summarising the ones held with Ataxia branches all across the UK) is now available and we are seeking permission to host this on our website.

Penny has joined Ataxia South Africa, an MSN group which has lots of useful information and articles (see web links below).

## **9. Dates of Next Meetings**







The next Branch meetings will be held on Saturday 15 March 2008 and the AGM on Saturday 10 May 2008 at Lasswade.

Dates for September 2008 could be Saturday 6<sup>th</sup> or 13<sup>th</sup> (not booked yet).

## **BRANCH ADDRESS FOR MAILING:**

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

## 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>
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Treasurer: Frances Wright		0131 555 5665 <a href="mailto:frances@ataxia-east-scotland.org.uk">frances@ataxia-east-scotland.org.uk</a>
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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](mailto: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](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

<http://www.brainandspine.org.uk/helpline/index.html> Brain and Spine Foundation online Helpline.

<http://groups.msn.com/ATAXIASOUTHAFRICA> It's worth joining this group as they have lots of useful articles (you have to apply online to join)..

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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