IPSWICH
SUPPORT GROUP

NEWS LETTER APRIL 2007

On such a lovely sunny day, I had hoped to see more people attending this meeting but there were only 6 of us in total that included one member other than myself and one new member.

Sheila came with her husband, Dave and daughter Lorna, who were very helpful with tea and coffee service.

We also had a visit from a new member, Dawn who lives in Basildon, Essex and her husband Steve. Steve's help was also very welcome.

Dawn and Dave have a daughter, Maddie who also has ataxia but who was not inclined to join us this time.

Dawn and her daughter both have episodic ataxia which I gather is very debilitating at intermittent times of varying extent and duration.

Dawn has had to give up work due to her illness but she and Dave have a new project which entails visiting craft fairs to set up their stand. Dawn explained that she makes sure that their stand is wheelchair and scooter accessible.

This commitment does mean that they will not be available for meetings most weekends so I was very pleased that they were able to come along to this meeting. Now when I speak with Dawn in the virtual chatroom, I shall know who I am addressing.

Hopefully Dawn will be able to send me a paragraph or two for our future newsletters.

Sheila is still soldiering on with the pain in her ankle which is still healing since her fall last summer. I was most surprised to learn from Sheila that she is only given an appointment to see her neurologist once every two years and even then the tests are very basic. I told her to be grateful that he did not subject her to the painful nerve conduction tests that I have undergone. No doubt many of you will be familiar with these.

I had a phone call from Amit Roy last week to tell me that although Sylvia and he had arranged transport and were intending to come to this meeting, Sylvia has taken a turn for the worse and is now in hospital. The news is not good and it is likely that she will be transferred to a care home. What a shame that all their attempts to come to a meeting have been thwarted. Amit has such a lot of information to share and I told him that he is very welcome to give a talk to the group should he be able to join us.

Thank you to various other members who have emailed, written or phoned me to say they were unable to come to this meeting. Sandra who lives in Walberswick sent her regrets and also enclosed a bit for the newsletter.

Sandra says that the exact type of her ataxia has not been found but CA was diagnosed in 1979, following a medical for a job at Ipswich hospital [as an orthoptist *[I looked that up – it means dealing with eye problems]*. Sandra worked there for 15 years before early retirement.

Sandra now uses an ordinary wheelchair or electric scooter outside but in the house she has an ordinary office chair, which is very manoeuvrable and good for the leg muscles! OR, she 'furniture-creeps' or crawls. She also attends weekly fitness classes in the village which helps her to keep flexible, mobile and strong and are great fun.

Thanks for that contribution Sandra – it reminds me of the things we talked about yesterday - particularly crawling in the dark. Dave remarked that he thought Sheila managed better in the dark so he has removed all the light bulbs.

We all [three of us] agreed that walking unaided in familiar surroundings was possible as you knew precisely where to grab or lean. I am sure other members can tell us about their preferred ways of getting around.

I would like to hear from you all as to when you would like the next meeting – preferably on a Saturday – but, if I receive enough interest, I will change the day. Please email, write, phone, or text a date to me

07801 544974.

I haven't received a picture of Nigel's baby yet but he has been very busy lately – perhaps next time. I did remember my camera this time but too late of course to get a picture of baby Rachael.

Blessings to you all

All good wishes, Patsy Riggs

Sheila and Dave at the front, me left, Dawn behind me [hiding] and Steve.