

# COVENTRY SUPPORT GROUP NEWSLETTER

## September 2011

### Our first meeting – held on Sunday 25<sup>th</sup> September at City College Coventry



Our first meeting went so well – I was so happy with how it went! The thing I was most nervous about was the prospect of nobody turning up - but I needn't have worried because in all 14 other people were to follow! For the first half-an-hour or so the group just had a laid-back mingle – we have such a lovely group and I really enjoyed meeting you all.

Then Tina Thatcher, Ataxia UK's Branch and Support Group Development Officer, formally started the meeting. At which point we all introduced ourselves to the group. There were people of varying ages who have FA, CA and various other types as well as undiagnosed ataxias amongst us. There were also family and friends there, who are very welcome as they are as affected by ataxia as the people who have ataxia themselves!

We agreed to meet monthly (see below for details of next month's meeting). The meeting was held in a class room at City College Coventry. The venue was a real hit and I personally really appreciated having our own room to relax in and being able to talk to each other without distraction or background noise. However this room cost £50 to hire and as we opted to be a support group and not a branch we are not eligible for any financial help (see below for more).

Tina also discussed Ataxia Clinics, leaflets and fact sheets, the helpline and advocacy and the Annual Conference (which coincidentally is in Leicester this year). Go to Ataxia UK's website <http://www.ataxia.org.uk/> or phone 020 7582 1444 for more info.

### Next and future meetings

Firstly I have booked a room for our next meeting so please put it in your diaries now – I'd love to see you there!

**Sunday 30<sup>th</sup> October 2 – 4pm**  
**Coventry City College Coventry**

See link on email/enclosed pages for a map and directions.

## **Future meetings**

As discussed above, everyone thought the room was great but it does come with a £50 price tag. I was more than happy to cover the first meeting, and there I received £27 in donations towards the next meeting and I am again very happy to chip in the rest (I was SO chuffed that people donated – a big thank you!). My aunty Monica said that she'd cover the cost of November's meeting – another big thank you to Monica.

I suggest that until we find somewhere suitable that is cheaper/free, everyone who can afford to do so donates £2 or £3 at every meeting (but absolutely no pressure). I am looking into other potential meeting rooms in the city centre and I know some of you are too (please contact me if you have any ideas).

## **A personal word about flu jabs**

Just before Christmas about four years ago I got the flu. I was very ill, took months to recover and in that time my ataxia progressed a massive amount. Please learn by my mistake and get a flu jab, ESPECIALLY if you have ataxia (flu jabs are available on the NHS to anyone who has a long-term health condition).

My mum (who was my carer until I moved out 12 months ago) tells me that flu jabs are free for carers too and found this information for me to pass on to you:

“Julia Ellis, Primary Care Liaison Worker, The Princess Royal Trust for Carers, has written to voluntary sector organisations saying that many carers are unaware that they can ask their GP for a free flu jab if they receive Carer's Allowance, or are the main carer for an elderly or disabled person whose welfare may be at risk if they fall ill.

As well as protection against seasonal flu, Julia says: "Every new carer who comes forward for a flu jab will have the chance to be registered as a carer by their GP and referred on to other services, which is why the Flu Vaccination Campaign is also a good opportunity to give carers the key to information, advice and support."

***I'd welcome any suggestions of anything specific you'd like to see in future newsletters and meetings – please get in touch! I hope to see as many of you as possible on October 30<sup>th</sup>!***

### ***Who I am and how to contact me:***

*I am Katie Henderson, friend of Ataxia UK and named contact for the group. You can contact me by e-mailing [katie@ohbother.co.uk](mailto:katie@ohbother.co.uk) or phoning 07565 247 183. I am also on Facebook and so is the group; search for "Ataxia UK Coventry".*