

**REPORT OF THE MEETING OF THE EAST OF  
SCOTLAND BRANCH OF ATAXIA UK  
LASSWADE HIGH SCHOOL CENTRE,  
SATURDAY 23 JANUARY 2010**



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

**Present:** Derek Main (Chairman), Tony & Mary Callow, Penny Gardner, Stuart & Doreen Greenwood, Calum Pringle (Speaker), John Reid, Richard & Anne-Marie Thomson, Tom & Doreen Vandeppear, Chris & Fiona Wragg and Frances Wright,

**Apologies:** Andrea Bothwell, Rhona Brankin, Ronnie Browne, Liz & Pete Dalby, Anne Green, John Hunter, Andy & Lesley Pringle

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

Derek welcomed everyone, especially our two new members Stuart and Doreen. Everyone made their introductions and explained their connection to ataxia. Derek has had idiopathic ataxia (means unknown cause) for 53 years, John Reid has Friedreich's Ataxia, Stuart has ataxia and Tom has had Spinal cerebellar Ataxia for 15 years Tony is from Falkirk and has been recently diagnosed with ataxia and Chris's mum-in-law has CA. Our guest speaker, Calum is the son of members Andy & Lesley Pringle who has CA.

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

Derek welcomed everyone to the meeting and told us the good news that Graham Kennedy from Ataxia UK has been awarded an MBE in the New Year Honours for his fundraising: [www.bigbadbikeride.com](http://www.bigbadbikeride.com) .

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

Since the November meeting, income has included the usual £10 per month standing order from the Anne-Marie and Richard's friends the Smiths. Jim Shepherd's daughter has transferred her regular £10 pm to the Aberdeen self help group. Derek handed in 2 tins from the Station Bar which are yet to be counted.

Expenses were £12 teas & coffees in November. The bank balance is now £894.28 (not much change since November).

Frances' new address is 55 Carrick Knowe Road, Edinburgh EH12 7BN

### **4. Speaker: Calum Pringle (Dundee University)**

Calum is a design student doing his thesis on interaction design. His dissertation centres around a research project on products for people with CA. He has spoken to doctors, manufacturers of communication devices, therapists etc.

His Mum Lesley has late onset CA (cerebellar ataxia) and people with CA can have speech problems. The currently available devices available are not very good – being designed for children, or to replace speech, which is not what she needs.. Now he's doing his honours project and asked members for their permission to test them as part of his primary research. Calum had brought along postcards with different typefaces on to see what is best, also some devices.

Calum asked our permission to be used as subjects ie did we mind our names being used, and photos being taken while looking at postcards. We all said OK and signed the ethics forms

We looked at postcards with 8 different fonts, then listened to 10 recordings of famous voices saying 'hello' and had to match the fonts to the voices (how we thought it would look if written down). Next we were asked to put the 8 fonts in order from formal to informal. Finally we looked at postcards depicting 8 products: a necklace, a hooded scarf, headphones, an iPod wrist strap, wrap around goggles, a hearing aid, a cycling mask and a shoulder holster and matched the 'hellos' to the products. While we were doing this, Calum took some photos.

Calum is aiming to identify the appropriate fonts to use from the user's point of view. We all thanked him for an interesting session.

## **5. Social Events**

We then had a break for the traditional haggis, neeps and tatties, NB The meal after the November meeting at the Laird & Dog Hotel in Lasswade was a great success as usual.

## **6. Any Other Business**

Derek suggested another Scottish Parliament tour - maybe on a Saturday if possible? – we could invite the West of Scotland members too in case anyone is interested. Derek agreed to speak to Rhona Brankin about a date, possibly in mid April (making sure to miss the Easter holiday).

Peter Smeaton rang Penny to say he's been finally diagnosed with SCA 28. He's only one in UK (so far) the other being an Italian family (in Italy). He plans to come to the March meeting and has information on CoQ10.

We talked about holidays for people with disabilities: the accessible Bond Hotel in Blackpool [www.bondhotel.co.uk/](http://www.bondhotel.co.uk/), Santa Ponsa Majorca where Derek went recently, Polis Cyprus <http://www.evas-apartments.com/>. In many hotels, even those with 'disabled facilities' there can be problems especially with the bathrooms, which may be too small, cannot turn around.

Frances reported a problem on a LRT bus – there was a child’s buggy in the disabled space, and a man in a wheelchair refused entry because there was no room. Action: Penny needs to write to LRT regarding their buggy and wheelchair policy. It was possibly the number 22 after Stenhouse where Frances got on, the incident happened soon after on the outskirts of Edinburgh.

## 7. Dates of Next Meetings

The next Branch meeting will be held on Saturday 13 March and Saturday 8 May (the AGM) at Lasswade.

## YOUR BRANCH COMMITTEE

<p>Chairman: Derek Main</p>		<p>0131 477 4371 <a href="mailto:derek@ataxia-east-scotland.org.uk">derek@ataxia-east-scotland.org.uk</a></p>
<p>Secretary and Vice-Chair: Penny Gardner</p>		<p>0131 332 5218 <a href="mailto:penny@ataxia-east-scotland.org.uk">penny@ataxia-east-scotland.org.uk</a></p>
<p>Treasurer: Frances Wright</p>		<p>0131 467 9023 <a href="mailto:frances@ataxia-east-scotland.org.uk">frances@ataxia-east-scotland.org.uk</a></p>
<p>Committee Member: John Reid</p>		<p><a href="mailto:johnreid@ataxia-east-scotland.org.uk">johnreid@ataxia-east-scotland.org.uk</a></p>
<p>Committee Member: Liz Dalby</p>		<p><a href="mailto:liz@ataxia-east-scotland.org.uk">liz@ataxia-east-scotland.org.uk</a></p>
<p>Email committee Member: Susan McPheat</p>		<p>Contact through: <a href="mailto:susan@ataxia-east-scotland.org.uk">susan@ataxia-east-scotland.org.uk</a></p>

## USEFUL WEB LINKS

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

[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.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

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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.