IPSWICH SUPPORT GROUP

NEWS LETTER JUNE 2007

As promised we had an official photographer at this meeting and with 14 of us present it made a very nice group. 7 of us were members and the other 7 were family. That included baby Rachael who is now 6 months old and looking a real bonny little girl. Mum and Dad, Nigel and Hazel smiled knowingly when I asked whether Rachael had made any changes in their lives.

Our photographer, Julia, brought along her parents. Dad, Mike has been diagnosed with ataxia as a result of a brain haemorrhage and although confined to a wheel chair is now playing wheelchair tennis. A great incentive to us all. Mike's wife, Margaret was very pleased to find our group so we now have another new member. Welcome Mike and Margaret.

We had another new face, Fred, who has been a member since my local radio interview last year. Fred's mother, Laura, persuaded him to come along but he didn't need any persuading to join in – much to his mother's delight. Fred contracted ataxia as a result of a virus and overnight was reduced to getting around by crawling. He speaks very highly of physio which has practically eliminated his tremor and enabled him to resume his hobby of model making. Well done Fred.

I was pleased to see my old faithfuls Sheila and Dave – I know they have a full calendar for June due to visits from family from overseas. Not to mention arrangements for Lorna's wedding in October and their son's in September. Phew!!! I am grateful to them both for coming.

I was also very pleased that Barry and Jo could make it – it was predicted that they would have moved to Yorkshire by now but luckily for us, they were there with their son Stephen – Stephen and Jo are always very helpful with tea and coffees. I did bring along my husband Ken for that purpose but he was a little shy!!!

That's Ken chatting up Mary. Barry is front left then clockwise, his son Stephen, Mike & Margaret, Mary, Ken, Nigel and Jo [Hazel hiding]

Mary was another welcome face as I know she makes a supreme effort to drive all the way from South Woodham

We discussed gardening which seems to be something common to many of us – I must admit my garden comes second to my computer to which I am addicted. This is me in our garden.

Another interesting topic was the disabled toilets. In this hotel they are situated at the far end – past all the cubicles in each of the gents and ladies. This means that if your carer is of the opposite sex, they have to ask the staff to check if it is okay to go in – the men into the ladies and the Ladies into the gents. I wonder who devised that idea – a graphic designer no doubt. Sorry no picture here!

However, as I have said before, other than that, this is an ideal hotel for position and service. They do allow us to spend 2-3 hours in the lounge which means we do not pay for hired room AND they provide tea coffee and biscuits for £2.50 a head - I only have to pay for the number of members present on the day. A waitress on hand to look after us and drinks available from the bar if required. Excellent.

Dawn and Steve … [sorry Steve, I referred to you as Dave in last newsletter] did anyone notice my deliberate error? If you did, I will send you a prize of a collection box – … anyway Dawn has been to Ataxia clinic in London and has kept me up to date on email. It seems a very worthwhile exercise. I propose trying it myself in due course.

You may recall in my last newsletter I spoke of Amit Roy's wife Sylvia and it is with great sadness that I must tell you that Sylvia passed away recently. Amit has so much knowledge of not only Sylvia's experience of ataxia but much more detail that it is very, very disappointing that all his attempts to bring Sylvia to our meetings were thwarted. Our fond thoughts go out to you Amit and please feel free to join us if ever the opportunity presents itself. I shall continue to keep you on my mailing list.

Thank you to various other members who have emailed, written or phoned me to say they were unable to come to this meeting.

To others who were too busy, otherwise engaged or indeed just forgot – **you are always welcome.**

Please email, write, phone, [or text 07801 544974] anytime.

Julia was very unobtrusive with her camera although very busy so it will be interesting to see the results. Watch out for their use in future promotions.

Sorry about my 'shaky' attempts at photography.

As my son and his family were unable to come along, I am including picture of my new grandson, Fin.

Blessings to you all

All good wishes, Patsy Riggs

I shall be at the Holiday Inn again on Saturday 4th August from 2pm and shall be delighted if you can join me.

If not but you would like to send me news about the progress of your ataxia, I would be pleased to include it in the next newsletter.

If you have mislaid your MEMBERS DETAILS LIST and/or would like a new one, please let me know.

I have volunteered to take part in study of physio for ataxia and will let you know how it goes.

Also I have volunteered for focus group – anyone else interested please contact Laura Stewart – as follows.

From: Laura Stewart [mailto:lstewart@ataxia.org.uk]
Sent: Friday, June 01, 2007 12:11 PM
Subject: Ataxia focus group on the 25th June

Participants wanted for focus group

Ataxia UK is carrying out a project to explore what could be done to improve the experiences of those who are having difficulties getting a diagnosis or getting access to specialists. In order to carry out this project, we are looking for people to take part in a discussion group. This group will be held at the offices of Peter Taylor in Uckfield (The Roller Mill, Mill Lane , Uckfield, East Sussex . TN22 5AA) on the 25th June. I am writing to members of the London branch as some of you, particularly those of you in South London are not too far away from East Sussex and may like to meet up with other branch members for this occasion. Please pass on this information to anyone else you think may be interested.

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.

If you would like more information or would like to register to take part please contact Laura Stewart at the Ataxia UK office (address below) or email lstewart@ataxia.org.uk.

Best wishes   Laura

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You should let Laura know by 15th June if you are interested.