Ataxia Newsletter South Downs Branch Winter 2006

Ataxia UK

Merry Christmas and Happy New Year!

I can't believe its Christmas time again. I apologise for this Newsletter being small, but its all about quality, not quantity! I wanted to take this opportunity to say a big thank you to everyone who voted for me to be a Trustee of Ataxia UK. Also for the nominations for the Anne Ford cup, both are an honour and a privilege.

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 1 Lake Close, Byfleet, Surrey, KT14 7AE. mob: 07884 186906. Thanks to everyone who contributed, please keep it coming.

On 21st of November I attended a Snowball in aid of Ataxia UK at the Royal Hospital Gardens in Chelsea. It was a in a most wonderful setting, fantastic food and great auction prises. The evening raised a great deal of money for Ataxia UK, so well done to all involved in organising the event.

New Years Get Together

Christmas dinners are so last year, so this year we are doing a New Years get together!

This will be on Saturday 27th of January, at the White Swan at Arundel, just west of the town on the Chichester Road. Its a private function room that is wheel chair friendly. Menus will be available at the January 4th meeting.

It will start at 7pm, and to book your place or places ring Barbara Uwins on 01903260919 or E-mail on theuwins@hotmail.co.uk. Hope you can make it!

Forthcoming South Downs Events

Thursday 4th January 2007 South Downs meeting at Climping Church Hall, Arundel 7 p.m to 9 p.m.

Saturday 27th January 2007 New Years Get Together at the White Swan, Arundel from 7 p.m.

Thursday 4th March 2007 South Downs meeting at Climping Church Hall, Arundel 7 p.m to 9 p.m.

Saturday 14th April 2007 (AGM) South Downs annual general meeting at Climping Church Hall, Arundel from 2 p.m.

Thursday 3rd May 2007 South Downs meeting at Climping Church Hall, Arundel 7 p.m to 9 p.m.

Thursday 5th July, 2007 South Downs meeting at Climping Church Hall, Arundel 7 p.m to 9 p.m.

Ataxia Conference Birmingham - November 2006

We arrived on Friday afternoon, in time to witness the fiasco with Disabled room bookings, which was eventually sorted out successfully.

Later we were all encouraged to go to a Branches meeting, which was attended by about 12 people, about half of whom were from South Downs – we also met Barnaby, Ataxia UK's new press officer, who encouraged everyone with a story to tell to contact him at the office.

Nursing hangovers from a (very) late evening, we turned up for the conference proper on Saturday morning, for what looked like a full programme of presentations.

Pit Rink kicked things off by talking about next year, with another talk-in weekend planned, and new office staff to ensure that families understand their rights and entitlements. Pit was followed by Chris who outlined our finances, who explained that Ataxia UK is in a much stronger financial position due to the October Club event (which will raise in excess of £400,000) and a substantial legacy.

Next was a presentation regarding branches, highlighted by Sheila's closing comments on how much being chair of a branch meant to her, and to other South Downs members. The research update followed, given by Julie of Ataxia UK, which concentrated on the latest potential breakthroughs in FA research.

The morning concluded with the presentation of the Anne Ford cup, which was presented to this years winner (I didn't catch his name*), by Katie Henderson, who won it last year.

picture right> Katie handing James the Anne Ford cup, with Paul Coia

Paul Coia, the chairman for the day, got everyone back after lunch, for a presentation by the Citizens Advice Bureau, followed by the Doctors Question and Answer session – featuring Dr Da Silva, and Dr Giunti – who both stressed the importance of having the 'flu jab, among many other answers given to questions, both from the floor and those put by Julie from questions sent via the office.

An NHS Expert Patient Trainer then explained the value of becoming an 'expert' patient through attending formal training.

The formal conference ended with 3 short presentations from 3 young ladies with FA. They all talked about 'what works for them' living with Ataxia – Sarah talked about life with her Canine Partner, and has us all laughing out loud; Nikki talked about her studies, and the importance of them to her, and finally Michelle talked about her travels and her amazing voluntary work in, among other places, Africa.. These presentations, to me, stood out from the others during the day – they were amusing, emotional, and coming from the heart clearly meant a great deal, both to the presenters and the audience.

Most of us then returned to the bar, before getting ready for the evening's entrainment, which was a dinner and disco, with an after dinner speech by the man with many hats, Peter Taylor.

As last year, it was a very successful conference, although, I think, most people enjoy the socialising, with the chance to meet old friends and to make new ones, in a relaxed atmospheres, where having Ataxia is the norm. The youngsters, particularly, seeming to enjoy this part of the weekend!

*I'm told the Anne Ford cup winner was our editor, James.

Andrew Downie

picture left< a view of the conference!

Meet The People
Eileen and Brian Harding

Eileen & Brian Harding, both previously married with two children and divorced, have known each other for many years, married in 2000.

Eileen was diagnosed with Idiopathic Cerebellar Ataxia in 2001. Her walking difficulty had previously been diagnosed a few years earlier as the onset of Arthritis of the hip. Her sister Lynda also had a similar problem, though significantly worse than Eileen. Lynda's problem was diagnosed as the side effects of her long-term medication that she had been receiving for epilepsy.

It was just by chance that Lynda attended hospital for a routine check up and saw a locum doctor who recognised her symptoms as Ataxia. He then arranged for Lynda and siblings to attend an Ataxia clinic at Guy's Hospital London where five out of ten of them were diagnosed with Ataxia and told to report to their GP's. (So, how many more of the population are being diagnosed incorrectly?).

On reporting to the local GP, Eileen was told not to waste their time as there was no cure or treatment available and to advise her employer of the fact. Soon afterwards, Eileen had several falls at work and was told that under the Health & Safety rules, she could no longer be employed.

Next came a letter from the DVLA saying that they had been advised of her situation and that she must return her driving license immediately to them. This meant selling her car and the loss of her independence. Having appealed against the loss of license, she was granted a temporary license for an automatic car some six months later.

Out of desperation and the feeling that no one cared, we scanned the internet and amongst the information, found Ataxia UK who immediately got a phone call. At last, somebody knew her problem, was sympathetic, cared and offered support. Next came lot's of information and a pack for the GP to understand what Ataxia was about and how he could help. This was followed up with further telephone chats and we were extremely grateful to them.

As a result, we contacted Ataxia UK to see how we could repay their kindness, advice and the support given. Their suggestion was fund raising and they put us in touch with Sheila Atkinson for advice. Sheila made fundraising sound exiting so we gave it a try.

Not having attempted this sort of thing previously, Sheila got many calls from us and had all the answers we needed. We were now on our own to get our first event together.

This took place in Kent, with a seven mile country walk including Ightham Mote and Knowle Park. As can be seen, Sheila and Barbara came along to keep an eye on us and tell us about the South Downs group, of which we soon became members. Later, and much to our surprise, Eileen's son and his partner, representing our supporters were able to present a cheque to Ernie Heath for £5000. Not bad for the first eh!

We were soon being asked what's next by our supporters, so we organised a walk through the Weald of Kent including beautiful views from Ide Hill and Chartwell, the home of Sir Winston Churchill. Unfortunately, this walk proved too difficult for some who had to be rescued, so a lesson learned for next time.

However, it was well supported and a donation of £7.500 made to Ataxia UK.

It was now suggested that maybe we should try and get higher visibility and combine it with the International Awareness Day. The result was the Princess Diana Memorial Walk through the Royal Parks. We certainly raised awareness, with many people showing interest, not least by the Royal Parks Constabulary and the Metropolitan Police.

Unfortunately for us, the events of 7/7, restricted the number of our usual supporters from travelling to London. However, we were able to make a donation of £5.500 to the Charity.

This year we were asked by our supporters to try something different and the event was organised by Eileen's son Paul and his partner Nicola, next page. Again held to coincide with awareness day and their first attempt at fundraising. This resulted in the Ataxia Summer Ball. They had many prizes donated for the raffle and auction, including, theatre tickets, a night at a top London hotel, a signed cook book by Gordon Ramsey, a football autographed by the whole Millwall team with many, many more prizes.

The ball earned Paul & Nicola's first event the sum of £3.145 to be donated to Ataxia UK.

Each of these events, has encouraged other sponsored events for Ataxia like pub darts matches, pub BBQ's and a race night later this month.

These events can be fun to arrange and very rewarding so why not give it a try?

Having been successful with our events after advice from Sheila, we would be happy to share this and help other members to do the same.

Go on try it!!!

various pictures from Eileen and Brians fundraising events

Contact List for South Downs Branch:

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

Secretary: Michelle Sleet
Tel: 01903 773905
Email: sleet11@hotmail.com

Treasurer: Terry Uwins
Tel: 01903 260919
Email: theuwins@hotmail.co.uk

Grants committee:

Andrew Downie
Tel: 01483 714699
Email: andrew@downies.plus.com

Eileen Harding
Tel: 01342 893245
bande106@btinternet.com

Kevin Merritt
Tel: 01903 773905
Email: mezzer124@msm.com

Terry Uwins
as above (Treasurer)