



FSP Newslink

The Newsletter of the Familial Spastic Paraplegia Support Group
Registered Charity No. 1109398

Issue 10 – February 2007

HSP & FSP – Hereditary Spastic Paraplegia,
Familial Spastic Paraplegia & Strumpell-Lorain Syndrome

LES DAY GOES UP, UP AND AWAY



As a small boy I was first introduced to the wonders of aircraft by my father who would take me to air shows and explain the various types of aircraft to me in detail.

At the age of thirteen I experienced my first trip skywards in a Piper Cherokee at Biggin Hill and from then on I was bitten by the flying bug!

I had always harboured thoughts of learning to fly someday but assumed that because of my FSP, this would be impossible to achieve (having greatly reduced mobility in my legs).

However, since joining The FSP Group, Ian Bennett has made me aware of the options available to disabled people wanting to experience the joy of flying.

With this information in mind, I contacted The BDFA (British Disabled Flying Association) to enquire about obtaining my own Private Pilot's Licence and am currently in the process of securing my first flying lesson in one of their aircraft.

On Sunday 14 January 2007, my sister, Lorraine, and her daughter, Emma and I met Ian at Lasham Airfield in Alton, Hampshire.

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Lasham Airfield was once an RAF Station but is presently used by The Lasham Gliding Society who allow The BDFA to hangar their aircraft on site. They also encourage flying for the disabled and have a 2 seater glider with modifications to allow flight instruction to be given using hand controls only. Whilst Lorraine and Emma took to the skies with Ian at the controls, I went about organising my first introductory gliding lesson. My instructor, Andy, explained the controls to me, strapped on my parachute and helped me into the front seat of the glider before the tow plane pulled the glider along the runway.

I was surprised at how quickly it gathered speed before smoothly taking off and rapidly rising in height to 2,500 feet as the glider was released by the tow plane. I found it extremely peaceful and relaxing floating on the thermals and listening to the wind rushing by, whilst admiring the stunning views towards the south coast. The duration of the flight was approximately 30 minutes and the landing was faultless - not even a bump!

Afterwards I met up with Lorraine, Emma and Ian to discuss the day's flying over a cup of tea.

I thoroughly recommend visiting Lasham Airfield to those of you who have always wondered what it would be like to fly in a glider/small aircraft. Everyone on site is extremely helpful and the facilities are very good too - there is a lounge bar, a great restaurant, children's play area and a TV room. I can't wait for my next visit!

For further information about flying, visit these websites:

The British Disabled Flying Association - www.bdfa.net

The Lasham Gliding Society - www.lasham.org.uk

Les Day – Region 1

From the Chair

Hello everyone

Well, yet another January has flown by. Whether it's the anticlimax after the big day or our wish to draw the longer warmer days forward I almost believe the year starts with February. Clearly I ought to get out more.

Firstly let me share some good news with you all. Mike Fawcett is now out of hospital. It maybe sometime before he has got a full head of steam up, as it were and so I thank Sonya & John Mason for their continued help in ensuring our accounts are maintained in the interim.

I'm sure we all subscribe to various disability magazines. I examine mine in great detail extracting anything relevant for action later. I live very near Epping Forest and have just been granted permission to take my scooter on the green rides (used by horses). In discussion I was encouraged to set up a disabled ramblers group but as you can imagine; spare time at the moment is a rare commodity. To my immense pleasure the Disabled Ramblers Association have an article in Life Style so for the moment I'll join and see just what they get up to in the woods. I've also sent off for a ServiceCall alert by which assistance can be sought; particularly at petrol stations (if of course they have the system). I'll update you all on results.

I know I've mentioned it before but our Chat page is really coming into its own now. I guarantee YOU know something WE don't and I was pleasantly surprised to discover that 105 of our members have now subscribed to this facility. Signing up is totally painless, simply follow the instructions at: <http://sentinel.mcc.ac.uk/mailman/listinfo/hspgroup>

I'm sure we have all noticed, it is generally the same people contributing to the body of copy in Newslink each quarter. Would you believe it, we have been complemented on its quality and content. If you have anything of interest, good news and of course negative issues for which the Group's accumulative experiences may be able to help, have a word with Ian re May's edition. Thank you to Les Day and Daniel Gibson for their contributions within this issue.

I look forward to seeing a really good conference turnout in Warwick on 16th June. As always, don't hesitate to contact me at any time.

Keep well

David

The Secretary's Spot

As we move into 2007, I hope that some of you are now better off as a result of following my suggestion in our last issue to look at the Money Saving Expert web site. Which reminds me that I had a letter recently from members Sally and Alec Langdon in which they recommended a nationwide optician service which will visit you at home. Although this may not save money, for those who find town visits difficult it may well be a great help. The name of the service is "The Outside Clinic". The following information is from the clinic's brochure:

"FREE Service

The Outside Clinic is free to those individuals who are entitled to NHS optical services and who are unable to attend the services of the High Street Optician without help or assistance.

Our Service

When requested, an appointment will be made for an Outside Clinic Optician to come and examine your eyes in your own home. Like our colleagues on the high street, an Outside Clinic Optometrist will be equipped to detect visual problems and abnormalities such as glaucoma, cataracts and macula degeneration. Following your test, should spectacles be required, a range of budget or designer frames are available to choose from along with advice and assistance on the best choice of lenses for you. Following manufacture of your new glasses at one of our dedicated laboratories, a second appointment will be arranged for one of our optical dispensers to deliver and fit them. Daylight lamps and magnifiers if ordered can also be delivered."

The Outside Clinic can be contacted on this Freephone number: 0500 295 245.

It's good that we keep getting responses from members who have followed up advice from the Information Booklet and from Newslink items telling us the benefits they have had. It's even better when we get additional topics or expanded information about a previous item. We can see examples of both these in this issue of Newslink.

So do let one of us know when you find out something which may be of use to others.

French Mice

HSP Mice are being bred all over the continent - or so it seems. Hot on the heels of our last report about "Italian Mice" comes the information that a different team of researchers (in France this time) have developed the first "Spastin Mouse".

The team of Professor Judith Melki (Anne Tarrade, Coralie Frassier and others) have now produced a mouse strain with a defective spastin gene. The mice show many of the specific characteristics found in humans with HSP. Using these mice and comparing them with normal or "control" mice, researchers have been able to identify and quantify various effects within the axons in the spinal tract of these mice.

The importance here is that the spastin gene is implicated in a large percentage of those with HSP. Depending on which statistics you choose, spastin is a factor in between 40% and 70% of cases.

Over the longer term, having such mice available will make research into the effects of possible treatments a little easier. This in turn may well help to accelerate research into the condition.

Having said all that, let us remind ourselves of the timescales which Professor Wood indicated in his talk to our 2004 AGM. He suggested that it was possible that some major breakthrough in treatment of the condition might occur with twenty years. This development is well in line with that prediction in that availability of the mice will really only provide another "foundation stone" on which future research projects can depend.

Dave Harris

FSP/HSP Websites

In the previous edition of Newslink I introduced members to the new European HSP website www.hsp-info.eu

I don't think I stressed enough that this website is under construction, and in time large improvements will be made. I'm sure UK members would be very surprised if they knew how much work was going on here

behind the scenes. I receive many emails discussing what should and shouldn't be included in the site and there is a lot of translating information and research details into English being done. Please keep an eye on this site as it'll soon become far more comprehensive than our UK site.

Regarding the administrative problems experienced with our own website recently, please accept our apologies. The website is now up and running once again. Thank you to those who alerted us to the situation.

We feel that we should now think about getting our website produced professionally. If any members can offer advice, assistance or experience with this, we'd love to hear from you.

Useful Information

Access to Work

On reading through the Information booklet put together superbly by Dave Harris, I got to the section on "Access to Work".

I read through it and thought this would be right for me.

All my life I have been travelling to and from work on public transport, which up until recently had not been too bad, but as time goes on I am sure, like many more of you, that this will become an effort.

I got in touch with the Job Centre who asked me to get some quotations for the cost of getting to and from work by taxi. They sent me a letter together with a Claim Form confirming that I would be able to go ahead with this.

The process is you pay what you would normally pay to get to and from work and the rest is refundable. This can either be paid by yourself or through your employer, e.g. my bus fares to and from work were £2.00 each day for the three days I work and the taxi fare is £12.00 each day. I pay the full amount of £36.00 and get £30.00 credited into my bank account. The claim form then needs completing in the relevant sections and can either be submitted weekly or fortnightly along with the receipts obtained from the driver, it's as easy as that

I now get from door to door, enabling me to still be able to go to work without all the worry, frustration and struggling on and off of public transport.

If any of you have read this article and think it might be the thing for you, please take some advice from someone who has already put this into practice.

It works and stops you from going insane being stuck at home.

Debbie Best – Region 10

Cruising

I hope this doesn't bore too many of you, but I know that a significant number of our members ARE interested in this type of holiday pursuit. In previous articles, other members and I have discussed the adequacy of cruise-ships for those of us who can walk so little that wheelchairs and scooters have to be utilised.

My wife (Carol) and I recently enjoyed a fortnight on Oceana (P & O fleet) in the Caribbean: this started and finished in Barbados, so we had to fly out and back. We've nothing against flying, but a good number of our cruises have sailed from Southampton or Dover, which has its obvious advantages. There was however one hiccup on this occasion, in that we were delayed 6 hours on the outbound flight. I'll exclude small detail, but the main cause was that one of the passengers experienced a heart attack about 90 minutes after take-off, and a doctor on board (thank God he was there) recommended a return to Gatwick! The blessing was that he appears to have been "saved"....and, as it was a package flight, where everybody on board was to join the cruise, there was no chance of the ship leaving before we arrived.

Anyway, our destinations were the islands of Aruba, Gran Cayman, Cozumel, Jamaica, Curacao, Margharita, Meyreau and Trinidad, and a small village on the Mexican coast after Cozumel. All very much enjoyed, in day-time temperatures consistently in the 70's and occasionally above 80F.

At two of the destinations, the ship could not go "alongside", due to the size of the port, so it was necessary to go ashore by tender (in

other words, on the ship's lifeboats, at Gran Cayman, or on special port craft at Cozumel). Unfortunately for Carol and me, there was too much movement between the ship and the tender at Gran Cayman that I could not dare, as-it-were, to jump one step across to the tender, with my feet on the ship, and my walking-frame on the tender. (Those of you who utilise such aids will probably understand.) Anyway, at Cozumel, I had no difficulty in getting into the small boat, and then there was a special gangplank ashore.

I had absolutely no difficulty manoeuvring in my wheelchair on board. Carol and I had been well-and-truly "spoilt" by our daughter and son-in-law, who had given us the cruise as a Christmas present in 2005 after selling Paul's business....and this was the gift of a "mini-suite" with balcony, so this guaranteed us flexibility of movement as well as glorious extra comfort (such as canapés delivered to the room before dinner each evening).

This was our first experience of P & O, and we are adequately pleased with their facilities and service, such that we could recommend them to anybody, but we give just a shade of preference to Celebrity Cruises (and one particular ship, the Constellation which we sailed on in the Baltic in 2005....and will again be using in 2007 for a trip from New Jersey to Bermuda, then southern West Indies before flying back from Fort Lauderdale).

And on a Different Holiday Subject

We're in Gran Canaria for a week in February, and I want to take up the idea of **hiring a mobility scooter while out there**. You will see from Page 26 of Issue 2 of our Information Booklet that such equipment, among other things is available on enquiry with a firm called Mobility Abroad. The article specifies certain items and certain Spanish and Portuguese territories. Although the article does not mention Gran Canaria, it may well be that it and other spots like Madeira, Tenerife, Lanzarote, etc are within their operable territories.

Anyway, a friend presently at his villa in Gran Canaria (whom we will be meeting out there later) phoned me the other day to tell me that he saw 2 British holidaymakers outside our destined hotel, sitting on scooters bearing a "hired" label. With me in mind, Geoff asked them how they had hired them, and the answer now relayed to me was that they ordered them in UK, and sought delivery of them to their hotel. The scooters were delivered half-an-hour after these people arrived!! Now that's service!

I am going to contact the firm shortly on either www.solmobility.com or telephone either 0844 734 5856, which is a UK local rate line, or 0034 928 735 311, which is a line in Gran Canaria operated by British staff.

A peep at the website indicates that a deluxe scooter which can be driven at 4 mph would cost 110 Euros for a full week. In my mind, I would be glad that this would ease the difficulties of transporting my own scooter, and any worries for its safety on the flight and in storage and disembarkation.

I'll report back to you on any success in the next newsletter issue. Meanwhile, if any of you want to try this or the Mobility Abroad facility in the Information Booklet, please feel free.....I wish you luck...and perhaps you would then submit an article to Ian, so that our trials, successes and tribulations can be made known to our members.

John Moore

Members Letters

I'm writing to say thank you to Emma, who put her letter in the Issue 9, November 2006 HSP newsletter, because she has been very enthusiastic to talk to my young sister Kate on msn. And also a big massive thanks to Ian Bennett, because if it wasn't for him, my young sister Kate, wouldn't be talking to Emma on msn.

Most people in the HSP group are quite old, so it was a god send for Emma to put a letter in the newsletter, saying she was wondering if any other young members would be interested in getting to know each other.

I've also talked to Emma, shes awesome to talk to.

Me and Kate will definitely be at this years AGM meeting in June, I cant wait.

Daniel Gibson Region 8

Thank you Daniel for your letter. If there are any more young members out there who'd like to join communications with Emma, Daniel and Kate (I know they'd love to hear from you!), please get in touch via Ian Bennett.

Forthcoming Events

Afternoon tea Regions 1 and 2

Saturday 21st April 3 – 6 pm

Milford Day centre

Contact Jane Bennett on 020 8853 4089 for further details.

Region 4 get together

May 12th 2 pm – 5 pm

The Dartmoor Lodge Hotel – Ashburton

All members welcome. For further details contact Ian Bennett on 01202 849391.

Mobility Roadshow:

19th, 20th & 21st June 2007 Kemble

Airfield near Swindon. visit

www.mobilityroadshow.co.uk

FSP Support Group AGM

Saturday 16th June

Trident Technology and Business Centre at Royal Leamington Spa.

New Members

We welcome the following new members:

Joanne Kirkbride Workington Region 9	Mrs Elaine Dellow Gateshead Region 10
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Miss Philippa Southern Essex Region 5	Mrs Lynne Harvie Edinburgh Region 11
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Mr Godfrey Van-Tongerren Wolverhampton Region 7	Mrs Mary Beavan Essex Region 5
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Mr P J Moule Nottingham Region 8	Mrs Samantha Hill Cannock Region 7
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If any members are interested in contacting one or more of the above new members, please contact the relevant area coordinator, or the membership secretary, who can then supply their full contact details.

Useful Contacts

	Email	Telephone No:
David Pearce - Chairman 8 Brinkworth Road, Clayhall, Ilford, Essex, IG5 0JS	pearcey david@yahoo.co.uk	020 85512905
David Harris – Secretary 18 Lodmoor Avenue, Weymouth, Dorset, DT3 5AF	dave@vadcar.org.uk	01305 772286
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Stephanie Flower - Help-Line 37 Alexandra Road, Great Wakering, Southend, SS3 0HN	FSPgroup@aol.com	01702 218184
Ian Bennett – Memb Sec/Reg 4 co-ordinator 37 Wimborne Road West, Wimborne, Dorset BH21 2DQ	ian.bennett@tesco.net	01202 849391
Sally Langton - Group Awareness		0116 2700450
Jane Bennett - Regions 1 & 2 co-ordinator	luckyjane82@hotmail.com	020 88534089
John Moore – New Member Co-ordinator	johnmoore@drift66.fsnet.co.uk	02392 592784
Ray Exley - Region 10 co-ordinator	rayexley@aol.com	01904 626799
Liz Ferguson - Region 11 co-ordinator	lizferguson1@ntlworld.com	01415 779695
Colm Treacy Neurogenetics Clinical Nurse Specialist	colm.treacy@uclh.org	020 76762115