

Ataxia Newsletter South Downs Branch Summer



Hi All,

What wonderful weather we are having, long may it continue into a lovely summer.

On April the 14th we had our AGM, at the usual meeting place in Climping. Michelle and Terry kept their roles as secretary and treasurer. However, Sheila stepped down as chairman. Leaving the role open, it is me who is going to try and replace the amazing lady as chairman, not a easy job! After the formalities we all pretended to go home and went to the local pub, where we were holding a surprise party to say thank you for all Sheila has done. I think all will agree it was a fun evening complimented by great food and music! On behalf of all at South Downs I want to thank Sheila for all she had done for people with Ataxia, her help over the years really has changed peoples lives.



Matt and Dids playing at the party for Sheila

As I am the new chairman I feel I have to write a little about myself, which I don't enjoy doing and is one of the reasons the newsletter is so late!

South Downs will miss Sheila as chair, but I am sure she won't be going far! An Ataxia branch is there of course to raise money, but primarily it is to help people with Ataxia. I know South Downs Branch has helped many people in the past. My life changed when I went to the South Downs run conference 2004. When I started coming to meetings I realised there were lots of other people

Forthcoming South Downs Events

Thursday May 10th South Downs meeting at Climping Church Hall, Arundel 7 p.m to 9 p.m

Saturday May 26th Bands and Buffet, Park School, Woking, 7.30-11.ish. Details page 3

Saturday June 23rd Ataxia Charity Disco and Auction, West Farnborough Social Club, 7.30-11.30. Details page 4

Thursday July 12th South Downs meeting at Climping Church Hall, Arundel 7 p.m to 9 p.m.

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

in the same position, who understood ataxia. I realised what I was going through I wasn't alone. I was 21 when I was diagnosed with FA and it wasn't until I started being involved in South Downs that I came to terms with my Ataxia. I stopped hiding from it, and with the support of others around me, I found the strength to cope. South Downs helped me realise I wasn't alone and I feel so strongly that no-one with ataxia needs to feel like that. If South Downs can continue to offer the same support now as it has done in the past I will be extremely happy.

I hope I can bring something to the chair- not just wheels! I am proud of what this branch has achieved and want to help it move forward and carry on being successful. I am a trustee of Ataxia UK, and help with various projects at Head Office. I get a lot out of working for Ataxia on all levels. Meeting others with Ataxia and seeing how they cope inspires and amazes me. My Ataxia is not going anywhere, and I want to keep doing my bit for Ataxia and South Downs for many years to come, or until we find a cure!

After the AGM Sheila gave me two boxes of literature regarding south downs. This has made amazing reading, as I am relatively new to the branch. From newspaper cuttings dating back to 1999, to the original branch forming documents. I felt quite emotional looking at everything south downs has achieved. Much down to Sheila, but down to every person who is involved, on whatever level. I feel honored to follow on and just hope I can do South Downs justice.

I am hoping for the continued support and help of those around me and already involved with the branch- unlucky guys! We would like to continue to hold bi-monthly meetings in Climping, and regular events.



Sheila handing me the Branch Standards Guide!

Just a note to say some of the email newsletters I have been sending have been bouncing back. If you are happy to receive the newsletter by email, please could you let me know by sending a email to james@downstar.co.uk with your name and stating its OK to email it! As some of you know I am currently putting together a website for South Downs. This will be found at www.ataxiasouthdowns.co.uk and will be launched at the end of May. Suggestions for the site and submissions are more than welcome, in fact encouraged! If you have any pictures, tips, information, poems, problems, events etc please let me know on the email address above.

James Downie

Previous events

Quiz Night at Eastergate Village Hall

Kevin's eagerly awaited Quiz took place on Saturday 24th March 2007. In all about 70 people turned up, making up 9 or 10 teams in total. As usual Kevin acted as question master, ably assisted this time by Michelle, as scorer. In a change to the normal rules, Kevin allowed an appeals procedure this time, to resolve any disputes, although as he said, his answer would remain the right one.

The quiz started with the usual jostling to get into the likely winning teams, an argument about the team name, and followed by a devilish 20 question brainteaser. After much internal dispute our team settled on a series of answers, as did most of the other teams. A couple of rounds of quiz later, and we were on to supper – a feast put together by Barbara, Sheila, and others, which was much appreciated by all.

The quiz moved through its final rounds, then as the tension built in the room, came the results. Unfortunately, we had to settle for second place behind, our friends from Woking who have supported us on many occasions, and who also won last time – they will not be invited again!

The prizes this time were Easter eggs – so much better than out of date Beer! These seemed to be evenly distributed by many of the winners to others who had failed to win.

Also we had a Tombola – and this proved as popular as ever, although I think a number of prizes have been won more than once before.

As always, we all had a lot of fun. Special thanks must go to all who made the evening such a success - particularly to Kevin and Michelle for preparing and hosting the Quiz. Oh, and we raised over £700, whilst having a good fun evening.

Andrew Downie

Forthcoming events

Band and Buffet, Park School, Woking, 26th May

This is the first event I will be organising, I am aware its strictly not in the area of South Downs, but I got the venue free, as my Aunties the head, so I couldn't turn it down! The evening will cost £10 and that will include a buffet dinner and three handpicked bands for your entertainment! My Auntie is helping me organise the event and thanks to her Barclays Bank are sponsoring the raffle. The sound system has been kindly donated by Sound By Design- a Woking based company.

Tickets will be sold in advance- but it will also be possible to pay on the door if I have your names beforehand. Woking station is fully accessible and only a short taxi ride to the venue. If you email soon I can try to find accommodation in Woking, and find out taxi prices/ availability.

Please email james@downstar.co.uk or call 07884 186906 for more details/book a place.

James Downie

Ataxia Charity Disco & Auction, West Farnborough Social Club, 23rd June

**ATAXIA
CHARITY DISCO**



**& AUCTION!
TICKETS £10
BUY TICKETS IN ADVANCE!**



SATURDAY

23RD JUNE

7.30pm- 11.30pm

**INCLUDES BUFFET,
AUCTION & DISCO!**



**West Farnborough Social Club Ltd
25 St Christophers Road,**

**Farnborough,
Hampshire,
GU14 0AH**

To buy tickets contact Nikki
26 Betjeman Walk, Yateley,
Hampshire, GU46 6YP
01252 692622

I will be raising money initially for the south downs branch of ataxia UK as this is my local branch and a branch I am highly involved in. South downs have benefitted me personally both with support and financially and I'd like to give something back.

For tickets and more info contact Nikki:
26 Betjeman Walk, Yateley, Hampshire,
GU46 6YP tel: 01252 692622

Nikki Stowe

Ataxia Crohns Bike Ride, London to Paris, July 2007

Two years ago Andy Sturt and Dave Rapley rode from Land's End to John O'Groats for Ataxia, in 10 days, raising over £20,000. They wanted a new challenge for 2007, and decided that non-stop from London to Paris, finishing to coincide with the Tour De France would be within their capabilities.

In planning this with them, a few others decided that taking a slower route would be enough for them. So we now have over 20 riders (including me), drivers and helpers. In 2006 Andy's son Darryl was diagnosed with Crohns, and we decided this time to split the proceeds of the ride between the two charities.

The ride starts from Ataxia's offices at the Oval, the slow riders starting early on July 25th, and the fast riders starting on July 27th. We plan to meet up on Saturday, to ride along the Champs Elysses as a single group.

For more information or to sponser please visit www.ataxiacrohnsbikeride.co.uk

Andrew Downie

Meet the People

This year I will be celebrating my 39th birthday, and for me it marks 20 years of having FA. During this time I have seen many changes in my personal life and with my health.

At 19, following symptoms such as lack of co-ordination, unsteadiness, tiredness, leg pain, I was diagnosed with FA. At this point my speech was quite good but my career and ambition to be a chef was to stop.

Following diagnoses I went to Egham ERC for four weeks to be assessed, I was given a metal walking stick to use and awarded mobility allowance and DOA allowance. After Egham I did some voluntary work whilst waiting for a place at Queen Elizabeth Foundation residential college. There I completed general office practice: typing, word processing and commerce. The aim of the college was to introduce you back into the work community. Following college I continued my voluntary work, this time at John Wiley.

Having met Ted at 22 I moved to Mansfield to begin my life with him, walking was now becoming extremely difficult and my tiredness more frequent, my speech was also starting to slur. A wheelchair was issued to me which I accepted, as the freedom from tiredness was a relief I could achieve far more.

Whilst living in Mansfield I attended a day care centre, I enjoyed many activities such as white water rafting, regular physio, massage and social outings.

My voluntary work continued for DIAL (Disability Information and Advice Line) and I also worked in a school bringing awareness to disability. My first class began to improve my English results.

Five years later Ted and I moved to the south of England to start a family. At this time I was wheelchair dependent, only able to weight bare.

I became involved with PHAB and started to attend SCOPE day centre and voluntary work for Age Concern.

At the age of 28 I gave birth to my beautiful daughter Jasmine, when Jasmine was 3 months old Ted went back to voluntary work almost full time, leaving me to care for our daughter independently.

When Jasmine was 5 we moved to a purpose built bungalow in Chichester. At the age of 34 I was introduced to Direct Payments. I was assessed as requiring 16 hours per week. This enabled me to regain my freedom and choices and to enjoy and maintain my independence. I also completed a psychology course.

At 35 I met Roger and having been with Ted for the last 15 years I realized that our lives were not as they should have been. I was informed by two solicitors that having a progressive disability I would not be awarded custody to Jasmine and following

a difficult year I left my purpose built bungalow. I concluded that seeing Jasmine at the weekend was preferable to Ted taking our daughter to Mansfield should he have moved out of our shared home.

Following legal proceedings regarding our legal situation Ted was awarded the bungalow and residency of Jasmine due to my FA. I and many others feel that it was a wrong decision, I was a still am capable of looking after my own daughter.

Roger and myself managed to obtain accommodation in the form of an un adapted flat. The only bonus being Jasmine visiting at weekends and school holidays. I now had to accept morning care from an agency to help me wash and dress. A year after starting to live with Roger I was awarded 35 care hours from direct payments.

In April 2006 we were finally re housed in Bognor Regis in an adapted two bedroom flat, and life settled down and all was good. I had regular visits from Jasmine, completed a counseling course, started volunteering work for the homeless at their daycare centre in Chichester. I was awarded ILF (Independent Living Fund) that meant that I had funding for my morning care, and three different PA's working six days a week providing me with the independence to live the life I choose.

I thought I had my soul mate in Roger however this was not the case for him. Shortly after we moved Roger began a relationship with a mutual friend of ours. October 2006 I found out and Roger left our home to live with another woman.

So another chapter of my life begins and my days continue with Jasmine growing up, uphold my independent living arrangements. I have my friend, family and voluntary work and SCOPE. I am thinking about my next college course.

"I may have FA but I certainly don't do FA"

Sheena Betsworth

Contact List for South Downs Branch

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Terry Uwins
as left (Treasurer)