IPSWICH
SUPPORT GROUP

NEWS LETTER August 2007

It was lovely to see new members this month. Thank you to everyone who contacted me to send apologies.

We had lovely weather this time and air-conditioning in the Lounge was very welcome.

First to arrive was our new member Suzzy who had navigated herself all the way from Bury St Edmunds. You may have met Suzzy on the Ataxia UK website forum.

Suzzy's mother had ataxia so she is very aware of the symptoms and determined to get on with life as much as possible.

Next to arrive was Tom who has 22 year old son with ataxia. His son had symptoms since he was 2-years old and was diagnosed at 4 years. Unfortunately Tom has not been able to persuade him to join us yet. Tom was at our very first meeting in July last year and it was nice to see him and enjoy his contribution to our discussions.

Nigel came with laptop to show photos of June meeting – unfortunately there were no people present from that meeting but it was nice to see photo's of Nigel's baby daughter, Rachael on screen.

Christine Scott has been on our members list from the start as a carer to her mother who had ataxia. Sadly her mother has died but Christine is now recognising symptoms in herself and tests at the London Clinic have confirmed this. Christine was accompanied by her sister, Jenny who is also interested as Ataxia is in their family and all members are naturally keen to be as aware as possible of any new research that would be useful to those diagnosed now and in the future.

We are very pleased to welcome Suzzy, Christine and Jenny to the group. I have added these to members' details list – if anyone needs one please let me know.

As I am hosting a Fund raising OPEN GARDEN DAY on International Ataxia Awareness Day:

TUESDAY 25TH SEPTEMBER

I shall not be having a meeting at the holiday Inn in September.

The next meeting will be Saturday 6th October 2pm in the Holiday Inn lounge unless *any of you* would like me to change that – I am quite flexible and open to suggestions.

Nigel cannot join us on Tuesday 25th but has very thoughtfully given a donation – if anyone else would like to donate in lieu that would be *very* acceptable. Suzzy has kindly offered to make a cake which she will bring along – that will be very welcome.

Diary note – I would be *so grateful* to see you all with family and friends at my bungalow – 66 Yewtree Grove, Kesgrave , IP5 2GL on

TUESDAY 25TH SEPTEMBER from 2 – 5pm. Entrance £2.

email, write, phone, 01473 621604 [or text 07801 544974] anytime or just turn up.

If anyone else is interested in fund raising please contact Sinead Devlin [sdevlin@ataxia.org.uk].

Thanks as always to Nigel for mailing newsletters and attachments.

I will let you know how the Focus group in Peterborough goes on 14th August – presumably as I have not heard, no one else from Ipswich Group is going.

A REMINDER – from Laura Stewart -

Being part of this focus group will mean having the chance to talk about problems you (or someone you know with ataxia) have encountered when trying to get diagnosed and the opportunity to get any issues off your chest. No names will be used in the final report so

participants can remain anonymous. The session will start at 1.30pm and is expected to take about 2 hours. Ataxia UK will provide a free lunch and pay travel expenses for people taking part. We would like to have about 10-12 people for each session, and would welcome a mix of people with any type of ataxia and their family or carers. The only requirement is that you are over 18 years old and able to get to the meeting.

Laura Stewart's email address is research@ataxia.org.uk and phone number is 02075 821444

Sorry no pictures this time as I forgot my camera – okay then – just a little one of my son, Joe, and his new son Finlay.

If you are able to display attached poster, I shall be extremely grateful.

It was slightly overwhelming having 3 new people at the meeting so am not able to relate much info – hopefully we shall have plenty of opportunity in the future to learn more about each other.

If you would like more information and cannot get to meetings do let me know and I will do my best to oblige.

All good wishes, Patsy Riggs

Joe and Finlay [2 months]