

**REPORT OF THE MEETING OF THE EAST OF  
SCOTLAND BRANCH OF ATAXIA UK  
LASSWADE HIGH SCHOOL CENTRE,  
SATURDAY 14 MARCH 2009**



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

**Present:** Derek Main (Chairman), Liz & Pete Dalby, Penny Gardner, John Reid, Mary Prentice of VOCAL, Richard & Anne-Marie Thomson, Tom & Doreen Vandeppear and Frances Wright.

**Apologies:** Andrea Bothwell, Rhona Brankin, Anne Green, Liz Griffin, Janice Heath, John Hunter, Jim Shepherd, Professor Bob Will.

## **ASK ABOUT WOOL DONATIONS**

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

Derek welcomed everyone; no need for the usual introductions as we all know each other. The report of the January 2009 meeting will be sent later.

### **2. Chairman's Reports**

"It's nice to see you all". Just a week ago Derek was being a guinea pig for the RCP (Royal College of Physicians) again and they have asked him to go to the Royal College of Surgeons at the end of May too but is not sure if he can manage it. We need to raise our profile for medical professionals who don't know about the condition and this is a good way of doing it. Prof Will has also asked Liz (RCP), and she said yes. The students have to diagnose the condition in 6 minutes, The 'guinea pig' is not allowed to say anything.

Anyone else wishing to volunteer, please notify Prof Will at the Western General on 0131 537 2115 / 0131 536 2000.

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

Frances reported that there has not been much activity since 24 January; the only income has been 2 standing orders from Jim Shepherd's daughter £10 and Mr & Mrs Smith £10. Also collecting cans from the Station Bar (not counted yet) and £247 from Anne-Marie from her knitting.

Expenditure included the haggis meal at the January meeting £30, we paid members' expenses of £120 and made a donation to Ataxia UK of £1,000. We got a thank you letter for the latter (eventually). The bank balance was £868.07 at the beginning of March.

### **4. Speaker from VOCAL Mary Prentice**

Voices of Carers Across Lothian <http://www.vocal.org.uk>

A carer herself with an autistic son (27) Mary knows a little about ataxia as she was a nurse a few years back, now retired, but not as much as we do.

Her son was diagnosed, after a lot of difficulty, with Asperger's Syndrome and she knows how difficult it is to obtain access to services. She struggled for 26 years after her son's diagnosis and only found out about VOCAL after seeing a form in her doctor's 'Are you a carer' with a lot of useful information. She enrolled on a course about looking after people with mental health and was asked to talk on behalf of VOCAL to groups of professionals & support groups. Seven of them trained for several weeks and this is only the 2<sup>nd</sup> time she has done it.

VOCAL cares for the carers – who is a carer? It can be anyone. People move in and out of being carers throughout their lives; as a parent, child, relative etc. Mary had her children late, & her mother had her children late, so by the time of her son's diagnosis both parents & in laws were also ill. This will happen more often as people have their children later in life & have fewer children & are often geographically separated. Caring is therefore becoming an increasing problem. Over the years carers have saved the government £millions.

The organisation belongs to the group of independent organisations, and is a member of the Princess Royal Trust which has many members through Britain and 34 organisations in Scotland. It is funded half through the NHS; Midlothian, West Lothian and Edinburgh Councils also contribute and some money comes from small grants, lottery etc. VOCAL is relatively well funded. Small grants sometimes arrive from unusual sources eg the Society of Haberdashers paid for her kitchen to be fitted. Lottery funding is only for new projects. VOCAL has 22 paid staff and 60 volunteers.

VOCAL offers Information and advice on community care, long term care, respite care, housing in the form of publications or they can direct people to somewhere else. They offer training services to provide expert carers, showing how to handle people safely, speech therapy etc. They also have an advocacy service, eg in the transition to long term care – can help you to state your case, directly helping you, the carer. There are counselling services for carers (unlimited) because people tend to lose contact with their friends, relationships change etc. VOCAL also offers family support services. The main office is in Johnston Terrace with branches in South Edinburgh & Dalkeith.

VOCAL supports people who provide unpaid care illness / disability. It also campaigns to improve carers' rights and has entered into partnerships with other organisations. Why do carers need support? Poverty, isolation, ill health, depression, giving up their jobs or at least half their income. Losing their pension rights. If you are working you have to juggle things.

VOCAL helps people with access to information & financial support. Mary's son was made redundant and has been having a terrible job getting benefits – even though Mary knows how she finds it's very difficult. The 2001 census showed 5.2 m carers in E&W and proportionally the same level in Scotland. 300,000 people become carers annually. No one asks you, or if you can do it, but it just happens. Tasks they might have to do include doctor, nurse, medication, dressings, food preparation, secretary, PA, paying bills, filling in forms, assessing risks, taking to appointments, entertainment, outings, teacher, personal shopper, roles they didn't do before, like changing light bulbs, mowing the grass etc. With dementia they are also a prison officer, acting as an advocate attending meetings, justifying behaviour etc.

70% of care is provided unpaid by family or friends. People don't always recognise they are carers; it can take up to 10 years to realise it. Voluntary provision is worth £13.9 billion – £57.3 billion and a 10% drop in voluntary care would result in a 33% increase in the costs of paid care.

Mary showed a sample of leaflets including one on dealing with diabetes. Give names and Mary can send whole pack. It's difficult for people to find out about the organisation. Mary was a nurse but didn't know about VOCAL. Talk to student nurses to spread the word. Publicity is so important. Doreen heard because she was in hospital and the nurse saw Tom having difficulty walking and mentioned it.

A general discussion followed, and it appeared that there can be a lot of difference in service provision for disabled people in different areas. Adaptations can be provided eg a ramp or wet room, you can apply to come down a council tax band.

Derek proposed a vote of thanks to Mary for an interesting and informative talk. She can send packs to anyone who is interested - please telephone Derek on 0131 477 4371. <http://www.vocal.org.uk>

## **5. Social Events**

The West of Scotland branch is holding a joint meeting at the Alona Hotel on 4 April 2009. If anyone has other ideas for social events can they please ring Derek on 0131 477 4371.







## **6. Any Other Business**

Doreen was at a Guild meeting last week and the speaker was from canine partners (dogs for disabled people) there are 130 commands that the dog learns – can assist with dressing, put washing machine on, do the shopping etc. <http://www.caninepartners.co.uk>

## 7. Dates of Next Meetings

Joint meeting Alona hotel 4 April 2009. The next Branch meetings will be held on Saturday 9 May 2009 (the AGM), Saturday 12 September 2009 and Saturday 14 November 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 467 9023 <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://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.