

ATAxia UK COVENTRY AND WARWICKSHIRE SUPPORT GROUP

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Hi all! I hope this newsletter finds you well. First some news from Ataxia UK. On their website you can read about what's going on in the research field and at the moment they have 4 videos that have been made specifically for people that are not scientists so the research aspect is much easier to understand. Have a look at <https://www.ataxia.org.uk/international-research-conference>. Ataxia UK gets no statutory funding so if you would like to help them to raise funds for research please take a look at the appeal they have for a research project on Friedreich's ataxia <https://www.ataxia.org.uk/Pages/Appeal/>. If you would like to and have some ideas about fundraising as a group, just let me know (contact details below). For the latest news on research go to <https://www.ataxia.org.uk/research-news> where you can read about a new phase 3 trial study to identify the safety, efficacy and tolerability of the drug ACTIMMUNE® (Interferon gamma-1b) on people with FA that has been initiated in the US. Have a look - its exciting news!

Have you joined Ataxia UK? If not it's free and easy to do on line - <http://www.ataxia.org.uk/forms/JoinAtaxiaUK/>.

I will be at Ataxia UK's UK Conference- Stansted at the Radisson Blu hotel 2-4 Oct. I have been to a few conferences and they're wonderful events. See <https://www.ataxia.org.uk/Events/2015-ataxia-uk-annual-conference>.

OUR NEXT MEETING
Sunday 13th September 2015
at 2 - 4pm at Exhall Old School Community Centre,
Exhall Green, Exhall CV7 9GL.

After paying for room hire for this month's meeting and money collected for tea and, we now have £34 in the pot. Thank you!!!

Please bring £1 to meetings for refreshments.

Our last meeting - Sunday 26th July 2015



Catherine (CA) and her husband Paul; Sarah (CA); my aunty Monica and her partner Rob and myself (FA) came along. This time we were joined by trustee Richard Brown - we enjoyed his visit so much that I suggested Ataxia UK make trustee visits an annual thing.

Richard reminded us that Ataxia UK gets no government funding and therefore why fundraising is so important. He spoke of a few events - see <https://www.ataxia.org.uk/fundraise-for-us>.

Ataxia UK's new look hasn't proved popular amongst us. We felt that the logo, being grey, isn't as bright and friendly as it used to be - it seems dull and depressing, which isn't 'ataxia' for us!

Richard said how important it is for disabled people to be seen on public transport. People are still surprised to hear how disabled-friendly buses, trains and planes are these days. I cam vouch for this - I've been using them for years as I have never had a car.

We also talked about assistance dogs - Richard retrained his pet as a helper dog and I've now been to 2 Canine Partners assessment days.



Tess (undiagnosed); Neil (FA) and his PA Jenny; my aunty Monica and her partner Rob; and myself (FA) came along for some yummy pub lunch and easy going conversation.

Neil was showing me his NHS power chair, which isn't too dissimilar to the one I have now, only I bought mine privately using my DLA allowance and as such I see a big cut in my allowance every month. I appreciated Neil showing me what's available on the NHS - I will definitely look into it next time.

The very affordable food was lovely!

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/>.