

ATAXIA UK COVENTRY AND WARWICKSHIRE SUPPORT GROUP

NEWSLETTER FEBRUARY 2016 ISSUE 25

Hi everyone! I hope this newsletter finds you well.

I couldn't recommend Ataxia UK Conferences enough and the next one is on 7th-9th October East Midlands Radisson Blu. New for the annual conference this year will be a branch and support group session 10am -12.30pm on the Sunday with lunch. 2 delegates from your branch or support group to be nominated to attend with carers if necessary. On attendance delegates can claim back 50% of accommodation for the Saturday night of conference. If you are interested in attending let me know.

Also new: Are you a budding photographer that just so happens to have ataxia? Perhaps art and painting is your thing or even poetry? For this year's annual conference, Ataxia UK is celebrating 'Ataxia and the arts'. They're looking to showcase the artistic endeavours of people with ataxia. So if you have an artistic hobby that you would love to showcase this October, get in touch with us at office@ataxia.org.uk.

Latest research news

A new research project launched on misdiagnosis and the undiagnosed The European Organisation for Rare Diseases EURORDIS is doing research for a position paper on the needs of people who are living without a diagnosis, who have been misdiagnosed or who waited a long time to get their diagnosis. They would like to hear from you if you

Our last meeting - Sunday 24th January 2016



have been affected by misdiagnosis or if your disease is undiagnosed. Please email virginie.bros-facer@eurordis.org.

A promising new collaboration in Australia hopes to gain approval for a new treatment for Friedreich's ataxia. The pharmaceutical company Jupiter Orphan Therapeutics, Inc. has joined with Murdoch Children's Research Institute in Australia with the purpose of eventually gaining approval for a new FA treatment. They aim to develop a more effective delivery system for a drug which utilizes the active ingredient in resveratrol, which has been found to increase levels of frataxin, a protein usually deficient in the cells of people with FA.

After paying room hire for this month's meeting and money collected for coffee we now have £111.85 in the pot. A huge thank you for donations from Marion Abort, Dave Hubbuck, Rob, Emily Ledson, and Mr C Foulkes. Thanks to you the group now has enough money to keep itself going until 2017!

Present were Dave (CA); Sue; Lorraine (CA) and her daughter Emily; Catherine (CA) and her husband Paul; me (FA); my aunty Monica and her partner Rob; and I was VERY pleased to see 3 new members, Lesley, Elaine and Mick, all of whom have CA.

It was great to meet so many new faces and I'm hoping that they got a lot out of coming along and seeing from others that you can live with this! I know how daunting everything feels when you're first diagnosed but you will get there and the best thing about the group is everyone can emphasise. Some of you weren't members of Ataxia UK - you can join at <http://ataxia.ritdns.com/forms/JoinAtaxiaUK>. You might also want to find out about Ataxia Centres at <http://www.ataxia.org.uk/Pages/News/Category/ataxia-centres>. If you're not online you can phone 0845 644 0606.

OUR NEXT MEETING

Sunday 20th March 2016
at 2 - 4pm at Exhall Old School
Community Centre, Exhall Green,
Exhall CV7 9GL.

Who I am and how to contact me: I am Katie Henderson (you can find out more about me at <http://ohbother.co.uk> and I am the named contact for the group. You can contact me by e-mailing katie@ohbother.co.uk or phoning 07565 247 183. I am also on Facebook. The group is on Facebook - search for "Ataxia UK Coventry". For news on group events and to download previous newsletters etc visit <http://ataxiacoventry.co.uk/>.

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