

CONTAXIA.

ATAXIA~EAST Newsletter 'Æ'

#108

Oct 2023

Dave's 'Dithering's'



Sue and I were to attend the AUK Conference in October, but alas Sue tested positive for Covid a few days before, so we were unable to attend. A disappointment but I am sure we would not have been welcomed if all knew! So I had to revert to the virtual version. This year, instead of me attending the Benefits 'Break Out Session' I opted for the Chair Pilates Session! [See conference notes]

It is unfortunate that we are not having a Christmas meal but can understand the reasons, we all must travel so far in what could be bad weather. Roll on next summer.

As this is my last Contaxia for 2023 may I take this early opportunity [too early] to wish you all a Merry Christmas & Happy New Year.....

Dave

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Meeting Notes 14-10-23

Introduction.

Dave thanked everyone for attending, we have a few things to sort which I will cover in AOB. The venue where we meet at had

several other events on, hence we have a much smaller room which is not ideal.

Present:- Fran & Paul Charman, Alison Gilby, Sheila & Terry Mckenna, Bob & Jan Robson, Elaine & Phil Sibley, Dave Stubley [Chair].

Apologies:- Keith & Jackie Croft, Lesley Gordon [Treasurer], Sue Stubley [Secretary]

Chairmans Report

The number of members attending has much depleted, whether it's because I do not hold interesting meetings I don't know, but comment would be appreciated whichever way. I was assured it was not me but a verity of reasons including Covid which had made people more wary.

Treasure's Report [completed by Chair in Treasure's absence]

Lesley let us know that we have £1914.47 in the account.

Æ Secretary's Report [completed by Chair in Secretary's absence]

Membership has remained constant for the last few months at 51 although no one has let us know of any change of circumstances apart from Jo Johnson who has moved to near Cromer from Kings Lynn. Please let us know if your contact details have changed.

AOB

1 – Christmas cards, why not make a small donation to A-E. This was agreed by those at the meeting. For the bank account details to pay via BACS please contact Dave.

2 – Fundraising does anyone know of fetes/fayres that we can attend. Phil noted that many venues now require Public Liability insurance that could reduce our takings by a considerable amount, hence creating a reluctance to participate.

3 – Tombola – The Tombola prizes that have been collected over a period of time, can they be passed on if not being used. Considering the situation in 2 above it would be retained until a solution is found.

4 – Christmas meal – Only 7 showed interest so that is not enough to arrange for a meal at the GAC has the minimum is for 15. After a lot of discussion, it was agreed to have a summer meal instead and possibly not at the GAC as space may be limited if we are in the same room as where we had today's meeting.

5 – Treasurers position – Lesley has said that she would like to stand down for personal reasons. Her work as Treasurer has been excellent for more years than I can remember Thank You. Alison Gilby has agreed to take the position on. The process of

changeover will begin as we get time.

6 – Future of branch – With Alison taking over from Lesley there should be no problem in the branch continuing.

7 – Security – At previous meetings we had discussed the use of security cameras for the home. Many of these options proved expensive but Phill had found a Ring doorbell that he had bought on Amazon for £60 and he said it worked perfectly.

List of future meeting dates

13 Jan 24 – Zoom Meeting TBA with AUK.

?? April 24 – AGM at GAC TBA

The raffle and hat sales raised £30.00 at the meeting, Thank You.

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### AUK Appeal



**In 2022 your generous support brought in a wonderful £38,542 through the Christmas Challenge.**

**A wonderful total which ensured the development and continuation of the essential Ataxia UK Helpline and we're bringing The Big Give Christmas Challenge back in 2023 from midday Tuesday 28th November until midday Tuesday 5th December. In support of Information, Helpline & Advocacy Services.....**

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AUK Conference notes 23

Sue and I were all booked into the AUK Conference weekend on 20-21 October 23 and were ready to go when the weekend before Sue tested positive for Covid. We quickly realised that it would not be advisable to attend and possibly pass it to the many ataxians that would be gathered there. After a few quick emails to the organisers in the office we were able to cancel our meals and accommodation and we were offered to attend the 'virtual' conference. A feasible option which we took up.

On the Saturday morning we dually registered on Zoom at 9am ready for the start at 9.30 and just like we had been there, Paul Coia opened the proceedings. The one thing that did cause me some disconcertment was that there was only one disabled toilet on that level, I was pleased I was at home for more convenience, considering how we had queued on previous conferences there.

Sue Millman, the CEO of AUK, then gave us an update on AUK's workings. Brexit had definitely affected the way they worked with other European countries though it is hoped this would improve.

Most of the adult specialist centre's now had a children's unit attached to them. There are more specialist nurses to be employed but this may not happen until 2025.

This year they have £115,000 deficit, so it is essential that fundraising continues. The work of Ataxia UK's Ambassador and Trustee, Carol McCudden, who

has FA, and who attended the International Congress for Ataxia Research (ICAR) held in Dallas, Texas, from 1st – 4th November 2022, helped the cause significantly.

One interesting talk in the 'It Works For Me' advisory category was Assistance Dogs where representatives of the organisation demonstrated how a dog could help ataxians by picking up things you drop or fill and empty the washing machine among many other things including helping you undress. This caused Sue to chuckle as she is my 'dog' [I Love Her] She said "But it doesn't help you dress". True!

In the CA update, the doctors admitted several 'specialists' asked "What is Ataxia". The Sheffield centre is investigating CANVAS (cerebellar ataxia, neuropathy and vestibular areflexia syndrome) which are present in people with ataxia of unknown cause. Also at the Sheffield Ataxia Centre, they have been investigating a type of ataxia, known as 'PACA', that could be responsible for a number of idiopathic ataxia cases.

So, there is a lot of research going on!

Then came our 'breakout' session, Chair Pilates, well what can I say, when taking part our upper bodies were being twisted all over and our arms going in every direction, all with controlled breathing! I'm not saying it was not beneficial but I need a bit more practice and Sue came out worse with aches in her arms

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especially. I'm sure she put a bit too much effort in. But overall, it keeps the muscles loose.

Sadly, the personal attendance at the Conference was down due to travelling in the bad weather, Storm Babet, Covid and possibly cost so next year Sue Millman will be recommending to the Ataxia Board to hold smaller regional events and have a virtual meeting? So, my concerns about queuing for the loo may be unfounded. I am told there was approx. 110 there and 80 'virtual'.

Extra information from Ataxia UK's web site. www.ataxia.org.uk

CONTACTS

**Æ Chairman
Dave Stubley
33, Grosvenor Road,
Frampton,
BOSTON,
Lincolnshire,
PE20 1DB.**

Tel: 01205 722771

djstubley@aol.com

**Ataxia UK Helpline
help@ataxia.org.uk
0800 995 6037.**

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Dates for your Diary

**13 Jan 24 – Zoom meeting-
TBA**

**6 or 27 April 24 – AGM at
GAC – TBA**

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