

## Ataxia UK West of Scotland Branch

[Ataxiaukwestofscotland@gmail.com](mailto:Ataxiaukwestofscotland@gmail.com)



# ATAxia



Sunday 4<sup>th</sup> June 2023



**Present:** Derek (Chair) Iain (Secretary), Debbie (Treasurer), Christine, Sally, Stuart, George, Haider and a new member Ken Synnot

**Apologies:** Janice, Roseann, Gerry, Rick, Sheena & Donald, Martin and Ross, Ronnie & Linda.

A Zoom link had been kindly provided by Sally. Johanna and Shona joined in for part of the meeting.

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### WELCOME

The meeting was fairly well attended with 9 members being present at Tesco Silverburn and 2 members on Zoom. Derek welcomed everyone especially Ken who has only recently been diagnosed with Ataxia. The members introduced themselves to Ken.

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### **ANNUAL GENERAL MEETING**

Derek gave the Annual Report of what the group had been doing over the previous 12 months

### **DEREK'S REPORT:**

It's been another busy and hopefully enjoyable and informative year

We got back to face to face meetings after what seemed like a lifetime on Zoom.

We've tried having hybrid face to face and zoom meetings for those unable to attend in person but with connection, time delays etc, it didn't really prove worthwhile

### **Some of the main highlights included;**

#### **Annual Conference**

The Scottish Annual Conference was on 18<sup>th</sup> June at the Leonardo Edinburgh Murrayfield Hotel.

There was a range of speakers and activities including dr's Q&A and breakout sessions on Pilates, Benefits etc

The day included some inputs from members under the heading "It Works For Me" where we recorded a video and edited from clips that most members of the group had recorded. I still have a copy of that video and it's on the Ataxia website if anyone wants to see it again

[West of Scotland support branch | Ataxia UK - YouTube](#)

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### **Summer Event.**

A little late for summer and a little early for Christmas, In September we returned to The Alona Hotel in Strathclyde Country Park for afternoon tea with about 25 attendees.

We have previously visited there as it was easier for group members who lived that side of Glasgow to attend.

We had invited the East coast branch hence it was a bit more expensive but no one from the East came.

We did welcome Jo & Chris who came all the way down from Perth

### **Calamity Kirsty, My wobbly world.**

Kirsty McPake's book about her experiences of living with Ataxia was on Amazon.

A donation was coming to us but I've not heard anything

### **Fundraiser**

Debbie's son Abdul Jabbar who is 8 years old raised £100 for us from sponsorship for gym exercises

### **Fi**

We were saddened that Fi, our pilates teacher passed away.

Fi was humourous and patient (especially with Martin who despite not having ataxia found the exercises challenging)

Some of us went to her Funeral where she had instructed everyone to wear bright colours in tribute to her personality

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### **DEBBIE'S REPORT:**

In the year we spent more than income received and we need to think about some group fundraising for the branch

Income for the year was £235.34 between donations and bank interest while expenditure in the year was £412.33.

This expenditure included £327.05 for a summer social event, £46.50 for food and refreshments at a meeting in lieu of a Christmas event and £38.78 on card/gifts for Fi who sadly passed away

Debbie gave a Financial Report and told the group that the current balance in the bank was £1232.57. She informed the group that there had not been many donations to the group recently and that we should think about some fund raising initiatives to bring some funds in to enable us to have our outings.

Iain didn't have anything to report except that Ataxia UK had commented favourably on the minutes that he, in conjunction with Derek, have been producing.

Derek said that it was time for the Office Bearers to stand down. Derek Iain and Debbie all indicated that they were willing to continue in their respective roles subject to nomination, seconding and election but should anybody wish to take on office they would support them. Christine nominated Derek as chairperson for the forthcoming year. George seconded and Derek was elected. Sally nominated Iain to be Secretary, Debbie seconded and Iain was elected as Secretary. Iain nominated Debbie to be Treasurer, Derek seconded and Debbie was elected to be Treasurer.

That was The AGM covered for another year

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### **Other points:**

### **CONFERENCE**

Derek told the group about the Annual Conference which this year is being held at the Radisson Blu Hotel at East Midlands Airport near Derby on Friday 20<sup>th</sup> and Saturday 21<sup>st</sup> October 2023 [2023 Annual Conference – Ataxia UK](#)

Its not cheap but it's a hybrid conference as well and that's worth the £15 for that online  
Booking opens on 7<sup>th</sup> June

### **IDENTITY CARDS**

During the introduction to the group Ken was told about the Identity Cards that are available from Ataxia UK. A link for anyone who may be interested in obtaining one is here

[ID Cards – Ataxia UK](#)

### **LEAFLETS**

Derek brought the revamped WOS Ataxia leaflet and each of the members took a quantity away for distribution to their local Doctors surgeries and hospitals. The latest version hasn't yet been uploaded but there is little change to the previous version which is on the Ataxia UK website [West-of-Scotland-Branch-leaflet-May-2019.pdf \(ataxia.org.uk\)](#) and a copy is attached as well as hard copies you could put in dr etc waiting rooms

### **CITIZEN ADVICE BUREAU RARE DISEASES AND ATAXIA PROJECT**

Derek reminded the group about Eilidh Clark who is a full time member of the Parkhead Citizens Advice Bureau in Glasgow. Contact details [ataxia@parkheadcab.org.uk](mailto:ataxia@parkheadcab.org.uk) telephone number 0141 554 0004. Eilidh explained that she was part of a National project in a partnership with AUK for Scotland that had started on the 1<sup>st</sup> April 2023 to provide information and advice on a range of topics including benefits, debt, housing and

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employment. She has spent some time at AUK HQ in London and she was willing to discuss any issues that Ataxia sufferers, their families and carers may have. She can be contacted by telephone, email or Skype. She will also be available in person by appointment

A leaflet explain services available is attached and a reminder its better to contact her via e-mail

### **PILATES**

Gerry had emailed Derek to say that he had asked his instructor if she would be willing to give a class to the group but he had not yet had a response.

### **MEDICAL GUIDELINES**

Many GPs may not be familiar with Ataxia in their Patients and Ataxia UK have published these medical guidelines which you could pass on to your dr.

A copy of this is attached to this e-mail

### **THE BIG MOTABILITY EVENTS**

[The Big Event Edinburgh - Motability One Big Day](#)

[The Big Event Birmingham - Motability One Big Day](#)

For those of you in the market for a motability car or Wheelchair Accessible Vehicle, you may find these motability events which will be live streamed



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### **JAMES ATKINS**

It is with sadness we bring the sad news that James Atkins has sadly passed away

James worked with Ataxia UK managing the InControl project from Jan 2020 until he moved on in November 2021

James was here during the Pandemic so many of you will remember James from presentations he made on zoom

You may remember we played bingo on Zoom and it was James that told me how to do it online.

We send our condolences to his colleagues, friends and family

### **ROUND UP FROM MEMBERS**

Derek told the group that he is not going to participate in progressive research trials as he was unable to carry out one of the physical tests. In addition to the Treasurer role that he has been carrying out for the Govan Community Project Charity he has taken on the role of Treasurer for a foodbank charity, The Scottish Pantry Network

Christine and Iain are still regularly watching two of their grandsons most weeks usually for two days but going forward it is being cut back to one day. They had been to their caravan a couple of times and enjoyed the break away. Iain said that things had stabilised with his heart problems and was learning to keep his activities within the limits of his abilities. He has also had a few sessions of having blood run off to reduce the iron level in his body at last it is having some effect.

Debbie had nothing to report again. She said that her son was moving up to primary 5 after the summer holidays. She said that they hadn't booked any holidays as yet.

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Sally, as usual, has been keeping herself busy in her garden and with her houseplants. She is also volunteering at the Royal College of Physicians and Surgeons of Glasgow being a case study for trainee Doctors to see if they can diagnose what condition she is suffering from.

Martin was unable to attend the meeting as he had arranged to take his niece who is visiting Scotland on a day trip to Arran.

George said he had enjoyed spending a few days away with his daughter in Ayr. Whilst he was there his granddaughter celebrated her birthday. He also updated the group with the result of his application for PIP. Having had his claim refused he had contacted the CAB at Cumnock who had helped with his appeal, which had been heard in Ayr, which had been successful and his award had been backdated to when he initially claimed.

Stuart told the group that his Dad had taken him over to Rothesay for a few days staying in the Glenburn Hotel. He had thoroughly enjoyed his visit meeting up with friends and seeing familiar places.

Haider said that after ordering his new Motability car a year ago it had finally been delivered a Seat Arona. He was very pleased with it and was enjoying having automatic gears. He said that due to mobility issues he had arranged with Strathclyde University to carry out most of his work at home. Only attending University when he wanted to use the laboratories. He was in his final year of his course and had still to decide where he would be living after he finished.

Johanna told the group that she was hoping to have a holiday abroad this year and had been asking for first hand advice / experiences about hotels and destinations. She said that she has had some recommendations for Lanzarote

Ken told the group that it had been a long and drawn out process to get a diagnosis of what has been causing the difficulties he has been experiencing. He has had all kinds of tests and scans. He has been diagnosed with Peripheral Neuropathy and Cerebellar Ataxia. He was finding everything very tiring and is relying on public transport even for relatively short journeys. He was advised to contact Eilidh Clark at Parkhead CAB and take her advice on what



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assistance may be available to him. He said that he had had some contact with the NHS Rehabilitation and Enablement Service nurses which had been useful.

## **HYBRID MEETING**

Having tried, and only having partial success, over several months to have a zoom link at the “in person” meeting it was decided that going forward we will not include the zoom link.

## **SUMMER RECESS**

It was agreed that we will not meet in July and our next meeting will be in August.

Derek thanked everyone for coming along and looked forward to seeing everyone after the break

## **Date of Next Meeting:**

**Sunday 6<sup>th</sup> August 2023 at 2pm**  
**Tesco Silverburn Community Room G53 6AG**

**Contacts:** Chair - Derek Taylor  
Treasurer - Debbie Lone  
Secretary - Iain Macpherson

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## The West of Scotland branch **Member Support Fund**.

The member support fund is for the members (people affected by Ataxia and their carers) of the West of Scotland branch using money raised specifically for the West of Scotland branch Member Support Fund. It has been agreed that the Member Support Fund should be used to:

- o Reimburse branch members, upon production of a receipt at a branch meeting, up to £35 per month for alternative therapies.
- o Reimburse branch members, upon production of a receipt, up to £35 per month for transport to and from our branch meetings when public transport or car sharing is not possible.
- o Reimburse branch members, upon production of a receipt, up to £35 per month for costs incurred in attending ataxia related events, i.e., Conferences, GDA events, Ashcraig Family Evening – either transport, or registration fees. If anyone goes to such an event, branch members would like to hear a short talk about the event.

Members can only claim up to £35 per month. This can be a combination of alternative therapies, transport or ataxia related events up to a total of £35 per month

- o The Member Support Fund will support branch members in branch events or outings, e.g., Christmas and summer events. The Member Support Fund is not able to pay for alcoholic drinks. There will be a £5 non-refundable deposit per person for each event. The non-refundable deposit will be capped at £10 per household.

Please note that members can only make a claim to the member support fund and be reimbursed if funds are available in the member support fund.

As monies in this fund are limited, reimbursement will be on a 'first come first served' basis. Therefore, please try to make your claim monthly (at branch meetings), try not claim for more than one month at a time and do not claim for reimbursement of more than £35 in any one month.

Ataxia UK will not be able to reimburse branch members who make a claim to the member support fund when the fund monies have run out.