

**REPORT OF THE ANNUAL GENERAL MEETING OF  
THE EAST OF SCOTLAND BRANCH OF ATAXIA UK  
LASSWADE HIGH SCHOOL CENTRE,  
SATURDAY 10 MAY 2008**



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

**Present:** Derek Main (Chairman), Andrea Bothwell & Netsai, Ronnie Browne, Liz & Pete Dalby, Penny Gardner, Chris Hill, Andy Hogg, John Reid, Jim Shepherd, Peter Smeaton, Tom & Doreen Vandeppear & Frances Wright

**Apologies:** Liz Griffin, Anne Green, John Hunter, Janice Heath, Alan Smith, Richard & Anne-Marie Thomson, Prof Will.

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

Derek welcomed everyone and said that the usual introductions were not needed this time as we all knew each other. This is our 13<sup>th</sup> AGM since becoming a Branch and the report of the meeting held on 15 March 2008 was approved.

### **2. Chairman's Report on the Year**

Welcome for coming to this very important meeting, with a special welcome to our patron Ronnie Browne & everyone who has travelled a long way to be here eg Jim from Aberdeen, Peter Smeaton from Bradford and John Reid from Hawick.

Everyone introduced themselves: Derek, describing himself as the 'poor chairperson', has had idiopathic CA since he was 14 months old (50 years ago). Idiopathic means that the doctors don't know what caused it. John Reid was born with FA (Friedreich's Ataxia) but it didn't affect him until secondary school. He comes from Hawick and has had FA for 40 years. Tom Vandeppear inherited CA (cerebellar ataxia) from his mother, it started to bother him 15 years ago, and has become progressively worse. Doreen Vandeppear said she had nothing wrong 'except Tom'. Pete has spent 25 years suffering with Liz, including 13yrs of Liz's CA. Liz has had CA 13 years – and she's a member of the Branch committee. Ronnie has been married nearly 50 years, so said he's worse off than all of them. Frances has been Treasurer since 1995, and originally joined because she had a friend (Andrea Bothwell) in the group, Peter Smeaton is 69 and has had CA for 40 plus years – his CA has no marker for it so it's idiopathic too. Andy Hogg has idiopathic CA and his gait and mobility have been noticeable for 10 yrs. Jim Shepherd from Aberdeen has CA and the big problem is his heart, he has to concentrate on picking things up.

Derek said that he was pleased to announce that Ataxia UK is holding a special Scottish conference in the Beardmore Conference, Clydebank,

Glasgow on 21 June 2008. It is being run by Head Office, and we have no details of the programme yet. Penny agreed to contact Head Office about the two versions of conference booking form & Access Fund application. People with ataxia can apply to Ataxia UK for complete cover of conference costs and funding towards travel costs and accommodation. There should have been a programme by now – we suspect that the turn out may be poor as people are reluctant to commit themselves before they know that the day will be worthwhile. It seems rather disorganised – there's been no liaison about the conference programme with us or the West of Scotland branch.

Last year's meetings were quite successful – but we can always do with more people attending our meetings. Going through them backwards:

In March 2008 there was an interesting talk by Dave Lee and Jon Perkins from Edinburgh University Perception Unit. Many of our members are hoping to take part in this project which involves research into the benefits of using music to enable movements.

In January 2008 we had a good number attending who enjoyed haggis neeps & tatties. There was an interesting discussion on physiotherapy.

In November 2007 we had a visit to Scottish Parliament organised by Rhona Brankin, MSP. This was a very interesting & worthwhile visit. All those who went thoroughly enjoyed it, finishing off with tea coffee and biscuits.

The November meeting was chaired by Penny as Derek went to a Scout do, but the water at Lasswade was cut off unexpectedly and we had to finish the meeting early – several of us went to the Laird & Dog Hotel in Lasswade for a nice meal afterwards.

In September 2007 there was a talk by Sue Millman, the new Chief Executive of Ataxia UK, & Nikki Joule who ran a focus group discussing people's problems at the time of diagnosis of ataxia. At that time Sue Millman mentioned the Scottish conference. NB Tina Thatcher wants people with Ataxia to talk at the conference but 'must be a clear speaker' (!)

In May 2007 (last year's AGM) Peter Smeaton talked about his experiences with CA.

Last year, or in fact earlier this year, our Treasurer spent time in Australia and New Zealand. We may be lucky to have a wee report from her later but I have it on good authority that the funds are still intact.

### 3. Treasurer's Report

Frances passed round copies of the 2007/08 accounts (attached), which were balanced by Penny in April and sent to Head Office (on her own this year, Frances being on holiday in New Zealand & Australia). We have decided to send £1,500 to the research effort as that leaves us plenty for operating. The balance on the latest statement, 30 April, is £2602.91 less the £1,500 leaves £1,102.91 (& more to pay in). The Branch committee may decide to make another donation during the year if funds allow.

Donations are up from last year; these mainly include funds of £1400 from the Dalhousie Masonic Lodge & £500 from Andrea Bothwell, which was earmarked for FA research. Sale of goods are up to £90 from £24 last year (ties, toys etc) Bank interest is up by £82 (CAF bank). Subs up £80 to £115 & more collected today to pay in. Expenses total for the year was £589, compared to £466 last year— these have only gone up £123.

May's income included standing orders from Jim's daughter & the Smiths plus £44.94 from collecting cans. Expenses were £12 for tea & coffee at the last meeting. Frances thanked everyone for fund raising, donations, sale of goods etc. We keep the outgoings as low as possible – most of the expenses are copying charges, postages and the website. **Committee Decision:** Agreed to send £1,500 to Head Office of Ataxia UK.

### 4. Election of Branch Officers

The committee formally resigned and was re-elected, unopposed. It is: Derek Main (Chairman), Frances Wright (Treasurer), Penny Gardner (Secretary & Vice Chair), John Reid and Liz Dalby (Ordinary Committee Members).

### 5. Peter Smeaton

#### Restful Recumbency 1

*In three parts narrated by Penny and additional thoughts from Peter.*

Introduction by Peter.

I have had a change of mind on sleep including bed rest for our ataxias. I believed like a good Presbyterian one was either asleep or up and about ones business. Now I understand all legs-up rest, that is sleep and time awake in bed is good for us.

*Aside: Sometimes I think depression plus sleep deprivation leads to a diagnosis of bi-polar disorder also known as manic depression.*

Coping with ataxia is mainly about three T's. It is always tiring, often tedious and in an instant can be troublesome.

Coping is only made possible by the cerebrum deputising for lack of cerebellar function. In the case of CA there is no cerebellar function and in Friedreich's Ataxia (FrA) all cells including cerebellar cells are working well below par and the cerebellum needs help from the cerebrum. This is Peter's take on FrA. The two words cerebellum and cerebrum, parts of the brain, are unavoidable in any discussion of ataxia.

*Aside: It may be useful to regard the 'c' in cerebrum as a hard 'c'. This is a change in thinking only, the cerebral cortex, grey matter of the cerebrum is the seat of thought. Do not use this dodge in speaking!*

Cerebral means to us means anything to do with the cerebrum indeed the structure is sometimes known as the cerebral hemispheres. However, in English usage cerebral means very, very clever.

We need to know the cerebrum is the big conscious bit at the top of the brain. When we hear the expression 'thinking cap' it is referring to this. The cerebellum is the little computer-like mass of cells and fibres below the cerebrum and behind the axis of the brain stem.

Functionally the cerebrum is rather like the pilot whereas the cerebellum resembles the auto pilot. The cerebrum is executive whereas the cerebellum is non executive.

*Aside: Story A CA tale of sail. (names changed).*

*We are familiar with tales of apparent intemperance and this one is a little different. Derek Spencer educated and dexterous had to retire from dentistry at forty when he began to be troubled by CA. Mike Mickle was enthusiastic about sailing when he got a new craft he was happy to let Derek Spencer, a former sailor, advise him on the repairs and new rigging. Eventually she was ready for the water, Mike invited Derek to sail with him and misunderstood when the invitation was refused. But we know why. Derek's help was cerebral he declined the sailing opportunity which would have been largely cerebellar.*

## **Restful Recumbency 2**

*Peter.* The next part is my hypothesis on the importance of legs-up rest in our ataxias. A hypothesis means not proven whereas a thesis is provable. It is based on my experience only and therefore is a subjective impression, it is not statistically significant when over a hundred people would have to be measured meticulously; therefore it is not evidence based as is required now by Western medicine. However it is plausible and the hypothesis is one explanation of the importance to us of rest.

## **The importance of rest in ataxia.**

Generous bed rest can be easily justified this is spent in sleep and there should be two hours allowed for lying awake and dozing. Indulging in day dreaming, planning, remembering and listening to the radio - these are all thinking pursuits.

The brain revives with sleep and the cerebral cortex, the conscious part of the cerebrum, is not tired, in the least, when thinking and it does not have to deputize for a wonky or under performing cerebellum.

So in bed rest we are like the standard majority with good cerebellar function that is the cerebellum is not required. Resist the Scottish Presbyterian work ethic and stay in bed a while longer.

*Aside. Peter sleeps for around seven or eight hours and remains in bed for two hours more. Derek will agree the moving average theory is mainly for marketing people. I find it useful and maintain my average time in bed on a three night moving average. (If this needs further explanation – perhaps Derek will clarify).*

## **Restful Recumbency 3**

As a result of spending longer in bed, we ataxians have a very short day. Probably time only for daily living with little time left for business affairs, keep this in mind and try to keep up with business matters. Before Penny reads the final rather pessimistic part I hasten to add that I am ever aware of the many people who are worse off.

## **The cerebrum stands in, warts and all.**

Coping with ataxia is only made possible by the cerebrum deputising for the lack of cerebellar function it is not perfect in this –

- Cannot enable the former writer to write again.
- Cannot enable the walker to run.
- Cannot make Peter move more quickly to help a falling child.
- Cannot slow Peter's rather bizarre over reaction to someone coming from behind.
- Peter cannot lateral think or multi task; if he gets distracted he will probably stumble or fall.
- Peter finds it hard to control the volume of his voice and to some loudness equals aggression.
- Cannot compensate for balance largely this is down to the ears and is routed via the cerebellum to the cerebrum.
- It cannot coordinate, meaning fine tuned movement as in writing and dancing.

*Aside: The cerebrum cannot help Peter to walk evenly. Pitmatic, the old dialect of the coalpit of the north east of England, would use the word hirple to describe a miner's gait after an eight hour shift, on his knees or side, cutting coal. Peter's example of an onomatopoeic word which seems to describe his personal gait.*

Final thoughts from Peter:

Keep fit both mentally and physically, sleep and eat well, and stay put in bed for 2 hours in the morning after waking up.

## **6. Frances' Trip to NZ & Australia**

Frances & her friend flew from Manchester and stopped over in Singapore for 2 nights. Singapore is very clean and efficient with many tall buildings; the orchid is the national flower. They had a Singapore sling on the plane. There are markets eg little India, China. Most people speak some English.

They then flew to Auckland in North Island New Zealand, arriving 2 days later. It's a very cosmopolitan city. They took a Magic bus tour covering North and South Islands, booking their own accommodation in hostels. They went north to Cape Rianga, down the west side to Wellington (the capital of NZ) took a plane / ferry to South Island, then a 20 minute flight to Picton top of South Island. There are lots of Scottish connections in NZ. They then went down to Nelson on the west side, took a private bus from Nelson to Dunedin where it was like being in Edinburgh but with better weather! They saw yellow eyed penguins, seals, albatross with its chicks, sealions coming out of water on to beach. Every Scottish name is there. Street names and places include Hanover Street, George Street, Hillside, Roslin etc. Stewart Island is also beautiful.

Then up to Christchurch, and flew on to Sydney where they stayed 3 days in a terrible hostel (didn't take Penny's advice!). They went to a concert in the Sydney opera house by a well known aboriginal man. There are many beaches all round Sydney and they took the ferry to Manly Bay. Then they went up the east coast by air, seeing the blue mountains 2 hours outside the city. Cairns & Port Douglas in Queensland are much less touristy. They saw crocodiles, snakes and one wild kangaroo. The Habitat park by Port Douglas is full of wildlife. Frances preferred NZ to Australia - it has pine, fresh air; a lovely country.

## **7. Social Events**

We are hoping to organise a trip to Falkirk wheel with the Seagull Trust – maybe at the end of August? Frances has the information will organise it and liaise with Andy Hogg.

Members are encouraged to phone or email any other ideas for social events.

**8. Date of Next Meetings**

The next Branch meetings will be held on Saturday 6 September 2008 and Saturday 15 November 2008 at Lasswade. We may have a meal at the Laird and Dog again, immediately after the November meeting.

**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>	
Secretary and Vice-Chair: Penny Gardner		0131 332 5218 <a href="mailto:penny@ataxia-east-scotland.org.uk">penny@ataxia-east-scotland.org.uk</a>	
Treasurer: Frances Wright		0131 555 5665 <a href="mailto:frances@ataxia-east-scotland.org.uk">frances@ataxia-east-scotland.org.uk</a>	
Committee Member: John Reid		<a href="mailto:johnreid@ataxia-east-scotland.org.uk">johnreid@ataxia-east-scotland.org.uk</a>	
Committee Member: Liz Dalby <a href="mailto:liz@ataxia-east-scotland.org.uk">liz@ataxia-east-scotland.org.uk</a>		Email committee Member: Susan McPheat	

**ADDRESS FOR MAILING:**

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

## 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

## 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

.....

## 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

**EAST OF SCOTLAND BRANCH OF ATAXIA UK  
FINANCIAL STATEMENTS FOR THE YEAR TO 31ST MARCH 2008**

INCOME	£	£	£
Donations - general	2,206.95		
Donations - earmarked	500.00		
Sale of goods	90.00		
Bank interest	82.28		
Members voluntary subs	<u>115.00</u>	2,994.23	
Fundraising:			
General			
Individuals			
Collecting			
tins	<u>169.42</u>	<u>169.42</u>	3,163.65
 EXPENDITURE			
Postages & office supplies	225.00		
Web Site			
Subs to organisations	5.00		
Meetings	77.20		
Travel expenses	32.00		
Welfare			
Sundries			
social			
expenses	<u>250.00</u>		<u>589.20</u>
Surplus of income over expenditure			2,574.45
			-
Sent to HQ (500 earmarked for FA research)			<u>1,500.00</u>
Increase in bank balance			1,074.45
Bank b/f			<u>1,508.46</u>
Bank c/f			<u><u>2,582.91</u></u>
Balance as per bank statement 31 March 2008			2,582.91
less unrepresented cheques			
add unrecorded pay ins			
Bank balance c/f			<u><u>2,582.91</u></u>