

AtaxiaSouthDowns.co.uk



Hello and welcome to the Autumn edition of Ataxia South Downs newsletter.

This is the new format of newsletters - hope you like it!

It feels strange to be putting together a Autumn newsletter when it seems we have missed summer. The newsletter is now much the same as the website but it includes a meet the people section.

If you have been posted this but don't mind receiving it through email please drop me a email to

james@downstar.co.uk tel: 07884 186906

Thanks and enjoy the read....

Forthcoming Events Posponed

A Treasure Hunt From Portsdown Hill in Hampshire

A treasure trail from your car, where the route has been planned to ive maximum enjoyment of this lovely area. This is not a race, its a time to take a leisurely drive around this beautiful area of Hampshire. A few clues to solve along the route and a opportunity to have a 'pint' or a '99' at the end!

Unfortunately due to the current foot and mouth crisis this event has been put back to the new year, to be on the safe side. Sorry for any inconvenience caused.

- Forthcoming South Downs events at a glance**
- 14/10 Treasure Hunt from Portsdown Hill 10 a.m
- 1/11 meeting at Climping Church Hall 7-9
- 8/12 Christmas lunch, Guildford
- 3/1/08 meeting at Climping Church Hall 7-9
- 6/3/08 meeting at Climping Church Hall 7-9

picture from Ataxia conference in Leeds



A Halloween Ball in aid of Ataxia UK

The venue is two minutes from Junction 4 on the M25. The evening includes the usual raffles etc. With Dancing to the live music of The Average Chalky White Band and a buffet supper All for £25 per head
Further detail and tickets available from Eileen & Brian at bande106@btinternet.com
Or call on 01342 893245



Christmas Lunch, 8th December, Guildford

On the Saturday 8th of December South Downs and London branches are holding a christmas lunch from 2-6ish. It is to be held at the Parkway in Guildford, just off the A3. If any other branches or support groups would like to go please contact me. The meal costs £15 (menu at back of newsletter). A £5 deposit is required by the 30th of October (details also at back of newsletter). So please let me know of your interest A.S.A.P, it would be great to see loads of you there!

Past Events

The Ataxia UK conference

Written by Andrew Downie

“Ataxia Conference, held at Queen’s Hotel Leeds, on Saturday 15th September. The conference was held up North for the first time in a number of years, at the Queen’s Hotel. The hotel has been recently refurbished to its original Art Deco style, the public rooms especially were quite magnificently decorated. There were also a reasonable number of disabled rooms.

In addition to the conference itself, there were a number of innovations this year including Yoga, massage, emotional freedom, and welfare benefits one-to-one appointments throughout the day. The meeting as usual was chaired by Paul Coia, and started with Pit addressing the conference for the last time. Pit was followed by Chris’s summary of the finances. Both stressed how much the charity had grown, both in terms of income (a great big thanks to all donors and fundraisers) and expenditure on research and other services.

Peter Taylor followed with a tribute to Pit for all her work in chairing Ataxia UK through the



last 4 very successful years. Sue Millman introduced herself as the new Chief Executive of Ataxia UK. Sue presented her draft plans for the next 3 years. She is keen for anyone who wishes to comment on them – the plans are, I'm sure available from the office. Her key areas for development and investment were – in Research, with possible fellowships granted to researchers; creating more Ataxia centres; more education and influencing of health professionals and others; and, more emphasis on direct services to Ataxia friends (e.g. development of the advocacy service). Tina talked briefly about the success of the branch development programme.

Throughout the day there were a number of 'it works for talks' from Dianna Kaye, Chris Norton and Darren. These were both emotional and inspiring, and a real highlight.

We then had a research update – which again is available from the office, and there was also a doctors Q&A session which will be written up in the next Ataxian. We also heard from Debi Holm, a specialist Ataxia nurse from Sheffield, and from Katie Best an OT based in London.

Next up were the award ceremonies. The Anne Ford cup is this year going to Jean Gillard, for her work especially in creating the Eastbourne branch. A new award was made this year – it is in memory of Ernie Heath, a great stalwart of Ataxia UK, and highly regarded past chairman. It is to be awarded to a person without Ataxia, who has done most to promote Ataxia UK, and all its aims. The initial winner is Margaret Evans, for her work over many many years in Belfast.

In the afternoon we also heard from Liz Carr about Independent Living, and what it and Direct Payments have meant to her and her life. Liz was both entertaining and enlightening, and left us all looking forward to hearing her uncut Edinburgh Fringe sit down, stand up routine after dinner! Liz's was keen to stress that independent living is about 'Choice and Control', which despite her disability she now has.

Talking of fringes, Alan, a regular and well known conference attendee, agreed to have his hair cut, if we stumped up some cash for Ataxia. The deed was carried out, and Alan, sporting his new haircut raised over £300. Of course, there was also a raffle, with many exciting prizes.

Sue rounded up the day, and repeated her request for feedback, on the conference, on her plans, and on any other relevant topic. Sue finished by announcing that next year's conference will be in Stanstead, on either the first or second weekend of October.

The evening dinner was, as always, a highlight, and was attended by about 90 people (there had been about 140 at the conference). We were entertained after dinner by Liz,

who started her talk quite gently, but increased the 'risque' joke by joke, leaving us all wanting to hear more – which you can do by going to BBC's excellent 'ouch' webpages.

So, what did I think? The conference exceeded my expectations, and everyone seemed happy with the content, the quality of the speakers and the information presented. Of course things could be better – disabled access to the room and other facilities, cheaper drinks, but what can't be faulted was the effort put in by both Ataxia staff (before and during the conference, organizing, presenting and manning stalls, etc) and the hotel staff. As always, too, we met loads of new people, Liz and Rachel, Deanna and Tony, Madeleine, and many others, and lots of old ones too!

This is the real reason for coming isn't it?

Will we go next year – yes of course, and we'll encourage more of you too!"

Foxhills Golf Club, 23rd of September

I am pleased to announce that this year Ataxia UK has been chosen as Foxhills Golf Club (in Surrey) captains charity of the year.

The first captains event was a drive in (captain in fancy dress, see pic!) followed by a round of golf for members (over 130 played).

After the golf prizes were given to the winners, a raffle and speeches were made. I even said a few words which went surprisingly well! Throughout the year the captain organises various events, all in aid of Ataxia UK. I would like to take this opportunity to thank the golf club and especially the new captain.

The new captain 'T' ing off in style



August Bank Holiday Sunday Charity Market

written by Eileen & Brian Harding

“Eileen and I had originally requested a plot for a stall at our local bank holiday Donkey Derby, which is always a big attraction. Unfortunately, the rules have been changed for this year meaning that only local charities were allowed to participate on the Monday when the donkey derby is held. However, we were not to be deterred so agreed to take part on the Sunday.

We had to arrive at 08:30hrs in order to get set up ready for opening at 10:00hrs. It was a cold dull and grey morning and did not look at all promising. We erected our gazebo, put up the banners, posters and balloons. We decided that the left hand side of the gazebo would be for the tombola, prizes and handing out leaflets and that the right hand side would be for our bric-a-brac sales.

After unloading boxes of goodies, we were eventually ready to open on time. It was now darker and colder and not a single customer in sight. Fortunately, we brought some flasks of hot drinks as well as cold drinks, so put on our coats, poured some hot drinks and sat it out.

By lunchtime, nothing was happening but the clouds started to break up, out came the sun and we were in business. From just after 14:00hrs to closing time at 16:00hrs we were rushed of our feet. The tombola was a good attraction raising £219 thanks to Eileen’s brother Dennis and his partner Joan, while our sales gave as a further £199 making a total of £418 for the day.

The purpose of the day was also to try and raise awareness of Ataxia locally and I believe we achieved this by the number of leaflets we issued, together with the enquiries that we had and in particular from the St John Ambulance Brigade”



Ataxia Crohn's Bike Ride

Written by my Godfather, Paul Warburton for a newspaper, after he did the ride.

“THE ORIGINAL aim was to raise around £30,000 for both the Ataxia and Crohn's Charities. The legacy from 21 cyclists who took on the task of cycling to Paris from London in four days, or in one group's case – 24 hours – was a lasting spirit of friendship.

Stiff legs, sunburned arms, and rickety backs that when straightened sounded like gunfire, were all eased by the balm of beer and bonhomie at a job well done. Among the group was Andy Sturt, who was in the 'fast group' aka 'a bunch of nutters', and does this sort of trip like he was cycling down to the shop for the paper.

Andy and his bunch of hardened two-wheelers did the trip in one 24-hour hit, cycling through the northern France night in wind and pouring rain, but still finding time to congratulate the amateurs, who in some cases mounted a saddle for the first time at the beginning of the year.

The celebratory dinner on Saturday, July 28, reinforced why everyone, including eight assistants in three vans, put themselves through the torture in the first place.

Crawling up a massive hill on the second day, one cyclist leaned over to Andy Downie, whose son is an Ataxia victim, and whispered in his ear: “you may find this tough, mate – but your James has difficulty in getting out of bed each morning”

Thanks to everyone who sponsored. Together loads has been raised for Ataxia and Crohns - Details to follow (around £30k!)

Why not join us at our
ATAXIA HALLOWEEN BALL
27th October 2007 7:30pm until 1am
Chelsfield Lakes Golf Course



The venue is two minutes from Junction 4 on the M
The evening includes the usual raffles etc.
With
Dancing to the live music of
The Average Chalky White Band
and a buffet supper
All for £25 per head

Further detail and tickets available from



BBQ

On the 11th of August South Downs held a social BBQ event at the usual venue in Climping. It was a thoroughly enjoyable day with wonderful weather! We had a great turn out, amazing food and great summer music provided by Matt Jones and friends. Special thanks to Barbra and helpers for the wonderful food and the band for relaxing summer day tunes!

Beyond Boundaries Live: 29/6/07

I was quite intrigued by this event, I have been to disability exhibitions before but not one that takes its name from a TV show. For those who are unfamiliar with the show it is a reality style documentary show on BBC.

The Event was at Sandown Park, close to where I live, and was in the main exhibition hall. The venue was, of course, fully accessible, although as the disabled bays were all obviously taken so I had to park quite a way from the venue, down quite a steep hill. I started making my climb up the hill but was clearly struggling- it was steep! Luckily a guy who saw me struggling came to my aid!

Once inside I was impressed, well laid out entrance hall and a fast checking in system. After check in you receive the normal stuff- programs and leaflets about various exhibitors. Once inside I went straight to get a coffee and look through the program. There were many exhibitors, from big banks, to a guy selling t-shirts and gadgets to pimp your wheels! There was a host of wheelchair companies, accessible holidays, hand bikes, cars, car adaptations, gadgets, and even a sports court. A few familiar faces were there from South Downs and some people who have worked with in the past. The turn out was good for a Friday and was busy but not packed.

I don't wish to advertise anyone, so if you would like any of exhibitors details contact me. However, saying that 2 products I hadn't seen before stuck out for me with benefit to people with Ataxia. The first is a company called Strawberi. They basically sell straw holders (and other drinking aids), doesn't sound like much, but a great drinking aids if you use a straw as they stop the straw from moving. The second I will mention is a 'vibration platform'. This product cost between 2,500 and 4,500, but it is a product aimed at gym's, rather than home use. I was made aware of these a while ago but hadn't seen one or tried one out. It is like a big plate you stand or rest various parts of your body on. The plate then vibrates between 30 – 60 times a second. I decided to have a go. I couldn't run after I used it, but I did make legs feel more alive, like they had been shaken into life. The feeling last's maybe 2 days, and is by no means a cure. However, if your gym has one use it, and if not ask them to get one!

After I had visited almost every stall, tried out a few different hand bikes and new chairs, it was getting towards closing. Then I remembered I hadn't taken any pictures for the site/ newsletter. By this time the hall was emptying so there would be no-one in my pictures of the venue. I was not sure what to do, then out of the corner of my eye I recognized someone from the TV show. It was Ade Adepitan, who is a is a British television presenter and wheelchair basketball player, who appeared on Beyond Boundaries. So I asked for a picture with him!

All in all I thought beyond boundaries live was a excellent exhibition and is well worth a visit, especially for young and active disabled people.



Bands and Buffet: 26/5/06

written by Andrew Downie

There's always a lot to organising an event, so it was with some concern that I heard James say the he was going to organise a 'bands' night, with his Aunty Karen.

I need not have worried, Karen who is the headmistress of Park School in Woking, organised the food, the raffle and the hall. James through many and various friends booked 3 bands – Matt Jones and Friends, the Humanity and the Wire, all of whom agreed to play for nothing. In addition a local company provided the sound equipment at minimal cost. One of Karen's friends was supported by Barclays Bank who donated £750.

So, expecting about 70 – 80 people James, Karen and others went about inviting people, all of a sudden realising that we had over 150 acceptances (one count had it at over 200)! Still the weather forecast was OK, so some could stand outside in the school grounds. On the afternoon all the preparation went according to plan, with a few raised voices, last minute dashes to the supermarket for more food, etc. Marquees were erected in the grounds, tables laid, balloons collected, sound checks carried out.

The evening kicked off abut 7pm, with Matt and friends playing for about an hour – lots of Paul Weller in deference to being in Woking, whilst the 120 or so who did turn up started to drift in. Outside of a conference I'd not seen so many youngsters with Ataxia at a 'do' together, and they included Nicole, who'd made the longest journey – from Sydney Australia! John did a magnificent job on the raffle, no-one getting past without buying a few tickets.

The (almost punk) band Humanity played next, to heated debates as to whether they were too loud or too quiet, either way they made a lasting impression on everyone. Next up Adriano worked the audience through the one-man show of the raffle, a never to be forgotten experience by itself. He then followed up with Toby, who is even more of a showman, as the Wire to play out the evening with a mixture of original songs and covers. They were joined for the last few numbers, and the well deserved encore, by others who'd played earlier.

A fabulous evening, everyone agreed as they left, which went without a hitch, and raised over £3,000 for South Downs. Thanks especially to James, John (x2), Karen's friends and helpers, Ben and all the others who contributed to before, during and after.



Meet the People

“I have Ataxia but I enjoy life”

by Sian Rhys

At sixteen I was diagnosed with Ataxia but that definitely has not stopped me having a busy but fulfilled life.....

I live at home with my parents in Ascot although I am soon to move to my own bungalow in Sunningdale.(YAY)

I have two sisters my youngest sister also having ataxia..

At college I wanted to be a nursery nurse, which I realised that I could not fully do, so I compromised and help out at a local nursery once a week and I also help out as a volunteer receptionist at my local hospice.

Travelling is also a huge part of my life and I try to take every opportunity that comes along! I have been to at least 19 countries and whilst you are reading this I will be in another two...

Being active is what keeps me going and I regularly go swimming and enjoy taking classes in pilate's and yoga.

In the past I have taken part in various activities including skiing (which as not for me!), parasailing and I intend to do a skydive next year.

Finally I first came to join the South Downs branch by partaking in the bluebell walk – yep I walked nine miles with friends, and since then I haven't looked back.

Festive east menu

Available from 27th November

£14.99

Starters

Garlic & Herb Breaded Mushrooms

Served with garlic mayonnaise and BBQ dips.

Pork & Bacon Pâté with Bramley Apple, Ginger & Raisin Chutney

Served with rusticata bread.

Prawn Cocktail

Served with salad leaves and brown bread and butter.

Soup of the Day

Served with rusticata bread.

Mains

All main courses are served with carrots and fine beans.

Hand Carved Turkey and Wiltshire Honey Roast Ham

Served with sausage & herb stuffing, sausage wrapped in bacon, new and roast potatoes, Brussels sprouts, Yorkshire pudding and cranberry sauce.

Grilled Chicken Breast with Roast Onion, Bacon & Tarragon Sauce

Served with Dauphinoise potatoes.

Braised Pork with Dijonnaise Sauce

Served with mashed potato.

Fillet Of Salmon with a Honey & Dill Glaze†

Served with new potatoes and a wedge of lemon.

Vegetarian Option

For a vegetarian option, please select from the menu any vegetarian dish.

Desserts

Christmas Pudding†

Served with brandy sauce or custard.

Chocolate Torte

Served with fresh strawberries and cream.

Vanilla Flavoured Ice Cream

Stilton, Brie and Mature Cheddar Cheeses

Served with butter, biscuits and half a red apple.