

# Ataxia Newsletter South Downs Branch Autumn



Hello! I want to start by surprising you all on my efficiency for getting this newsletter out! Hope you are all enjoying the long drawn out summer.

If you have comments, questions or items you would like to see in the newsletter please contact me at [James@downstar.co.uk](mailto:James@downstar.co.uk) / [james\\_downie@msn.com](mailto: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.

## Isle of Wight Coastal Walk

Starting on the 26th of August Rob Hammond and Paul Vincent are walking the Isle of Wight coastal path (see pic below). They are doing the walk in aid of Ataxia UK (Rob) and the MS Society (Paul). It will be very hard work covering 70 miles of extreme terrain. Rob and Liz are great supporters of the branch and Ataxia UK (Liz's story in this newsletter), so spread the word!

To sponsor them couldn't be easier. If you have the internet go to [justgiving](http://justgiving.com/robhammond) and search for Rob Hammond. Or type into browser [www.justgiving.com/robhammond](http://www.justgiving.com/robhammond).

Alternatively if you wanted a paper form contact me and I'll get you one!

Good luck Guys!



## Forthcoming South Downs Events

### **Saturday August 26th**

Rob and Paul's walk (see left)

**Saturday September 23rd** Eileen & Brian's Summer Ball, Bromley (see page 3)

**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 (see next page)

**Thursday November 2nd** South Downs meeting at Climping Church Hall, Arundel 7 p.m to 9 p.m.

**Weekend of 11th November** Ataxia UK conference, Birmingham

<Left< a picture of the 'The Needles' on the Isle of Wight Coastal Path

forthcoming events

## **Historic Treasure Trail**

Sheila Atkinson

### **Old Roman City of Chichester, West Sussex**

#### **Sunday 8th October**

South Downs invite everyone to join them on this lovely 2 mile sponsored walk. The route is suitable for everyone and whilst enjoying the lovely parks, old city walls, Bishop's gardens, and history, of this old Roman City, there will be clues to solve and special clues/collections for children.



**Various pictures of Chichester**

In short, something for everyone. Light refreshments will be available afterwards.

For an entry form or for more details please call Sheila on 01243 544645 (evenings) or email: [sheila.atkinson@bigfoot.com](mailto:sheila.atkinson@bigfoot.com)

Entry forms and further details will be sent out in early September to our local friends and to all those who usually join us on the Bluebell Walks.

We also need helpers at this event so to volunteer, please call or email Sheila.

## **Ataxia UK Conference 2006**

### **Birmingham**

#### **10/11/12th November**

Booking forms and further information on the Conference will be in the next Ataxian due with you in early September.

South Downs will be running a mini bus to the Conference and if you would like to make use of this, please call Sheila as soon as possible.

# **Summer Ball**

Eileen and Brian Harding

## **Great Hall, Civic Centre, Bromley**

### **Saturday 23rd September**

Eileen and Brian's annual fund raising walk will not take place this year as our principle supporters requested something different, hence the Summer Ball which they are arranging on our behalf for Ataxia UK.

It will be held on Saturday the 23rd September 2006 in the Great Hall at the Civic Centre, Bromley Kent. Entry by tickets at £20 each which includes a buffet supper. The venue is completely disabled and wheelchair friendly as is the multi storey car park next door. Car parking charges are £0.90 for all night parking after 19:30 hours and free at anytime for blue badge holders. There are several local hotels nearby.

Tickets are available from Eileen & Brian,

Telephone :- 01342893245 or e-mail :- [bande106@btinternet.com](mailto:bande106@btinternet.com)

## **A reminder about our 'Grants Service'**

Andrew Downie

As a reminder to ALL South Downs members – don't forget that we are now able to offer grants to help out where we can.

The sort of things we're thinking about are

- taxi fares to our meetings or other Ataxia related events,
- items to help with mobility, and communication,
- items which will to improve things at home, in the garden, or outside generally,
- companion's expenses to accompany someone shopping occasionally, etc – where not covered by existing allowances,
- attending Ataxia's conferences, and
- other items as they may crop up.

Particularly relevant at the moment is our offer to help those who want to attend the Conference in November. We already plan to use some money to pay for transport to the Conference, as we have in the past.

We're really open to your suggestions, and we're really keen to make a difference locally, so if there's something you've thought would help you, or you'd like to come to more meetings, now's the chance. Get in touch with one of us, and we'll take it from there.

If you want to get in touch with us, please do so. Contact Terry, Kevin, Eileen, or me (Andrew) – our numbers are:-

Terry – 01903 260919, [thuwins@hotmail.co.uk](mailto:thuwins@hotmail.co.uk)

Kevin – 01903 773905, or [mezzner124@msn.com](mailto:mezzner124@msn.com)

Eileen – 01342 893245, or [bande106@btinternet.com](mailto:bande106@btinternet.com)

Andrew – 07798 927785, or [andy@downies.plus.com](mailto:andy@downies.plus.com)

previous evens

## **Barbeque and Quiz Night**

Andrew Downie

On the 24th June, South Downs held our first social event of the summer, at Clymping Village Hall, where we hold our regular meetings.

The evening started in the usual frantic way – did we have everything, were the burgers de-frosted, were we going to get people to help themselves, how could we get the answers to Kevin's questions without him knowing?



Anyway, over the course of a couple of hours, in warm sunshine our 2 cooks – Chris and Andy (the cyclist), slaved over a very hot Barbie, watched over by me, and various (queue jumping) tasters.

**<Left< a picture of Andy and Chris showing you can still look cool while cooking!**

Thanks to their excellent efforts, and those of the ladies in the kitchen, we finally defeated the 60 or members and friends, although it was at times a close run thing, as to whether the food would run out before appetites were exhausted.

Next came the quiz, preceded by a lot of milling around to try to get into the winning team. As ever Kevin's quiz was excellent, 80 questions on a variety of subjects, which had appeal to both the youngsters and us oldies – and they weren't too hard, either.

**>Right> a picture of the Quizmaster**



**<Left< people pondering**

The results were really close, with about 5 teams still in the running up to the last round. We waited with breath held... and the winners were our friends from Woking. I reckon it was fixed, because we came second, 1 point behind. Still all the top 3 teams won an assortment of alcohol, so all disputes were soon put to rest.

In between all the excitement, we held a raffle, and the superb prizes seemed to be well shared out around the tables.

All that was left to do was to reflect on the evening. So, overall the evening was a great success, with a number of new faces, and many people bringing friends and family with them, so a great big 'thank you' to all the organisers – well done. Oh and we raised £670!

## A Day at the Races!

Rebecca Orr (Ataxia UK)

On Friday 28th July The October Club invited a few people from Ataxia UK to join them at Ascot to act as representatives of Ataxia UK. Although there were grey clouds threatening at the beginning of the day they soon cleared and it became another sunny day. We were treated to a champagne reception followed by a 3 course meal. There was also a raffle and auction and a sweepstake and the money raised will go towards the cost of the main event.

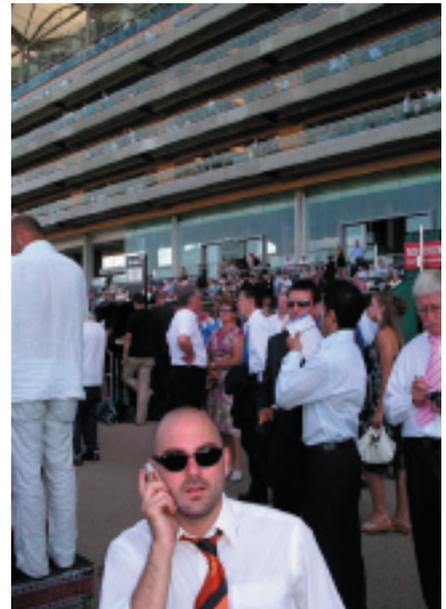
We were given some tips by the racing correspondent of the Sun, they went straight over my head, but Andrew Downie was busy jotting it all down. I'm not sure it helped him as by the time it came to the racing everyone had given their view on which horse would win, and I think it pretty much covered every horse!

As I am not a seasoned race goer my tactic for choosing the winner was not very scientific at all. I went for the horse which had a nice name! So 'Italian Girl' it was, and at 16 to 1 I wasn't very confident. But I put my £2.50 each way and sat back to enjoy the race....it only went and won!!!

I think James would agree with me if I said the wheelchair access was there, as it should be for a new building, but the staff were not well informed at all. But once we found our way to the front of the racetrack there was a good viewing point for wheelchairs where we got prime position!

All in all, a great day out was had by all.

**>Right> Me losing money at Ascot**



## Appeal for help with selling books for Ataxia UK

Kevin Merrit

I have been selling books successfully, to raise funds for Ataxia UK, for some time now and am always grateful for more books to sell. This appeal, however, is as a result of the particular success of bookselling on the internet (approx £800 raised in the first 6 months this year).

In a good week I can sell up to 30 books, all of which I have to post to the buyers. I have now almost exhausted the large stock of envelopes I had. I desperately need A5 (normal paperback book size) and A4 sized envelopes or jiffy bags. If you get any in the post please keep them for me-I can re-label them. Perhaps you open the post at work and then throw the envelopes away?

Envelopes can be left at my home, 124 Sea Lane, Rustington, West Sussex, BN16 2RZ, or given to Barbara&Terry Uwins or Sheila Atkinson. You can bring them to our next meeting, at the Climping Church Hall, or if you have a large quantity and need them collecting please tel.01903 773905 and I will see if I can arrange it. If I don't have to buy envelopes it helps keep more money for the charity. Hope you can help.

# **Meet the People**

## **Liz Hammond**

I always wanted children. I was always sure I would be a good mum, I had so much love to give. So, a year after Rob and I married we started talking about having a baby. I knew that I was disabled, but I never thought of it as a reason not to have a baby. Seven months later I was pregnant and absolutely loving it! I sailed through my pregnancy, and suddenly Emily was born.

The night feeds were the worst, I felt like a zombie during the day, and unfortunately when I'm tired my FA gets a little worse. My main concern was how I'd transport Emily around the bungalow so Rob bolted a car seat onto a trolley and I wheeled her around, it was brilliant!

My FA has never really got in my way, there's a few things I can't do, so I don't do them. Now Emily's a bit older she wants to do things like go to the park, go on the swings, and I can't do that but I've got lots of friends that are happy to help and I have a carer through direct payments. I've also recently bought a scooter and it's excellent, I can go anywhere I want without someone having to push me.

Being a mum is a full time job, and you've still got to run a home etc, but I wouldn't swap being a mum for anything, I love it, it's so rewarding. Emily being two and a half now, copies everything she hears so we have to be careful. We've been potty training her recently and we were in the bathroom the other day trying to get her to wee before we went out. Emily was adamant she didn't want to go so she simply turned around and said to me 'mummy, you do my head in!' kids aye!

## **Last Word**

Recently I have been helping Ataxia UK with a couple of projects. Including on the 21st - 23rd of July a young persons 'Talk in Weekend' which was very successful. It was Treloar School in Alton. The weekend was for parents/careers and young adults with ataxia. The weather was wonderful- like the food! A good weekend was had by all and I think everyone there got something out of the weekend.

Attached is info about the Ataxia clinics, at the National Hospital for Neurology and Neurosurgery, London

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