

ATAXIA

LEICESTER SUPPORT GROUP OCTOBER NEWSLETTER 2021

Hi all,

I hope you are doing well and wrapping up warm, as, I'm sure you don't need me to tell you..... IT'S GETTING COLDER NOW! Our heating clicked in at the weekend!

We had a nice little meeting 23rd September at The Local Hero Pub, Aylestone Road in Leicester. There were 7 of us. We enjoyed a light lunch, while talking about the importance of exercising and keeping going. Suki suggested that it was possible to hire a room at Age UK on Humberstone Gate, the Clarence House. So I have book the Activities room on Friday 15th October at 11am – 12.00pm, to do a little seated exercise. It is fully accessible, on the ground floor. Please, with accordance to the current Government Guidelines, that masks will still need to be worn. I will take sanitiser gel with me. A few people have confirmed with me that they will be able to make it. If you could bring a drink with you, and there will be a small charge of £3.50 to cover the hire of the room. If you feel that you want to join us, either ring me or email me, and of course, please let me know if you can't.

Unfortunately, neither Anastasia nor James could make it to our meeting, due to prior commitments. But Anastasia did email the

presentation that they were going to present. I will include some of it for you now:

- All our volunteers are part of the [“InControl”](#) project- decrease feelings of social isolation and increase people’s feelings of wellbeing
- Funded through the [National Lottery Community Fund](#) till end of 2022
- Keen to look at developing new services for ataxia community- always looking for ideas/suggestions. This is especially important as UK moves out of lockdown restrictions
- Always keen to hear from volunteers/members on how we are delivering the service- what can we do better ?

VIRTUAL WELLBEING SESSIONS:

Held on Friday from 1-2pm or Tuesday 11.30am-12.30pm

Held on Zoom if you are free- you just need to register using the links below:

Friday 24th September: Music Club <https://bit.ly/2XGG10s>

Friday 8th October: Travel and Holidays <https://bit.ly/2XH5xDd>

Friday 22nd October: Music Club:- <https://bit.ly/3mhxoEm>

Friday 29th October: Film and TV Helen Mirren <https://bit.ly/3iZIP1h>

Friday 12th November Care Needs: <https://bit.ly/3k56Tz3>

Tuesday 16th November: Pilates

Friday 19th November: TV Club Happy Valley/Last Tango

<https://bit.ly/3CZbsUm>

Friday 26th November: Music Club <https://bit.ly/37WJzho>

Tuesday 7th December: Pilates

Friday 10th December: Film Club Home Alone <https://bit.ly/3mlOllp>

Virtual Chair Pilates

- Virtual Pilates session designed for people living with ataxia
- Had 21 people attend our pilot session on 2nd March, 18 23rd March, 22 April 27th
- People like instructor's tone and pace as felt workshop was inclusive.
- Way to become involved in exercise, without the need to feel self-conscious around their ataxia
- Updated website with future sessions, which you can book onto;
- **16th November 2021 11.30am-12.30pm**
- **7th December 2021 11.30am-12.30pm**
- £5 per household to cover costs for instructor
- Please contact us on volunteering@ataxia.org.uk to book yourself a place

AOA2 Facebook Group

- Created for people affected by AOA2(**Ataxia with Oculomotor Apraxia Type 2**)
- This includes parents/carers /medical professionals and those living with the condition
- Created in partnership with the [AT Society](#)
- Recruited 3 volunteers with AOA2 as moderators for the group
- You can join the group through the link below;
- <https://www.facebook.com/groups/285323423092568>

Annual Conference 2021

- **Friday 15 - Sunday 17 October 2021**
- Virtual conference – last year we had over 120 households joining us on Zoom!
- Weekend of guest speakers, research updates, virtual workshops, entertainment and plenty of opportunities to meet others living with ataxia. See the full agenda [here](#)
- Tickets cost £20 per household for the whole weekend: available to book on the website now
<https://www.ataxia.org.uk/latest-news/virtual-conference-2021/>
- Neuro Life now is partnership between [The Brain and Spine Foundation](#) and the [Neurological Alliance](#)
- **NeuroLifeNow** is an – an app and website that supports you to share your experiences in order to influence change. We're committed to improving treatment, care and support for every person with a neurological condition.

- Straight forward and easy to use, and update health information on a monthly basis.
- Not many people with ataxia have registered, want to ensure your voices are heard in this work
- Further information can be found on the links below;
- <https://neurolifenow.org/about-neuro/>
- <https://www.facebook.com/NeuroLifeNow/>
- Thank you for reading about developments within InControl and Ataxia UK
- We're always happy to hear from you- especially if you would like us to develop a new service for people affected by ataxia.
- Can feedback on our existing services as well
- James and Anastasia can be reached on volunteering@ataxia.org.uk

I will book our Christmas Lunch for Thursday 16th December at 12.30pm at the Local Hero Pub, and confirm it with you all in another email together with the scrumptious menu.

Here are a few photos from our meeting:





Stay safe all.

Claire

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