

Ataxia Newsletter South Downs Branch Winter



HAPPY NEW YEAR!

I just wanted to take this opportunity to wish you all a very happy new year. I hope everyone had a wonderful Christmas, and is enjoying the cold and icy mornings!

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. Also if anyone has any pictures they would like to send that would be fantastic. Thanks to everyone who contributed, please keep it coming.

Forthcoming South Downs Events

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

Sunday 5th February at 10.00.a.m. Rob invites you to join him for a walk in Burpham (details page 3)

Sunday 12th February at 11.00. a.m. Rob again invites you to join him for a wheelchair accessible walk in Arundel Park. (details page 3)

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

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

Saturday June 24th South Downs Summer barbecue at 6.p.m. at the Climping Church Hall, Climping followed at 8.p.m. by a Quiz Night.

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



A picture of me at the Quiz night, with some of the organisers. Its only because Shiela didn't want to be on the front, her picture is on page 4! So is the write up.

Saturday 4th March 2006 **South Downs AGM 2.p.m**

At our usual venue, the Climping Church Hall, Climping, near Littlehampton

Please try and support your local branch by coming along to our AGM on Saturday 4th March at 2.p.m. We will be having a very short meeting to attend to the business of the branch, to hear what we have been doing for the last year both socially and on the fundraising front. We will also have a report from the Treasurer about the money raised. There will be an election of officers for the coming year and if you would like to stand as a nominee for any of the posts of Chair, Treasurer, Secretary or as a committee member, please let Sheila know as soon as possible. We will talk a little about our proposals for the forthcoming year.

There will be plenty of time to share a cup of tea and some rather good home made cake and just to chat and share ideas. This is your chance to come along and join in. All are welcome, friends and family of those with ataxia as well.

Anyone belonging to South Downs who has not yet been to any of our meetings is invited especially to join us and we are very happy to help with the cost transport if that is a problem. Please don't be afraid to ask – we want to help – it is why we raise money – and we particularly would like to see some of it used locally.

Telephone Andrew on 01483 714699 or Kevin on 01903 773905 if you would like help with transport.

Telephone Sheila on 01243 544645 if you would like to stand for election at the AGM

Sheila Atkinson

Ataxia Promotional Items

We have a selection of goods advertising Ataxia which will be available for sale at our A.G.M.in March and other meetings through the year. Tee shirts, baseball caps, pens and badges. If you wish to purchase but are unable to attend meetings please ring Barbara at 01903 260919 for sizes and prices.

Barbara Uwins

Winter Hikes With Rob

On Sunday 5th February 2006 at 10.00.a.m. Rob will be at the Recreation Ground car park behind the George and Dragon at Burpham where he invites you to join him for a seven and a half mile hike. There is only one significant hill, a couple of stiles and all on off road footpaths. This is definitely one for sensible walking boots. Rob will arrange for a cuppa at the end or, of course, there is the option of calling into the George and Dragon for a pint.

PLEASE CALL ROB on 01243 552750 to book for this walk

On Sunday 12th February 2006 at 11.00.a.m. Rob again invites you to join him for a wheelchair accessible walk in Arundel Park. 2 mile walk all on tarmac. Meet at the cricket ground entrance to the park near St Mary's Gate.

PLEASE CALL ROB FOR DIRECTIONS AND TO BOOK YOUR PLACE 01243 552750

There is no entry fee for these walks, or sponsorship, but please, if you able, consider putting a small donation into the AUK collecting box at the end of the walk.

Thank you

Rob Hammond

Saturday 24th June 2006 **Barbeque And Quiz Night**

South Downs will be having a Summer barbecue at 6.p.m. at the Climping Church Hall, Climping on Saturday 24th June 2006. This will be followed at 8.p.m. by a Quiz Night at which Kevin will preside as Quizmaster.

More information in the next Newsletter but put the date in your diaries now.

Kevin Merritt

Quiz Night for Ataxia

Some friends of ours agreed early in 2005 that they would hold a Quiz night for Ataxia, as they felt that they would like to make a contribution towards Ataxia research.

But this was going to be no small affair, as we found out over the coming months. The hall was booked, and then a drinks licence applied for, raffle prizes begged from local firms, menus and decorations discussed and a professional quiz master selected.

Everything was organised to perfection down to the table decorations. The quiz was excellent – lots of fun, and not too difficult, and extremely well run. The ploughman's served in the interval was more than enough for everyone, extremely well presented and delicious.

Sheila brought a team from South Downs, who, I'm ashamed to say, beat our team hollow – but of course, we consoled ourselves with the fact that we were there to raise money – and what money was raised. From the 128 people who were there, our friends raised £2,220, from the sale of tickets, drinks and raffle tickets, and also received a donation of £800.

Our thanks go to the organising committee - Stuart, Dee, Richard, Doreen, Malcolm, Heather, Dave, Chris, Mike and Zoë - and to Sheila, Liz and Kevin for bringing their team.

The photos below show – Sheila, Liz and Kevin's team, Sheila making her thank you speech.

Andrew Downie



Announcing our 'Grants Service'

Over the last couple of meetings we have been discussing how to get the best value from all your fundraising activities, which raise a very substantial amount of money all of which goes through the accounts of South Downs. In the past, with almost no exceptions, all the money raised is passed to the general fund of Ataxia UK. Ataxia UK then have a free hand to decide how to split the money – for research, for support activity, etc.

During our discussions we concluded that, in future, we would retain a small sum within the branch accounts to assist Ataxia sufferers and their carers locally. This fund is therefore available to anyone, for any valid purpose. The vast majority of the money raised would, of course, be sent to Ataxia UK as now.

We have created a small team to allocate funds once assistance has been requested and agreed. The team consists of Eileen Harding, Kevin Merritt, Terry Uwins, and myself, Andrew Downie. We can be contacted by phone or e-mail – see contact list elsewhere in this Newsletter. By the way you only need to talk to one of us!

So, what sort of things will qualify? Well, we don't intend to replace Social Services, who can supply many things. We're here for things outside their scope. We're thinking of such things as;

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.

We'll also use the fund to pay for transport to the annual conference, as we have in the past, and other events, and maybe to have guest experts at South Downs meetings – e.g. occupational therapists, physiotherapists, etc.

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.

Andrew Downie

Meet the People

We have been thinking that it would be rather nice for you to 'meet the people' that make up South Downs. This is entirely voluntary but already several members have offered to share their stories with you. We hope to feature one or two in each of our newsletters. So, to start us off please meet:

Michael and Wendy Kimble

Michael (who has ataxia) first noticed a feeling of increasing unsteadiness during 1998. By the year 2002 it was suggested he should cease work as he was a 'liability' in his occupation in the construction industry.

Having always led a very active life, it seemed that at age 64 all the things we looked forward to achieving in retirement were being taken away. When early in 2005 Michael was diagnosed with late onset cerebellar ataxia, we had something of a feeling of relief. Relief at getting a diagnosis, but, wait a minute, what is this thing called 'ataxia'? All we were told was that it was progressive and there was no cure.

For a few months we wondered what the future held for us. We have our Christian faith which has always sustained us but felt unable to voice our thoughts and fears to others. Eventually we confided in a close friend who searched 'the web'.

This was when things started to change for us. He found the Ataxia UK web site and more importantly a helpline telephone number. As a result of that we are now members of South Downs Branch, meeting people of all ages who are sharing the same experiences as us, giving support and encouragement. We are no longer alone.

Although young at heart Wendy and I have now reached what is considered retirement age, our interests are very varied, from the arts to fell walking, although in some cases slightly disrupted, we are still keen caravaners so are able to take our second home into the fells and experience the grandeur from the safety of a wheelchair. We plan Scotland for 2006 – are they ready for us?

For the last nine years Wendy and I have been involved in providing through 'Marriage Preparation and Counselling' a positive response to the increasing number of broken families and marriages.

From our own experiences during those early months after a diagnosis of ataxia we would have so liked a couple who truly understood what we were going through, available to listen and talk to in a supportive role. This could have paved the way for quicker and ongoing encouragement. I am sure there are many that could relate to our experiences, particularly carers and loved ones who have seen their futures change so much.

Once you have taken that first step, there is so much help and support out there and yes, it can mean a change of lifestyle, but that's life. Every day is a new experience within our own control.

As one door closes another truly opens and this is an area in which Wendy and I feel we could help. We are available to offer support and encouragement in any way we can and would be happy for contact with other sufferers, their families or friends.

Either call us direct on 01403 784718 if you would like a chat, or through Sheila if you prefer.

Please, don't be alone.

Contact List for South Downs Branch:

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

Secretary: Elizabeth Hammond
Tel: 01243 552750
Email: liz@hammond220901.wanadoo.co.uk

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: mezzzer124@msm.com

Terry Uwins
as above (Treasurer)