

# Central Ataxia News

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## Introduction

Issue Six

November 2006

Hello and Welcome to this the 6th issue of our branch newsletter. I hope that everyone is well and refreshed after the summer holidays.

Christmas is looming and already shops are starting to display their Christmas offerings, I don't know about any of you but I'm sick of it already and there's still a few months to go.

If any one has read the latest Ataxia magazine they might have read the small article about free admission to the person accompanying you (as long as you are in receipt of DLA) to the cinema, well for all people without computer access I have included the application form

Has anyone out there got SKY because if you have they offer a great phone package. Just £5 a month for all calls local and national and mobile costs are cheaper than BT. Last month my phone bill was just £8.16 (£5 + a few 08 numbers and mobile), you still have to pay for your BT line rental.

If you don't have SKY and your phone bill before line rental is over £20 it would be no more expensive to get a basic SKY package and then sign up for SKYTALK their phone package.

The added benefit would be that you now have digital tv and don't have to worry about when they turn off the analogue tv signal. If you arrange installation before Christmas then the installation is usually free or VERY cheap. Any questions please ring me and I will be happy to answer any questions (01789 294145)

I hope everyone who attended this years conference had an enjoyable time.

Unfortunately I have now broken my arm and will be in plaster for a few weeks therefore the newsletter has not been fully completed and I hope that no one minds, also please ignore any spelling or editing mistakes as typing is near impossible.

### Next Years Meetings

Tuesday 6th February  
(AGM)

Tuesday 1st May

Tuesday 7th August

Tuesday 6th November

All meetings to be held  
at 11.00 am

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# Meeting Minutes

## CENTRAL ATAXIA

### MINUTES OF MEETING HELD AT FORDHOUSES & OXLEY COMMUNITY CENTRE, MARSH LANE, W-TON., ON TUESDAY 5TH. SEPTEMBER 2006

PRESENT:- Brian & Edith Doody, Tina Thatcher, Arthur & Doreen Hampshire, Kathleen & Terry Evans, Jenny Whitehouse, Cheryl Cooling, Margaret Arkwright, Brian Hanmer, Sue & Sarah Murkett, Chris Dymond.

APOLOGIES:- Marguerite Greenwood & Miles Paterson.

1. Brian welcomed everyone to the meeting especially Terry & Kathleen Evans who were here for the first time and Tina Thatcher our Branch Support and Development Officer who was going to talk to us about her work. Brian also informed the meeting that Miles could no longer drive any distance and would not be attending future branch meetings. However he would still continue to prepare our newsletter. The meeting expressed their continued gratitude to Miles although we would all miss seeing him.

2. Brian reminded the meeting of the forthcoming A.G.M. and Conference in November and asked people to let him know if there were any items that they wished raised .

3. Our Speaker for the meeting was Tina Thatcher - Branch Support and Development Officer.

Tina spoke enthusiastically about her new role in Ataxia U.K., confirming that her employment had been made possible by a three year lottery grant. It became obvious that she was making considerable progress in the short time since her appointment. The main areas that she had looked at so far were the successful encouragement of new branches and support groups, the simplifying of branch development guidance packs and constitutions, the establishment of a 'buddy' system and improvement in effective communication between branches and the main office.

There were several questions and comments from the group members and it was noted that Tina's appointment represented considerable improvement upon previous arrangements. Brian thanked Tina for her attendance and keeping us updated on her progress.

4. International Ataxia Awareness Day is to be celebrated on 25th. September and the group were asked what, if anything, we should do in our area. It was generally accepted that an information stand should again be mounted. (last year it was in The Civic Centre, Wolverhampton). Margaret, who was there last year, suggested that we should attempt to hold it in a shopping centre this year (better foot-fall and more interest from passers by). Brian did not share this view feeling that the Mander Centre, Wolverhampton, particularly, wanted to push us up a corner and therefore we would not gain the prominence needed. He felt that other shopping centres, being commercial enterprises, would adopt a similar approach. Chris was asked to investigate the possibility of arranging a stand in The Civic Centre again.

# Meeting Minutes

## 5. CHRISTMAS LUNCH

Sarah & Sue Murkett have been to Goodyears Pavilion in Wolverhampton for a meal with the Wolverhampton M.S. Centre and found it very enjoyable. Sarah said that she had asked about Christmas Lunch there and found that they can do this (silver service) for £13.95 per head. Although numbers would be limited the meeting was very enthusiastic about this and Brian agreed to visit the Pavilion to check availability.

6. Brian confirmed that he had written to several companies and football clubs to see if they would donate A. a prize for a national raffle (if H.O. would organize it) or B. a prize for the raffle at our A.G.M. and Conference. He had received no response so far. He had also written to the Mayor of Wolverhampton asking for inclusion in the list of Mayoral charities this year. Our application was unsuccessful.

7. The next meeting will be at 11-00 a.m. on Tuesday 7th. November at this venue. There being no other business the meeting closed at 1:45 p.m.

MINUTES OF MEETING AT FORDHOUSES & OXLEY COMMUNITY CENTRE, MARSH LANE,

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## WOLVERHAMPTON TUESDAY 7TH. NOVEMBER 2006

PRESENT: Marguerite Greenwood, Margaret Arkwright, Brian Hanmer, Sue & Sarah Murkett, Cheryl Cooling, Harry Fancott, Liz Crook, Edith & Brian Doody, Chris Dymond

APOLOGIES: Jenny Whitehouse, Lucy & Margaret (Helpers), Doreen & Arthur Hampshire, Miles & Elaine Paterson.

1. Brian welcomed everyone to the meeting and spoke first of all about 'the radio interview that wasn't'. He had been invited by Radio Coventry (via h.o.) to talk about Ataxia from his perspective as a carer (Brian's wife, Edith, has Ataxia). The broadcast was to take place on 25th. September (International Ataxia Awareness Day) and a time had been booked for him at the Mailbox (BBC & Radio W.M.'s Midland headquarters) a link was to be set up with our own Dr. Julie Greenfield. Details on page 5.

## 2. FUNDRAISING

Some time ago Chris's sister who works for Birmingham Midshires B.S. Head Office in Pendeford, Wolverhampton offered to arrange that Ataxia U.K. be the beneficiary of 'dress down day' fundraising at their offices. These now take place every week on Fridays. We had to wait something like a year before our turn came and we had really no idea what the response would be. However on the afternoon before Chris took a few leaflets, our trusty horizontal banner and the two vertical banners which we'd borrowed from London for awareness day and positioned them in the staff foyer. Morning dawned on the 27th. October to find Chris's sister standing by the banners exhorting people to put money in the 'bucket' for us. She was there from 7-30 a.m. to 9-30 a.m. and in those two hours raised £750.30 for Ataxia. We should be and are very grateful for her efforts and the generosity of Birmingham Midshires staff.

# Meeting Minutes

I haven't received the cheque yet but if there is any sort of publicity to be gained we'll ensure that there's a picture in the Ataxian. Stop press - since heard that because they also did a small collection at their admin. Centre in Cardiff, the total amount raised is £812.00

## 3. TABLE TOP SALE

The table top sale held in September was not very successful. We sold a lot but most items went for pennies so it was a lot of work for little reward. Chris confirmed that the unsold items (now having been in two sales) would be passed to another charity for disposal. Other sellers at the event seemed to have the same experience. However there is another Table Top Sale/ Christmas Fayre to be held on 2nd. December and we are going to try again. Any donations of Christmas stuff/toys/ bric a brac will be gratefully accepted by Brian or Chris before the date. Similarly if anyone fancies coming along for an hour that morning they will be most welcome. Brian also confirmed that if anyone wanted to arrange a Table Top sale that was nearer to their home it would be much appreciated as the money is used to help run Central branch. Additionally he would always make arrangements to travel over himself to help out.

## 4. INTERNATIONAL ATAXIA AWARENESS DAY

Although the awareness day is on 25th. September each year we could only get the display space in the foyer of Wolverhampton civic centre on Friday 22nd. September. The event was attended by Brian & Edith Doody, Sue & Sarah Murkett and Chris Dymond. The Mayor came for all of five minutes, had his photo taken, then went home to rest after his exertions! All in all the event was disappointing and even less successful than 2005. Saying that, a fire drill taking place destroyed most of the morning and lunchtime saw the rain arrive and pedestrian traffic disappear. We may adopt a different format for celebrations for the day next year

## 5. CHRISTMAS LUNCH

Brian confirmed that a table had been reserved for lunch at Goodyears Pavilion in Wolverhampton on Monday 4th. December. Although lunch wasn't to be served until 1 p.m. the restaurant manager wanted us there for 12 midday so everyone coming please note. Also if Chris is collecting you from Wolverhampton station you will need to be there by 11-45 a.m. at the latest.

## 6. DATES, TIMES, VENUE FOR MEETINGS IN 2007.

The next meeting will be at this venue at 11-00a.m. on Tuesday 6th. February 2007. The meeting will incorporate the Annual General Meeting. Subsequent meetings in 2007 will be at the same venue and time on Tuesday 1st. May, Tuesday August 7th. And Tuesday November 6th.

## 7. ANY OTHER BUSINESS

There being no other business the meeting closed at 1-15 p.m.

# Members Articles

## An article from Brian Doody

Coventry and Warwick radio rang to see if I would do a radio slot about living with Ataxia for the International Awareness day 25/9/06 and to link up with Dr Julie Greenwood who would be covering the medical side of Ataxia on a station in Kent. So myself Chris and Edith set off for the Mail Box in Birmingham (the home of BBC radio for the Ataxia for the area) to link up with Coventry. With help of Chris I managed to get us there on time where we eventually found the BBC, on arriving at reception. I presented myself and told the receptionist why I had come, she checked her desk for the appropriate form and duly informed me that she had nothing down for Ataxia on which I noticed my name on a piece of paper and informed her of this she then got on the phone and spoke to some one and then told us to take a seat and someone would be along in moment, the time was 11-15 the time they told us to be there 11-20 arrived no one came, 11-25 no one came, 11-30 no one came, by this time we began to wonder what was going on as the show was supposed to be at 11-30 at 11-35 some one came and called me .

He took me down a corridor to a room ( no bigger than a broom cupboard) opened the door and there was someone already using the room. head phones on sitting at a table

Wait there I was told and off went the gent, thereafter a few minutes he came back had a word with the another person in the room and said to me that he would be back in a minute. This happened three times and after the third time he said he was sorry but they have overrun and we've missed the slot

So after I'd built up myself to go on air, my 15 minutes of fame came to nothing so off we went and drowned our sorrows with tea and pastries before driving home .

That's the sum total of my radio fame, a visit to BBC radio station in Birmingham just to have a look around and tea and pastries.

## Picture of Brian, Edith and Chris with the Mayor on Ataxia Awareness day



# Members Articles

## An article from Chris Dymond

### 20,000 LEAGUES UNDER THE "CUT"

Back in January this year, I visited my local G.P. . Forget why I went now but it doesn't matter since he is reluctant to prescribe anything but always likes to try and heal you with a few well chosen but often blunt words. Anyway the conversation drifted to the importance of exercise and physiotherapy. He seemed keen on the M.S. Therapy Centre at Newbridge, Wolverhampton, and since it is only round the corner from my home I thought I'd give it a whirl. My first visit was really a "recce" and chat with the administrator there, Dot Whitehouse, who explained that I didn't have to have M.S. to use their facilities and the upshot was that I made an appointment to see the physiotherapist there. After several visits to the physiotherapist I read their literature about High Dosage Oxygen Therapy. This therapy involves you sitting alone or with others in a decompression chamber and breathing oxygen in a pressurized environment. Potentially there are two benefits:- Giving you more energy (not proven in every case) and the proven benefit of improved bladder function which every person with a neurological complaint seems to get problems with. Although there are several of our members who visit the centre, they don't use the chamber. However there is one C.A.er (not known to the group) who does. So I decided to give it a try. The centre is next door to the canal at Newbridge and I don't know if it's that or that this type of chamber is the same as that used by deep sea divers when stricken by the 'bends'. Anyway each session in the chamber is called a dive. There are two decompression chambers; a small one seating 3 and a larger version seating 9. Each is equipped with fans and radio headsets for each occupant. The chambers are pressurized to a maximum equivalent of 32feet below the surface pressure of water and a patient once assessed and approved, and with their doctors permission, has to do fifteen dives (one per weekday for 3 weeks) and then normally one dive per week afterwards. The fifteen are free and then it costs £5 each week for non M.S. sufferers. It was with much trepidation that I commenced. I needn't have worried because apart from claustrophobia it's not too bad. However you do work harder breathing with a mask on. Also the temperature does go up as air pressure increases. It takes about ten minutes to pressurize the chamber, then you put the masks on and breath oxygen for an hour, then takes the masks off while the chamber is depressurized ( about another ten minutes). I find the biggest problem is staying awake (apparently it's dangerous to go to sleep). The other inmates are sometimes friendly but I found that you have to speak to them before they'll speak to you. Actually you can't talk with the masks on (your voice is muffled and everyone's breathing sounds like Darth Vader from Star Wars. After it's all over you're left with four times the normal amount of oxygen in the blood and you're encouraged to sit quietly with a cup of tea for ½ hour so the oxygen doesn't 'leak out' and settles into your system. The therapy is also recommended for healing injuries more quickly than normal and the centre is used extensively by one of the local hospitals for speeding up post jaw-cancer surgery healing. As a matter of fact Wayne Rooney used just this therapy to heal his broken foot prior to the World Cup. But does it do what it's supposed to? I hear you mutter. Well my experience was an immediate improvement in bladder function ( I didn't get up so often during the night to visit the bathroom). This has worn off now so I'm increasing the therapy to twice per week to see if that helps. There has been no marked increase in energy. My balance has got worse but that may just be a coincidental deterioration in my condition. Would I recommend it? - if you're the slightest bit wary of confined spaces - NO At the end of the day it's up to