

# East of Scotland Branch of Ataxia UK



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

25 November 2008

Dear Branch Members

Here at last are the three reports for the AGM last May (including the 2008 Accounts) and our September 2008 and November 2008 meetings. I'm sorry these have taken so long but hope you find them interesting. They have been posted on the Branch website too.

I also took copious notes at the Scottish conference last June but have not finished typing these up. Hope to send them out with the next meeting report.

Please make a note of the next two meetings in your diary:

- Saturday 24 January 2009 (with Haggis, neeps and tatties)
- Saturday 14 March 2009

Both meetings will take place 1.30 – 4pm at Lasswade High School Centre.

We are arranging for Susan McVicker to come along before the January meeting to provide aromatherapy / massage treatments for members with ataxia. These will be paid out of Branch funds. If you would like to book a treatment please let Derek know on [derek@ataxia-east-scotland.org.uk](mailto:derek@ataxia-east-scotland.org.uk) or ring him at 0131 477 4371.

If you prefer an emailed report to a hard copy please let me know using the form on page 16.

With best wishes,

*Penny*

Penny Gardner, Branch Secretary,  
3 Craigleith Gardens, Edinburgh EH4 3JW

**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, Professor 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 turnout 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 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.

### **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			<u>1,074.45</u>
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>



**REPORT OF THE MEETING OF THE EAST OF  
SCOTLAND BRANCH OF ATAXIA UK  
LASSWADE HIGH SCHOOL CENTRE,  
SATURDAY 6 SEPTEMBER 2008**



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

**Present:** Derek Main (Chairman), Liz & Pete Dalby, Penny Gardner, John Reid, Susan McVicker (speaker) & Frances Wright

**Apologies:** Andrea Bothwell, Ronnie Brown, George Foulkes MSP, Liz Griffin, Anne Green, Andy Hogg, John Hunter, Janice Heath, Jim Shepherd, Alan Smith, Richard & Anne-Marie Thomson, Tom & Doreen Vandeppear and Professor Will.

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

Derek welcomed everyone and we all made the usual introductions. Susan McVicker lives in Bonnyrigg and works from home providing beauty therapy reflexology & aromatherapy treatments. Penny apologised that she has not yet typed the report of the AGM held on 10 May 2008. Derek introduced Susan McVicker, our speaker for the day – this arrangement was kindly made by the school

### **2. Speaker - Susan McVicker, Aromatherapy and Reflexology**

Susan said she would talk first about aromatherapy and asked if anyone has had treatments. The oils are very potent can be used medicinally for variety of therapeutic relief purposes as well as emotionally. Floral oils can lift emotions eg rose oil (which is very expensive) only use a tiny little amount. Come in 10ml bottles which give 100s of treatments (mix the essential oil with a base oil before treatment, 2 or 3 drops to 100ml). The oils are absorbed through your skin into bloodstream. Tea tree oil is antiseptic, helps kill infections – even kitchen work surfaces. OK for bathing cats & dogs – use very diluted eg one or drops in the water (less is best). It is good for insect bites too. The best oil for warding off bugs is citronella.

It is very important to use a very tiny amount. For example lavender oil can help you sleep - put a drop on a tissue and waft it a good distance away – or one drop on a cotton wool ball on the radiator. Don't throw it all over your pillow, your brain will be over stimulated and you'll wake up with a headache. Citrus oils are invigorating – good for a massage if you are achy or sore. Need to take height and weight into consideration – quantity needs to be adjusted.

If essential oils are used properly by a qualified therapist, they can be very effective. If using them yourself, be very careful and sparing with quantities. Maximum 2 drops around the home in minimum egg cup full of water.

Susan got into using the oils after she had a very premature baby at 24 weeks. He weighed 1lb 4oz – the odds were against him. He celebrated his 10<sup>th</sup> birthday last May. You have got to understand how oils work eg people with diabetes & epilepsy have to be careful; medication you are taking may have a reaction etc.

Susan then gave Liz a treatment on her hands and Liz felt a definite benefit. Susan used a different oil on each hand – a body shop one first, then a more expensive pure aromatherapy oil. The Body Shop one left more of a residue and was also quite strongly perfumed. She then gave John Reid a hand treatment too, to improve his circulation. Frances and Derek followed. Various treatments and their benefits were discussed.

Susan gets 'Muscletone' from Iso in Newington, a rub which has glucosamine & mussel extract and she charges £15 for a back massage and £25 for a full body massage - prices for hands, feet, neck shoulders on quotation. The Branch committee has agreed that 1 free treatment for each person with ataxia would be paid for by branch and available before the next meeting on 15 November eg 11 -1. People can put their names forward & say what they want done. Foot to knee takes about 20 minutes. Hands to shoulders takes 15 – 20 minutes. If treating head, neck shoulders with oil she will need a screen for privacy. Head, neck & shoulders without oil through a T shirt is quicker and easier. Back, neck & shoulders takes about 30 minutes.

NB Because the report of this meeting didn't go out in time, and Susan was not well on the date of our November meeting these treatments will now be available before our meeting on 24 January 2009. Alternatively, local members can contract Susan directly to arrange a treatment in their own homes. Phone number is 454 9480, email [Soosin.mcvicker@btinternet.com](mailto:Soosin.mcvicker@btinternet.com)

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

Since May income has been approximately £216 including regular standing orders from Mr & Mrs Smith and Claire Sheppard, collecting cans from Lasswade and members' subscriptions.

Expenses included a donation of £1500 to Head Office of Ataxia UK for research, £50 to the Seagull Trust (which arranged the barge trip at the Falkland Wheel), £70 social expenses and £12 for teas and coffees at meeting. £1,632 in total.

The bank statement on 31st August showed a balance of £1256.93, with £33 miscellaneous income (received today) still to be added.

#### **4. Social Events**

The Falkirk wheel trip on Sunday 10th August was a great success. Derek, Frances & her niece, Penny, Gus, Liz, Pete (and grand daughters) Anne-Marie & Richard came. A new member also came along to say hello but did not come on the boat.

John Reid has a lot of 1p 2p 5p pieces to pay in. Frances advised him to use the coinstar machine in local supermarket or bag it up and local shop keepers often happy to take it (they have to pay the bank for small change).

We are planning a meal after the next branch meeting on 15<sup>th</sup> November at the Laird & Dog in Lasswade. This was excellent last year, good value for money and staff very friendly and helpful.

#### **5. Date of Next Meetings**

The next Branch meeting will be held on Saturday 15 November 2008 at Lasswade. We are planning a meal at the Laird and Dog again, immediately after the November meeting.

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



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

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

**Apologies:** Andrea Bothwell, Ronnie Brown, Rhona Brankin, John Reid

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

Derek welcomed everyone and we all made the usual introductions. The report of the AGM last May is on the Branch website (but not posted out yet). These were approved. Penny apologised that she has not yet typed the report of the branch meeting held on 6 September 2008. Derek introduced our speaker for the day – Dr Jon Stone, consultant neurologist at the Western General. Jon passed on a message from Charles Boyce who says hello.

### **2. Scout Post**

This costs just 21p per card in the Edinburgh area. The deadline for collection is 8 December and they are being delivered from 12th to 21st December. Collection points Station Bar, Cadzow Place, Margaret Blackwood House Abbey Court, Greenside Church, Castle Rock Housing, Norton Place, Rossie Place.

### **3. Jon Stone**

One of the consultant neurologists at the Western General and he covers West Lothian as well. All neurologists need to know about ataxia but very few have a specialist interest. It would be difficulty to run an ataxia clinic in Edinburgh as so few people. If there was an intervention (treatment) available, the position would be different.

One member asked if the cerebellum has a left and right side and Jon said definitely, "yes". An injury of the left cerebellum would cause problems with the left arm and leg. With generalised (inherited) ataxia there is usually symmetrical damage.

#### **3.1 What is Ataxia?**

Jon showed an MRI scan showing the position of cerebellum. It has very fine details with fern like fronds and is quite beautiful. Severe ataxia causes atrophy (shrinkage), and the cerebellum becomes much smaller. Symptoms include unsteady walking, slurred speech (scanning cerebellar

speech), lack of co-ordination in arms / legs, 'jumpy' eye movements (nystagmus), possible slowness in cognition and subtle changes in emotional control in some patients.

Medical terms you might come across are:

- Slow saccades (eye movements L to R)
- Scanning speech
- Finger nose dysmetria
- Dysdiadochokinesis (unsteady gait)
- Heel shin test
- Broad based gait

Lack of co-ordination is key indicator.

Jon then showed us some short videos of nystagmus (horizontal, upbeat) and intention tremor - a man with injury to left side of cerebellum (finger nose test) having problem using his left arm.

### **3.2 What are the causes of Ataxia?**

- a) Genetic / congenital (most common)
- b) Stroke (can be a bleed in the cerebellum)
- c) Inflammation
- d) Brain tumour
- e) Head injury
- f) Toxins (alcohol is no. 1)
- g) Other causes

#### **3.2 a) Genetic Types of ataxia**

**(i) Spinocerebellar ataxia** – all cause ataxia but have other symptoms as well. There is a subtle problem with spinal cord as well as cerebellum.

- Type SCA 2 (patients often get cramp)
- Type SCA 3 (Machado Joseph disease)
- Type SCA 6
- Type SCA 7
- Type SCA 8
- Friedreich's ataxia

These are mostly dominant ataxias (except FA) and it can be helpful to know which one you have as people can be offered genetic counselling. However, it is still up to individual choice on whether to be tested or not. Blood samples are routinely retested when new genes identified.

Some other SCA numbers (eg 30) occur in only one family.

**(ii) Ataxia Telangiectasia** (recessive) visible blood vessels in the eyes

(iii) **Hereditary ataxias** with genes as yet unidentified. Runs in the family but cannot find the gene.

**Inherited Ataxias can be caused by dominant or recessive genes.**

### **Autosomal Dominant**

Only one parent needs to have the gene. If one part of chromosome has it, it will be inherited (eg brown eyes dominant over blue). On average 2 children will have it and other 2 will not have it. There will be a clear family history of ataxia.

### **Autosomal Recessive**

Both parents have to be carriers ie child must have 2 copies of the gene to get it (eg blue eyes). On average 1 child will have it, 2 will carry and 1 will not have it. Don't usually see a family history.

Genetic counselling – may help to know about problems in advance even if continuing with the pregnancy.

Repeat copies of bits of DNA are responsible for most hereditary ataxias. Bit of chromosome makes frataxin (don't know what it does!). Normally pattern 'GAA' is repeated 20 times. In FA the GAA code is repeated 500 times so patients makes less frataxin than they should – this must be important in the cerebellum.

Other SCA types eg SCA 8 have too many 'CTG' repeats and different proteins are probably involved.

## **3.2 b) Stroke**

2 halves of cerebellum joined in the brain stem

## **3.2 c) Inflammation**

- Multiple Sclerosis (MS) is the most common condition caused by inflammation
- Gluten sensitivity eg coeliac disease of the brain (controversial area) but cause and effect not proven yet.
- Paraneoplastic ataxia (very tiny cancer somewhere else in the body)

## **3.2 d) Brain Tumour**

- Can be coming from the cerebellum
- From nearby structures eg acoustic neuroma
- Spread from elsewhere in the body eg lung

## **3.2 e) Head Injury**

Can result in direct damage to the cerebellum.



### 3.2 f) Toxins

- Alcohol
- Drugs eg phenytoin can have long term effect on cerebellum
- Hormonal eg underactive thyroid
- CJD, MSA and other degenerative conditions
- Episodic ataxia

If you have ataxia and drink a lot it might make you feel worse. But it could also make you more steady by calming your nerves!

### 3.3 Is Ataxia associated with changes in thoughts & emotions?

In some patients only (especially strokes in cerebellum) there may be:

- Slowness of thought
- Lack of emotional ability: laughing outwardly instead of inwardly, crying when watching films or when happy. Also called 'pathological laughter and crying' or 'emotional incontinence'
- Occurs also in stroke, Motor Neurone Disease and MS
- Rarely – there may be disinhibited behaviour.

There can be thought changes (again, some patients only):

- Impairment of executive functions eg planning, verbal fluency, judgement, insight, abstract reasoning
- Working memory difficulties
- Visual - spatial cognition & memory language deficits.
- Problems with thinking about more than one thing at once (disco-ordination)

A neural circuit in brain may be responsible for this.

Some of these symptoms may be treatable

Information may help patients & carers understand what is happening.

### 3.4 Are there any promising drug treatments?

Unfortunately, there is nothing very dramatic as yet.

Co-enzyme Q10 – showed some promise on FA – but changes not dramatic, eg heart becoming abnormal a bit less slowly.

Vitamin E / Vitamin C - no evidence of these helping, nor N Acetylcysteine (Information from Nature Clinical Practice Neuropathy)

No other promising treatments at present

With Co Q10 there was a follow up study over 5 years: 84 treated, 15 not.

Only a trend to slower deterioration for some patients.

Heart looked different but cardiac function was the same.

Co Q10 is now moving to bigger trial – it's promising in Friedreich's Ataxia but not a wonder treatment.

Possible anti-oxidants Vit E and Vit C may be a help but nothing certain yet

So many false hopes are offered eg on internet – this is irresponsible.

The cost of Co Q in the much higher doses needed is £41,000 per year per patient (mega doses). Dr Stone was asked, if he had ataxia what would he take? He said if he had CA he would eat healthy food to ensure plenty of vitamins in his diet. If he didn't think his diet was healthy he would take multivitamins to include Vitamin C, E and A.

### **3.5 Other treatments**

Many of these are available at the Astley Ainslie Hospital in Edinburgh.

- Physiotherapy
- Occupational Therapy
- Speech therapy
- Dietition advice
- Psychology
- Disabled Living Centre
- Symptom management

### **4. Treasurer's Report**

Since 6 September, there has not been a lot of change. Income £12.61 interest and the usual standing orders from Mr & Mrs Smith and Claire Shepherd, collecting cans from Lasswade and members' subscriptions £33. Elaine Scott wants to set up a standing order and will be sending a large cheque from her Halloween fund raising (to come). Anne-Marie has raised £117 from the sale of knitting. The collecting can from the Laird & Dog and Tom & Doreen's wee box from their house have not been counted yet.

Expenditure: copying charges to come once Penny has finished typing up the meeting reports. Members' treatments from Susan McVicker the Lasswade therapist who will be coming in January will be billed to the Branch (about £15 each) and we will be taking bookings for this.

The Bank statement balance was £1268.90 at 15 November.

If anyone wants to set up a direct debit for donations please contact Frances on 0131 555 5665.

### **5. Social Events**

There will be a Meal at the Laird and Dog following the meeting (4pm). If anyone has other ideas for social events ring Derek on 0131 477 4371.







### **6. Any Other Business**

Penny mentioned Ataxia South Africa who send round an information filled weekly newsletter by email. <http://groups.msn.com/ATAXIASOUTHAFRICA>

## 7. Dates of Next Meetings

The next Branch meetings will be held on Saturday 24 January 2009 (with Haggis, neeps and tatties) and Saturday 14 March 2009 at Lasswade.

## 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		Contact through: <a href="mailto:susan@ataxia-east-scotland.org.uk">susan@ataxia-east-scotland.org.uk</a>

## 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://groups.msn.com/ATAXIASOUTHAFRICA> you need an MSN ID for this (eg hotmail address) and have to apply for membership by emailing [ATAXIASOUTHAFRICA@groups.msn.com](mailto:ATAXIASOUTHAFRICA@groups.msn.com) . They are moving to Multiply in February 2009: <http://multiply.com/> Worth joining for the excellent information and news every week.

### **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](mailto: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, Flat 8, 25 Queen Charlotte Street, Edinburgh EH6 6AX