

**REPORT OF THE MEETING OF THE EAST OF  
SCOTLAND BRANCH OF ATAXIA UK  
LASSWADE HIGH SCHOOL CENTRE,  
SATURDAY 15 March 2008**



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

**Present:** Derek Main (Chairman), Andrea Bothwell & Netsai, Liz & Pete Dalby, Penny Gardner, Chris Hill, Dave Lee and Jon Perkins (Perception, Movement, Action Research Centre at Edinburgh University), John Reid, Tom & Doreen Vandeppear

**Apologies:** Ronnie Browne, Anne Green, Liz Griffin, Andy Hogg, John Hunter, Jim Shepherd, Peter Smeaton, Alan Smith, Richard & Anne-Marie Thomson, & Frances Wright

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

Derek welcomed everyone and they all introduced themselves and explained their type of Ataxia and / or connection to the Branch. The report of the January 2008 meeting was approved.

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

Derek mentioned the Ataxia UK money boxes for collecting loose change in the house; he has a stock of them if anyone wants one. He also has a copy of the Ataxia UK report on physiotherapy practice and the experiences of people with ataxia.

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

Frances is away in NZ / Australia and Penny had not got hold of a bank statement, so this was held over the next meeting.

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

This has now been organised for the weekend of 21 June 2008. The cost is £25 for the Saturday conference plus £20 for the social evening dinner and dance or £110 for both including an overnight stay on Saturday night. It is being held at the Beardmore Conference Centre, Clydebank, Glasgow. Please ring Asantwaa Brenya on 020 7582 1444 if you require further details. There is help available from the Access Fund towards the costs.

### **5. Speakers**

Dave and John introduced themselves and explained the role of the PMA research centre (set up by Dave after his retirement to continue his research into Ataxia, Parkinson's etc) and John's PhD studies which are focussed on finding ways to help people living with ataxia. John has 3 years funding for the PhD (supported by Ataxia UK) which is to investigate perception, movement & action in people with ataxia and CA in particular.

There was a general discussion on the benefits of physiotherapy and exercise in maintaining muscle tone and avoiding further deterioration.

Dave's life work is understanding the underlying principles of controlling movement. This can be described as 'closing gaps' between one state & another. People have a 'guide' in the brain for an action, for example to pick up a cup. Each action has two aspects: – the movement itself and the motor action. Perception can be conscious (as in picking something up) or unconscious (as in breathing).

Dave explained that a colleague of theirs had a non-malignant tumour on the cerebellum and developed ataxia after the operation to remove the tumour. Pete asked if ataxia that developed as a result of such an injury would be progressive. Dave said that his colleague's ataxia had actually improved slightly over 15 years. So this is a different experience from someone with an inherited ataxia (CA or FA).

The general approach to their experiments so far (Derek has been involved as a volunteer with these) has been to enable people to make helpful movements. They have a theory that action is driven by a pattern in the brain – from analysing brains of monkeys – so is it possible to 'inject' that pattern into the person having the problem? They are also working with sports people & musicians. Putting a sound into the ears – copies the pattern of a well formed movement – enables the person to reform their movements with a sonic guide. Has anyone tried moving when there is music on?? It can help. Andrea said that hearing problems in FA are not to do with the ears but in the brain (the sounds are not correctly discriminated) so would music help, if it isn't heard properly? She can still listen to music but cannot hear every instrument any longer. Dave and John said that their research ideas should help with speech.

Underlying idea: When making movements (speech, walking, reaching etc) central part is the aim (eg picking up a cup) secondary movements could be leaning forward, moving shoulders, getting hold of the handle etc. Get the main aim right and rest could follow.

Penny asked if ears & hearing connected directly into to brain (not having to go via the cerebellum) and if that is why music / sound can be helpful. Liz said that people with ataxia have far more knowledge of their condition than most medical staff. Derek goes in for every test available – not that it will necessarily help him, but maybe someone else down the line. Derek's trainer Jimmy says you must concentrate on what you are doing all the time. Able bodied people don't appreciate the difficulties that ataxians have or will have – especially as they get older.

There are so many SCA varieties of ataxia – most GPs have never heard of any of them and when confronted with a diagnosis of ataxia, ask ‘what’s that?’. Derek pointed out that the normal problems of aging can be worse when you have ataxia – they creep up on you. Tom had late onset at 50 odd but others are youngsters. Misdiagnosis still happens eg MS and diagnosis of ataxia can take a while. One member, on being told that she didn’t have MS but had ataxia, punched the doctor!

The research project may also have promise for diagnosis of ataxia as well as treatment. They are working intensively with individuals – cannot lump everyone together as different ataxias vary in symptoms, responses, rate of progression etc. Tom has extreme discomfort in his legs and only gets relief by lying on his stomach. Makes flying very difficult.

Using sound can help to control movements by replacing the visual clues. If you have no feeling you can’t find out where your feet are. Perception of where your body is eg feet, hands is very important to movement.

We now understand the symptoms of ataxia more, using a different way of exploring it. The central goal of the research project is to develop a non-invasive user-friendly, sonic device to help people practice their movements, It will need to be small, portable, easy to use,

Dave and John were thanked for their interesting presentation.

## **6. Social Events**

It was agreed that it would be good to hold a social event or two during the summer and several ideas were discussed. Let Derek know what you would like to do: 0131 4774371 or [derek@ataxia-east-scotland.org.uk](mailto:derek@ataxia-east-scotland.org.uk)

## **7. AOCB**

Ataxia South Africa have an MSN discussion group – you have to email them with your details to join. When we get the web address, we’ll add it to the website.

## **8. Dates of Next Meetings**

The next Branch meeting will be the AGM, to be held on Saturday 10 May 2008 at Lasswade followed by a Branch meeting on 6 or 13 September 2008

## **BRANCH ADDRESS FOR MAILING:**

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## YOUR BRANCH COMMITTEE

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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) \_\_\_\_\_

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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.

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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