

Ataxia Newsletter South Downs Branch Summer



Hello! I want to start by apologising for not having a spring newsletter, but at least the summer newsletter is not *that* late!

If you have comments, questions or items you would like to see in the newsletter please contact me at James@downstar.co.uk / james_downie@msn.com or Flat 8 Lansdowne Court, 25 Lansdowne Road, Hove, East Sussex, BN3 1GB. mob: 07884 186906. Thanks to everyone who contributed, please keep it coming.

Summer Quiz Night and BBQ

On the 24 June 06 we will be holding a quiz night and BBQ. The Quizmaster for the evening will be Kevin Merritt. The venue will be the Clymping Village Hall, where the usual bi- monthly meetings are held.

The BBQ will be held in the evening, and will begin at 6 p.m. Tickets will cost £10 per head (includes both quiz entry and BBQ-bargain!)

People can bring their own drinks, and please remember glasses.

Due to limited space there is only enough room for 60-65 people, so to avoid disappointment get your tickets early! In each team there can be a maximum of 6 people.

Cover incase it rains and with prizes to win, this is a event not to be missed!

Sheila needs to know numbers at least a week in advance (by 17th June 06 please)

See you there!

Forthcoming South Downs Events

Saturday June 24th South Downs Summer barbecue at 6.p.m. at the Climping Church Hall, Climping followed at 8.p.m. by a Quiz Night.

Thursday July 6th South Downs meeting at Climping Church Hall, Arundel 7 p.m to 9 p.m.

Thursday September 7th South Downs meeting at Climping Church Hall, Arundel 7 p.m to 9 p.m.

Sunday October 8th Historic Treasure Trail, Chichester City

Weekend of 11th November Ataxia UK conference, Birmingham

London Marathon

Sunday 23rd of April arrived dull and drizzling. However safely ensconced in The Royal Hospital at Chelsea (where the Chelsea Pensioners live), and eating a lovely full English breakfast we watched the runners preparing for the Marathon on T.V. At the same time somewhere in that heaving throng was one of our runners, young Warren Brayn was preparing for the Off. Boy did we envy Him. He was hoping to do it around between three & half & four hours, and as one of the early starters meant that he should finish one & half past.

So at about 10.15, Mary (Warrens Mum), Barbara, 3 Pensioners in Full Scarlet Uniform, Medals and all, and myself, were dropped off at Bird Cage Walk. The crowds out in their thousands, the atmosphere was terrific, despite the weather. Well the combination of 3 Chelsea Pensioners, and 3 collecting buckets is a very potent Charity weapon, that and the fact that so many people want their photo taken with them, it was like shooting fish in a barrel!! Thus we ambled, up past Buck House, nothing from there alas, down The Mall to the Finish.

By this time the lads, including myself, were starting to flag a trifle, it was not only the runners that were tired, the buckets were getting a bit heavy. So moving on down Whitehall, the lads just pausing briefly to salute the Cenotaph as they do whenever in their Scarlet Uniforms, we Retired to a pleasant Hostelry Called The Albert, where the Pensioners Get cut price drinks. The idea being that as it was nearly one o'clock we would stay for about 1 hour, by which time Warren should have finished, been picked up, and we would all go back to Chelsea for a meal.

However the best laid plans etc, unbeknown to us, Warren, who had been averaging just over 8 minutes a mile at about 18 miles his knee had given out, slowing him down considerably. Meanwhile back in the Pub, still collecting, having their photos taken, and drinks being bought for left right and centre, I suddenly realise we have been in the Pub getting on for two and a half hours, and the lads are looking decidedly happy. Thankfully just then our lift arrives and we were returned to barracks more or less intact. In the meantime Warren had finished, in just over 5 hours, could not find anyone around, so came back to Chelsea on public transport, free to all Marathon participants. Thus ended an "exhausting day for all".

The pensioners collected on the day something in excess of £300, and Warren has raised in excess of £3000.

Barbara & Terry

Ataxia UK Conference 2006

This year's Annual Conference is at the same venue as last year in Birmingham on Saturday 11th November. It would be helpful to know as soon as possible how many who intend going would require help with transport. If numbers permit we could run a mini bus as in previous years. Alternatively, we may be able to manage with cars and offer lifts.

A quick email or telephone call to let Sheila know would be helpful.

Sheila Atkinson - sheila.atkinson@bigfoot.com - Tel: 01243 544645

Historic Treasure Trail, Chichester City **Sunday 8th October 2006**

Back by popular request! As a change to our usual bluebell walk in the spring, we have decided to arrange again an Historic Treasure Trail around the City of Chichester. This walk of just a couple of miles will involve clue solving and was huge fun the last time we did it in 2001.

It will of course be entirely suitable for the accompanied disabled. Help will be available for those who need it.

This walk is NOT suitable for dogs, other than guide/helper dogs.

Refreshments will be available afterwards.

More details to follow later – please put the date in your diaries now.

Contact Sheila for more details

Meet the People

Ataxia & My Employment by Sharon

January 1988 Hurstwood Park Hospital, and various tests later "You have Ataxia" said my consultant, puzzled and blank faced. "I have what?" I felt quite shocked and very alone when it was explained to me.

What am I going to do I thought, well I'm certainly not going to crawl into a dark hole and cut myself off, and so from that day, my life has gone on.

Telling my family was the hardest part, they were speechless like me, to start with. I thought long and hard about it for several days, and thought well I'm not really any different, just unsteady and a little slower than most.

I work for the health authority. My biggest fear was telling my employer. Could this be curtains for my job? How wrong I was. My employer sought information on this progressive condition and referred me to occupational health within the hospital. There was never a mention of me having to give up my job, but my position had to be reviewed for health and safety reasons. It was made clear that I could no longer assist patients if they could not stand or assist themselves, or move any equipment that may cause me to fall. I could still work in ultrasound, but not physically handling patients. So I took up the position of entering all patient data results and reports that were recorded for patient follow up appointments. This was a full time sitting position with a computer that I was used to using. But the area was not disabled friendly. I virtually had to climb over my desk to get to my chair, stretch to reach the computer, and nearly fell off my chair reaching a drawer unit next to my desk.

Occupational health were called in again. They referred me to 'Access to work' who came and did an assessment, and made various suggestions for a new workstation and chair. This was all agreed, and a grant was allocated for my improvements. It took quite a few months for this to happen but I eventually got a new workstation, curved, that I could swing round without hitting my legs on table legs. A new chair which rotated, has arm rests, high back and lockable wheels so it doesn't move away from me when I get up. I have a slip mat under my computer so I can move it if needed, tilted keyboard with wrist rests, very comfortable, an anti glare shield on my screen, and low on the wall behind me I have an emergency alarm button , if I need assistance at any time.

I have a review with occupational health every six months. They seem to be happy with my work, and I can contact them if a problem arises at any time. I feel I am in a safe working environment with full disabled facilities, and I am quite happy working there. I hope to continue working for as long as I can.

Sharon

Useful websites for anyone interested:

Radar – Disability Discrimination Act 1995 – Nov 2005
[http:// www.radar.org.uk](http://www.radar.org.uk)

Jobcentreplus – Access to work
www.jobcentreplus.gov.uk

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