

# Ataxia Newsletter South Downs Branch Autumn 2005



## ***Hello and Happy Autumn!***

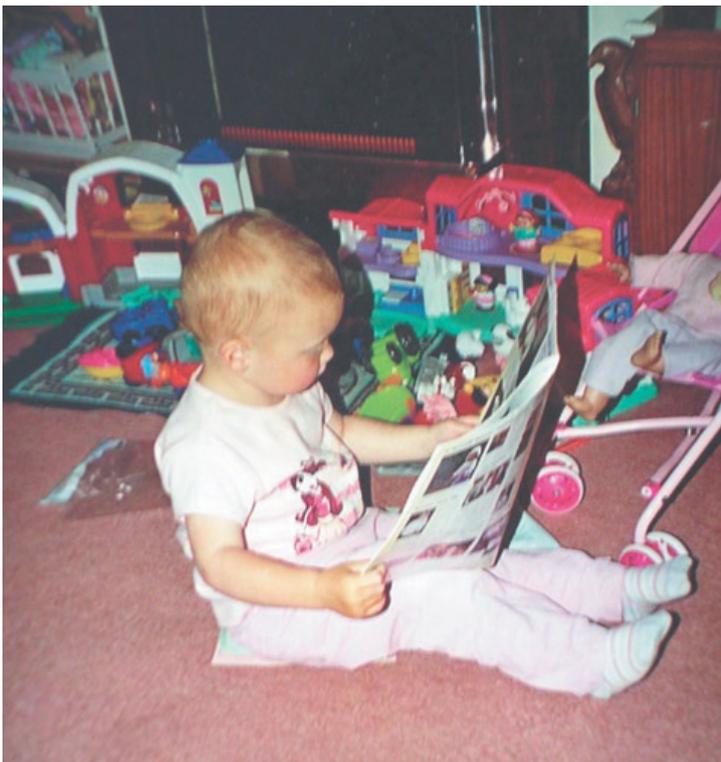
Sorry this newsletter is a little late (again!). To those who went to the conference, I hope had a good time. If you have comments, questions or items you would like to see in the newsletter please contact me at James@downstar.co.uk / james\_downie@msn.com or Flat 8 Lansdowne Court, 25 Lansdowne Road, Hove, East Sussex, BN3 1GB. mob: 07884 186906.

Sheila has recently moved, her new contact details are:

**Sheila Atkinson**  
**Chair – South Downs Branch of Ataxia UK**  
**23 Rosvara Avenue,**  
**Westergate,**  
**Chichester,**  
**West Sussex PO20 3RB**  
**Telephone: 01243 544645**  
**email: Sheila.atkinson@bigfoot.com**

Wishing Sheila and family much happiness in your new home.

Rob and Liz's beautiful daughter Emily, is she **The youngest Ataxian reader?!**



### **Forthcoming South Downs Events**

**Thursday November 3rd** next South Downs meeting at Climping Church Hall, Arundel 7 p.m to 9 p.m

**Saturday December 3rd** Christmas Dinner (details in this newsletter)

**Thursday January 5th** South Downs meeting at Climping Church Hall, Arundel 7 p.m to 9 p.m

**Saturday January 28th** Disco at Billingham Village Hall, holds up to 150, Fish & Chip Supper/ veggie burger or Sausage. Tickets £10 each, bar with cheaper than pub prices!

**Saturday March 4th** South Downs AGM, from 2 to 5 p.m.

# South Downs Events

## Treasure Hunt

On Sunday 24th July a car treasure hunt was organised to start and finish at Climping church hall(our usual bi-monthly meeting place). Despite the wet weather several hardy drivers and navigators completed the course, along the coast from Climping to Littlehampton, Rustington, East Preston and back. A tie-break question was needed to determine the outright winners of the large basket of fruit, donated, as 1st prize.

A barbeque was planned but due to the weather the food was cooked in the hall kitchen. Our thanks go to Barbara Uwins for organising the food and Bernadette Downie for providing the desserts. With sales of books and plants and Ataxia merchandise adding to the treasure hunt entries, over £300 was raised.

*Kevin Merritt*

## Golf Day

On 1st July 2005 we held a golf day in aid of Ataxia UK, at Sutton Green Golf Club near Guildford.



I would like to thank George Kelly and Jack Redman, who are both keen golfers, who put in lots of work before and on the day in order to ensure the event was a success. They were ably assisted by a number of our friends, who collected money and measured distances, etc.

On the day we had over 80 golfers, who played 27 holes, in good weather. Their day also included breakfast, lunch and dinner. Throughout the day there were prizes for the tee shot nearest the pin, a hole-in-one (which wasn't won!), the longest drive and other golfery things.

During an excellent dinner we finished with the day's highlight – a comedian paid for by one of the golfers. Whilst he was brilliant, I really can't repeat any of his jokes here.

Everyone seemed to enjoy the day, with many of them taking home prizes – including tickets to the World Matchplay Championship at Wentworth, and an electric golf trolley. The generosity of the players meant that we were able to raise over £4,500 for Ataxia – through the fees paid by the players, sponsorship of the holes, the raffle, and sales of Ataxia goodies.

*Andrew Downie*



## **Christmas at South Downs**

On **Saturday 3rd December at 7.p.m.** South Downs will be meeting at The **Roundstone Pub in Angmering**, (on the A259 between Littlehampton and Worthing) for a Festive Christmas Feast. There will be live music, entertainment, and a four course meal for £12.99 each. The pub is a Brewers Fayre and fully accessible. Please book your place with Sheila by 31st October. A deposit of £10 each is required (cheques payable to Ataxia UK please) On receipt of your deposit I will send you a menu and directions. The pub cannot take unlimited numbers so first come, first served – book soon.

## **Ruby Anniversary Grants**

Our recent competition asking you to nominate an item which would help you, has been won by:

Elizabeth Hammond, Kenneth Jones and John Bond.

Their requests were for non-slip tableware, a wheelchair bag which would attach to the front and not the back of a chair and a means of transporting a cup of tea from A to B whilst using a 'wheeler' and dodging a lively two year old!

We are in the process of procuring their gifts and hope to have pictures and further details in our next newsletter.

Well done Ken, Liz and John – enjoy your gifts.

*Sheila Atkinson*

## **Football Club Collection**

On Saturday the 1st of October my Dad (Andrew Downie) organized a collection at Woking FC's home match against Scarborough FC. Raising £635 for ataxia UK.

## Where Shall We Spend Our Money?

At South Downs, the vast majority of the money we raise is passed on to the National Committee into what is known as 'the general fund'. This fund is used by the Directors of Ataxia UK for whatever need they feel most important to all of you.

We particularly don't put the money into the 'research fund' as we feel this is too limiting. This does not mean that none of our money goes to research, a great deal of it does.



What it does mean is that it can be used where it is most needed. Apart from research it is important for those with ataxia, to receive help and support to live and manage TODAY. Some of our money may be used for welfare grants to help with adaptations to equipment, for special beds, for wheelchairs. It makes sure that there is someone at the end of a telephone when you need them. It makes sure that you are kept in touch with what is going on through the Ataxian and through information leaflets.

Recently, we have asked ourselves if some of the money we raise should be held at the Branch for local use. We would need to have a clear policy as to what it will be used for and ensure that beneficiaries were not being helped both locally and nationally.

At the moment the branch sponsors a mini bus to the conference each year but not very much else locally.

A recent competition asking you to nominate a item that would help you brought very little response. Does that mean that you have everything you need or that we did not offer enough?

It is very important to us to have your opinion before we contemplate changing our policy. If we did make changes and held back a sum of money for local use each year, we would at the end of each financial year, pass it on to the national committee if it had not been used.

The Branch next meets on 3rd November and we would like to have an agenda item dealing with this. Can I ask you to let me know please, by post or e-mail ([sheila.atkinson@bigfoot.com](mailto:sheila.atkinson@bigfoot.com)) of your feelings on this. Responses by 22nd October would be helpful.

*Sheila Atkinson*

# ***Ataxia Awareness Day***

## **Hyde Park**

On awareness Day 25th September- various events/ fund-raisers were put on in order to raise money and ataxia awareness, here is news on a couple of them.

Brian and Eileen Harding organized a charity walk in aid of Ataxia UK in the Royal Parks, London between 12 noon and 4pm. There were wheelchair friendly routes between two and seven miles. I went to this event and had a great day, the weather was lovely. There was a good turn out and they hope to have raised over £5,000 for ataxia UK.



Pictures from Hyde Park.  
You can even see what good weather it was!



## **Sky dive**

Jon Kay a friend of mine who has FA and his friend Alison who also has FA, did a tandem parachute jump to raise money and awareness for Ataxia UK. They both did the jump, afterwards Jon told me it was beeping awesome! So far they have raised over £3,000. Nice picture!



## **Feature**

### **Independent Living Exhibition**

*"Independent Living London is an exhibition created exclusively with you in mind, aiming to celebrate the practical possibilities of living independently in London and the South East."*

[www.independentlivingevents.co.uk](http://www.independentlivingevents.co.uk)



I have added this feature as I thought some of you might find it useful. The conference itself was very busy, but it didn't take too long to fill in the forms and enter the main hall. Alexandra Palace is a huge place, with good disabled facilities- which of course it needs to have to host such an event.

I wasn't sure what to expect as it was a spur of the moment decision to go, but I am glad I did. The exhibition was in two huge rooms each with nearly 100 well laid out stalls. There were the usual companies exhibiting their products or services (eg Motability, canine partners) but there were also lots of companies selling products and services which I didn't know existed. For example a kitchenware company that fits wire kitchen adaptations to your existing kitchen layout, for use of people in chairs- very cleverly designed. Another of my favorites (I love gadgets!) was an all in one remote control for EVERYTHING using radio waves- very cool!

I do not want to advertise but I am listing the exhibitors which took my eye and including their websites and contact numbers. If you would like more information I will gladly help as much as I can. I am definitely going to the exhibition next year, so I will let you all know when it is.

[www.putmans.com](http://www.putmans.com) 01752 345678

A company specializing in items to improve posture. Products such as memory pillows, cushions, car seats etc.

[www.herbertdirect.com](http://www.herbertdirect.com) 0870 770 7656

Specialist in wirework kitchen systems. All kitchen modification to enable easy use for people with disabilities. Very good design and great use of space.

[www.caninepartners.co.uk](http://www.caninepartners.co.uk) 08456 580 480

Training assistance dogs to transform the lives of people with disabilities. Amazing dogs who can do so much for you.

[www.portramp.co.uk](http://www.portramp.co.uk) 01953 714599

Ultra light and strong access solutions. Ramps for all occasions!

[www.srstechology.co.uk](http://www.srstechology.co.uk) 0845 230 0430

Remote control systems for people with disabilities to ease independent living. Quite expensive products but very useful.

[www.neaco.co.uk](http://www.neaco.co.uk) 01653 695721

Assessable showering systems with special flooring meaning no slips. Impressive products at a good price.

*James Downie*