

CONTAXIA.

ATAXIA~EAST Newsletter 'Æ'

#114

Jan 2025

Dave's 'Dithering's'



Happy New Year to you all, I hope you enjoyed your festive celebrations and are looking forward to a bright 2025.

Barbara & Steve, now living on the Isle of Lewis, have sent us a message as well as contributing to Contaxia in the form of recipes gleaned from a 1980's ataxian publication. I will include some of the recipes in Contaxia as they are fairly simple and look tasty.

I did contribute to the Big Give on behalf of the Branch and AUK received £225 from our £100 donation [with Gift Aid]. Hope next year we can do the same.

The return to our original George Alcock Centre proved to be beneficial to everyone present even though it is a little more costly.

I've had a couple of interesting 'virtual' meetings that I have summarized for you in this Contaxia.

As usual any contribution to Contaxia would be welcome, though I have added a 'personal experience' this time.

See you at our next meeting.

Dave

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Meeting Notes 30-11-24

Introduction.

We are back at our original venue so that we can hear each other, and I hope the early start has not caused any problems for you all. In fact, it is good to see Bob & Jan here because of the early start.

We have had an early Christmas card from Barbara and Steve, passing on all their best wishes to the Æ Branch.

Present:- Fran & Paul Charman, Alison Gilby [Treasurer], Sheila & Terry Mckenna, Bob & Jan Robson, Dave Stubble [Chair], Sue Stubble [Secretary]

Apologies:- Trudy Brown, Keith & Jackie Croft, Nigel Davis, Jo Johnson, Elaine & Phil Sibley. Steve, Barbara & Angie Trafford

Chairmans Report

AUK Big Give starts next week, 3rd Dec.

GAC has had a price increase but I have found another contact that has responded to my emails so avoiding the contact problems I have had previous meetings.

Treasures Report

Alison was able to tell us we have £ 1977.97 in the account. There was a variation of £15 between Alisons account and the banks, to our advantage, Alison would investigate further but I suspect it happened during the long and frustrating change over from Lesley to Alison. Alison now has all documents from the bank going to her.

Æ Secretary's Report

There had been little change in the membership though we were awaiting full contact details from a couple of new members which Æ [Dave] need to know but they will not be available to other members under the GDPR rules.

AOB

1 – The Big Give, this was discussed and agreed that we would pay £100 as a lot of our funds have been given for our use only. Dave said he would pay it on behalf of the Branch so that AUK would benefit from Gift Aid giving them £225.00.

2 – Power of Attorney [PoA], Sue brought problems that had occurred with her father who had had to go into a nursing home and they had asked if she had PoA, which she didn't and the home preferred she had. According to our solicitor, her father would have to agree to this by himself but sadly he would not understand what was happening so PoA could not be achieved. It was asked how many other members had PoA set up, with about 50% saying Yes. It was advisable that everyone sought PoA before it was 'too late'.

3 – Fran had said that she had recently had Covid and spent a few days in hospital and it had taken the 'stuffing out of her', Many of the members reiterated this and said that a lot had lost all strength and it takes a long time to get over any ailment that a 'normal' person would easily 'shake off'.

4 – Future meetings, Dave asked if everyone was happy to have the next meeting as a Zoom one but most felt they would prefer a face-to-face meeting at GAC even though it costs more and the weather could be bad. Starting an hour earlier did help and by the time we meet again, probably in early February, things might not be too bad.

List of future meeting dates

15 Feb 25 – GAC- 1300hrs start

?? Apr 25 – GAC - AGM

The raffle raised £21.00 - Thank You.

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### A Message from Steve & Barbara

Happy New Year to one and all – let us hope it will be a better (and drier & warmer) than last year.

After our epic move to the Isle of Lewis way off the North West shores of Scotland, I came across the wonderful recipe book which was ‘devised, printed and published’ by the then Friedreichs Ataxia Group – later to become the Ataxia Charity. This book was put together by many people connected to the charity giving their recipes free of charge to help raise money for the research into Friedreichs Ataxia.

The book, named FAXSNAX was published in 1986, with illustrations by Dennis Cordwell and the whole idea was dreamt up by Mrs Beryl Holt who saw it through to final publication.

The book is full of wonderful recipes which I will share with

you all by sending recipe’s taken from this book and include the persons name who originally sent it in for Dave to pop into Contaxia..



So

look out for the regular recipes....

Once again Happy New Year from Steve and Barbara Trafford

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Volunteers Zoom 10/12/24

During December I attended a Zoom meeting, set up by AUK, for Self Help groups and Branch leaders. Some of the interesting things discussed are noted here:-

- They liked the idea of us donating our end-of-year account surplus money to the BigGive during December, so doubling the money and adding gift aid.
- Most groups/branches enjoyed the conversation side of the meet, thus helping one another.
- Though groups/branches have several members, often above 30 or more, on average only about 5-20 attend meetings.

- The pandemic cut numbers down and many are housebound.
- Ataxia is not known of by many GP’s. One example was an ataxian changed doctors, the new one asked what ataxia was?
- 70% of benefit claims for ataxians are rejected, AUK can help many appeal through the Helpline.

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### PPIE Meet at SHTH

Also, during December I attended a virtual meeting with Prof. M. Hadjivassiliou at Sheffield Hallamshire Teaching Hospital, where the Ataxia Clinic is, along with other doctors and ataxia sufferers known to the Prof. The aim was to get an update on the research the Sheffield team had done and how ataxians could help.

We were told about the drug Skyclarys and how it may slow or prevent the progression of FA, research is ongoing.

The Mitochondria in cells are affected and these provide the energy we require for everyday living. They are trying different drugs to see if there is any change, often drugs that were used to treat other conditions like Parkinsons may help.

It was also asked if anyone was willing to volunteer to go through movement test, example being could they get on to an examination table or chair.

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You support us and we support You!

From Personal Experience

As mentioned in my 'Ditherings' I thought I would share an experience that occurred and I had not planned for even though I thought I had a 'master-plan' for every event???

On New Years Eve after attending a family funeral we [Sue & I] were not in the mood to go out celebrating and with bad weather forecast, a quiet night in looked the best option. Settling down on my riser/recliner chair with my legs and feet up, as advised by the doctor to reduce swelling, we watched TV. Low and behold at 9.15pm the lights flickered twice and then complete darkness, and I mean black, as the electric went off. Our comments to one another were 'how long will this be' and as we sat there unable to see each other, reality set in. Sue felt her way to the kitchen to get a torch that we always leave on the worktop for said emergency's. Returning with the light source, we were able to locate a battery operated 'candle' that provided sufficient light to see in the room.

Then reality, really set in, when I realised that of all my battery-operated equipment, stair lift, emergency lift cushion [Elk] and mobile hoist would work, my Riser/Recliner chair wouldn't! There I was, laid back with my legs in the air, STUCK. After a few frantic minutes of trying, I was unable to move and I started to think would I be here until the electricity supply was returned? Further thoughts went through my mind, should I need to go to

the toilet with my legs in the air, water does not run uphill.

Something had to be done with whatever was available, with all of this, our phone kept ringing telling me my electric was off and being a person of priority, they would get the supply on asap, I knew that! Train of thought was to get my mobile hoist and lift myself out, imagine all this in relative darkness, but we persevered with relative success and as many of you know these excellent hoists do not run easily on a carpet so it was a matter of getting my wheelchair as close as possible to the R/R.

Safely deposited onto my wheelchair a great relief set in and we sat there in near silence as we didn't have a battery radio, 'it's on the 'to-do list'. Within half an hour the supply returned and the 'status-que' returned.



My

thoughts now are you can't prepare for every eventuality.

Get out of that!

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## FAXNAX Recipe [a bit late!]

### **A Christmas Yule Log with a difference.....**

1 Packet Chocolate Chip Cookies  
1/2 Pint Whipped Cream  
Sherry

#### **METHOD**

Dip each biscuit into the sherry..... (not through the neck of the bottle 😊 )

And sandwich together with the whipped cream to for a log shape. (do not leave the biscuits to soak in the Sherry for too long, as they will become soggy and unmanageable).....**(same could be said of the Cook)**

Pour any remaining Sherry over the log – please note: the recipe doesn't say what quantity of Sherry should be used!

Cover the Log with remaining Whipped Cream and decorate with chocolate flake or grated chocolate and Glace Cherries.

Source: submitted by Marilyn Millington Connah's Quay, Clwyd

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Dates for your Diary

15-Feb-25 – GAC, PE2 8QZ
– 1300 hrs
??-Apr-25 – GAC, AGM -
TBC.

If you know of any venues or
places, we could visit please
let us know for the future?

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