



# FSP Newslink

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

**Issue 7 – May 2006**

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

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## Helping those who help us

**Now we have achieved charitable status and raised a reasonable level of funding, we were very proud to be able to support a medical team researching HSP. This was the first time we have been in a position to fund a research programme, and it is hoped that the group can do more of this in the future. The following words are from Dr Evan Reid who is head of the research team.**

I was very grateful to receive a donation of £3,000 from the FSP Support Group, to help fund our research into HSP. Our group is based in Cambridge Institute for Medical Research (<http://www.cimr.cam.ac.uk/>), a research facility of Cambridge University situated within the Addenbrooke's Hospital campus. In addition to me, the group consists of James Connell (post-doctoral research fellow), Tom Edwards (PhD student) and Hilda Tsang (PhD student). We are all working to try to understand the cellular functions of proteins involved in causing HSP, with James and me concentrating on spastin and atlastin, Hilda focusing on NIPA1, while Tom Edwards is investigating the function of spartin. We plan to use the funds generously provided by the FSP Support group to help buy materials

required for Tom and Hilda's projects. Tom is currently in his second year as a PhD student and is trying to get clues about spartin's function using a "guilt by association" technique- i.e. he is trying to identify other proteins which bind to spartin within cells, in the hope that what is known about the function of these proteins will help us to understand what spartin is doing. Hilda has recently started her PhD, and is trying to assess the relevance to human cells of what has been found in a fly model of NIPA1 HSP.

Unfortunately medical research is an expensive business, with bills for chemicals, reagents and other necessary supplies typically running to £12,000+ per year for a full time researcher. This means that any additional funds are gratefully received, since they allow us to develop projects further and faster, with more flexibility than would otherwise be possible- in some circumstances, even relatively small amounts of money can make a significant difference, for example, in allowing us to be able to secure funding so that we can offer a place to a PhD student. I am therefore very grateful to all of the members of the FSP Support Group for the donation, which we will put to good use.

*Dr Evan Reid*

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### Inside this issue....

Useful information Page 3

## From the Chairman

Hello everyone

I did something recently I haven't done for quite sometime. No, not buy a round of drinks; but open up my doors and windows and let the warmth of the sun into my home. Hooray, Spring has sprung at last!

What a great benefit it was bringing together our conference early this year. On offer is a great venue, superb speakers and to date something like 60 plus of us already booked in. Instead of the conventional theatre style seating arrangement we are experimenting with circular tables seating 5/6 ALL facing the top table. Rest assured speakers will be wired to ensure everyone will be able to hear. Once again we welcome Gita Rampharry. She will be covering the Physiotherapy segment. Dr Marsden, who you will all have read about in February's Newslink will be expanding his survey on Factors affecting Walking, Standing and Sitting with HSP. This has to be a golden opportunity for us all to learn from each other, and by our input help the medical profession in a better understanding of assessing and dealing with HSP in the future.

In one of my Mobility Show trips I came across The Calvert Trust (activity holidays) and was so pleased when Karen Varker agreed to present at conference. I believe their headline statement "Challenging Disability through outdoor adventure" is so very pertinent. In fact I intend visiting them at some time before the AGM. Hopefully I can handle sailing, horse riding, swimming, archery and much more. Anyone want to join me?

For those of you who have joined us just in the last twelve months or have not yet experienced a conference, let me assure you of a warm welcome. If you would like any assistance or further information please contact your area coordinator or any committee member or myself. This is an occasion not to be missed. Wouldn't 100 attendees be nice? Don't forget, we are looking for nominations for the committee.

I would just like to end with thanking two gentlemen, firstly to John Moore for his

persistence and detail in sorting outstanding subs. I have learn so much so quickly on problem solving and having fun via our new Email list, so a big thank you to Phillip Stringer. Like all new things you need to weather the initial storm. If you haven't got on board yet, go for it.

See you at conference.

*David Pearce*

## From the Treasurer

### Subscriptions and Gift Aid

We have now reached the end of our financial year and subscriptions are due for the New Year 2006-7 from 1<sup>st</sup> May. Ian Bennett will shortly be sending out the membership forms for you to complete and please return your fees to him. For members who are at work and those who are pensioners you are subject to tax deductions so please tick the relevant box on your renewal form. With the agreement of the tax inspector we will then be able to reclaim gift aid on your subscriptions, and this can be back dated until 6<sup>th</sup> April 2000. This alone will make a considerable difference to our funds.

### The A.G.M. Leamington Spa 17<sup>th</sup> June

At the latest count, members attending amount to 61. I am pleased there is a very good attendance from those members who came to the N.W. conference last year and the West Midlands, Oxford and Gloucestershire are well represented. Anybody else wishing to attend please let me know shortly. There are few coming from the East Midlands, and there are only 4 from the S.E.

*Mike Fawcett*

## From the Helpline

Hi Everyone, I hope you are all keeping well. Not a lot to report regarding the helpline, I have been busy. It is lovely to talk to so many of you and I hope my information has been of some help. It would be great if you could ring back and let me know the outcome of some of our chats.

We look forward to seeing many of you at the A.G.M. in June; please take the opportunity to meet some new and old friends. You will find it well worth the effort.

May I suggest that maybe an overnight stay at a reasonable B+B for those of you that will struggle with the distance + possibly the exhaustion of traveling, that affects many of us. Take care all of you.

*Love Stephanie Flower*

## A heartfelt thank you from the team at the Institute of Neurology

The research team at the Institute of neurology would like to thank the HSP society for their financial help with our ongoing study which we discussed in the last newsletter. The study is investigating the factors that may influence walking in uncomplicated HSP such as leg weakness, muscle stiffness, spasticity and poor balance. The money you have given is being used to cover the cost of equipment that measures lower limb muscle activity while walking and during the strength and stretch reflex tests. The response from members to the article in the last newsletter also means that we are already halfway to recruiting the required number of people with HSP. We are aiming to complete the study by late summer 2006 and provide a write up of the results in the newsletter in late 2007.

In order to fully interpret the data gathered so far we need to assess a comparison control group of people of the same age, sex and height who do not themselves have HSP or a family history of the condition. Most people we have assessed so far are in the 45-60 age group. If anyone would like more information on the study or would be interested in volunteering in either the HSP or control group please contact me on 0845 155 5000 Ext 3965 or E mail me at [j.marsden@ion.ucl.ac.uk](mailto:j.marsden@ion.ucl.ac.uk).

Thank you

Jon Marsden & Gita Ramdharry

## Useful Information

### How the Motability Scheme opens the road to greater freedom

Motability's car and wheelchair schemes provide freedom to 400,000 disabled people and their families across the UK. Since 1978 nearly two million cars and powered wheelchairs have been provided. More than 140,000 new cars are supplied each year.

Behind the statistics are countless stories of millions of lives broadened and enhanced by affordable convenient, trouble free motoring.

The scheme is open to anyone who receives higher rate mobility component of the disability living allowance or the war pensioners' mobility supplement and who has at least 12 months' award length remaining when they apply. They can obtain a new car, powered wheelchair or scooter through a contract hire or hire purchase scheme. Non drivers can apply for a car as a passenger, nominating two other people as drivers, and a parent or carer can apply on behalf of a child aged three or over. Extra grants may be awarded to people whose allowance alone will not cover the cost of special cars, adaptations or driving lessons.

The scheme currently purchases over five per cent of all new cars and powered wheelchairs sold in the UK. Over 20 car manufacturers supply the scheme and there is a national network of over 3,500 Motability dealers.

### Positive Aspects

I recently heard from a lady via our website, who is producing a publication for disabled people called **Positive Aspects**. I thought the first edition was excellent, full of useful information and it is available to anybody with an email account, free of charge. If you would like to receive your own copy, all you need to do is email [trudy.1@ntlworld.com](mailto:trudy.1@ntlworld.com) and put 'subscribe' in the message/text box.

## National cinema concessionary card scheme

The cost is £5 for a 3-year card, which allows free entry for a person with a disability and their companion.

Applicants must be either in receipt of DLA allowance or attendance allowance, be registered blind or be a holder of a disabled person's railcard.

For more information contact: The Card Network, The Technology Centre, Rossmore Business Park, Ellesmere Port, Cheshire, CH65 3EN. Tel: 0151 348 8020 Email: [info@ceacard.co.uk](mailto:info@ceacard.co.uk) or visit their website, where you can download the form, print it out, complete it and send it off. You can also get the application form from participating cinemas. It is worth checking the cinemas that operate this scheme – you can do this on the website too. There is also a link on this website which will take you to the "Disabled Persons Railcard" website [www.disabledpersons-railcard.co.uk](http://www.disabledpersons-railcard.co.uk)

## FSP Computer Help

### Sharing documents between computers

Last time I said that there are probably as many types of computer as there are types of car. This seems fine until you want to share things with other computers. Computers made by different manufacturers have different ways of doing things. This makes things complicated. With the internet things have become a little easier and I'll try and explain how in this article.

Some organisations set simple "standards" up over the history of computing. These were independent of manufacturer. They were found to be useful in the early days of computers and have persisted until this day:

Rich Text files (usually have ".rtf" at the end of the filename). These are interchangeable between many computers but cannot contain graphics, only text and some formatting (i.e. Fonts, Styles and Sizes).

Plain Text files (usually have ".txt" at the end of the filename). These can be interchanged, but only contain plain text.

With the Internet, newer standards were introduced to allow more complex sharing:

Joint Photographic Expert Group (have ".jpg" or ".jpeg" at the end). This is a standard for sending a picture encoded in a string of data.

Hyper Text Mark-up Language (have ".htm" or ".html" at the end). These files contain both the text and coded descriptions of the way the text is to be presented. This standard is the backbone for most of the information files transmitted across the Internet.

All of these can be sent to most types of computer and can be opened and read by the normal set of programs on those machines.

A few organisations have developed "standards" as a means of making a profit, and one that has been very successful is called Portable Document Format (".pdf" at the end) created by a company called Adobe. This works by allowing free use of a program which can read the format and thus allow many people to access the documents. The charge was made for that part of the program which creates the .pdf file in the first place. This is still how it works today, and you can download a free piece of software for your computer from:

<http://www.adobe.com/products/acrobat/readmain.html>

Another free reader for this format on PCs (a much smaller program) is Foxit available from:

[http://www.foxitsoftware.com/pdf/rd\\_intro.php](http://www.foxitsoftware.com/pdf/rd_intro.php)

The last type of file for today is a proprietary file such as Microsoft Word (.doc) files which are not freely shareable in the same way as the others. They can usually only be read on a computer if some form of licence has been paid to Microsoft. So often there are computers which cannot access them. Nevertheless, Word has become a sort of standard because it has been licensed on so many computers.

I hope that this little amount of information about files is helpful to you in understanding a bit more about your computer and perhaps in spotting different file types as you use it.

So that's all for now. Please let me have your questions and suggestions for the next items... you can send them to me at dave@vadcar.org.uk.

Dave Harris

## Members' Letters

Ron Williams (Region 6) sent in a letter with three pictures showing the wheelchair he uses for bowling. Here is an extract from his letter:

Dear Sharon,

I used to play Outdoor Bowls with my father back in the 1960's so I know the basics of bowling. Before that during my school days I used to be very fit and athletic, and after getting married in 1968, I started playing golf and running marathons. However the dreaded HSP caught up with me in 1993, but it was not until 2001 did I require a wheelchair.

The Bowling Centre I visit is in the village of Mountain Ash, approx 4 miles from my home in Aberdare in the Cynon Valley, approx 23 miles north of Cardiff.

I found out they were arranging a course for beginners and on a previous social visit to the centre I'd discovered they had chairs for disabled persons. I joined up and haven't looked back since. The only disadvantage with the chair is you have to be wheeled by somebody, but either the coach or one of the fellow bowlers push me from one end of the rink to the other. No problem!

I found that having being so active in earlier years, as time went by the frustration and anxiety was immense.

All I can say is if there are any members who feel they can do the same, get out there, make enquiries, get involved and have fun. It's brilliant!

Ron Williams

## New communication facility

Following the announcement in our February newsletter, our new group emailing list was launched in early March. It has been very well used and a number of interesting topics have been discussed. For the benefit of those who haven't got an email account, the following four articles are examples of emails received recently within the mailing list.

Hi all,

My name is Andy Barrett, another relatively new member of the group (just over 12mths). My experiences with HSP have been since birth (now 45), and my current circumstances are - use a wheelchair for most of my outdoor mobility - 2 x elbow crutches at home (increasingly with FES) - Spasticity uncomfortable - balance zilch - and a number of the other complications that have appeared here recently!!

It's been great receiving loads of e-mails outlining how so many of you do so well in the 'getting on with it' department, which has been a really welcome 'extra little nudge' to get me into more action. Of particular interest has been the recent 'swimming ones' which helped get me into the pool for c.30 mins last Monday, something which I did 'one off' about 12 months ago, and before that was way back in history!! Have to say that the experience wasn't as enjoyable as it clearly is for many of you (beneficial too), but I'm keen not to just give in. The big problem was that my legs just didn't move, and simply followed the very big effort that my arms were putting in to both keep me afloat and move me forward (unfortunately I'm not a lightweight either!). A warmer pool might have been beneficial. If anyone has any common experience / possible solutions it would be great to hear from you.

Whilst writing I thought it may be useful to mention a 6 week course that I've just completed called the NHS 'Expert Patient Programme', which was also a trigger for the venture to the swimming pool. Basically it's available to anyone over 18 living with a long term health condition and is aimed at helping participants improve their Quality of life -

Pain Management - Energy levels - Use of Services – Stress levels.

Whilst there were a long list of different conditions the common features were Frustration - fatigue - pain - low energy – depression which crop up for many of us. There was no rocket science, just some useful tools to help find ways of doing things, and a good forum to share experiences / solutions (a lot like our group in many ways). It's NHS PCT funded i.e. no cost, other than getting there.

Different people will get different things from it, but all I can say is that it's helped me lots. If you want to learn more, click on the attached link -

<http://www.expertpatients.nhs.uk/>

Best wishes

*Andy Barrett*

Hi Everybody

Thanks to all of you who have written so far about the diagnosis of HSP.

I was thinking, as I dressed this morning, about the shoes I wear, as I have found that the propensity for tripping that I have makes the choice of shoes very important. Just before Christmas I bought 2 pairs of stylish, fairly lightweight shoes from the local Brabanto store as I thought they would be just what I needed. Both pairs proved to be quite useless as I was tripping worse than ever, so I gave them away. Last week I went to the new "Padders" factory shop in Kettering and bought four pairs of their shoes just like others that I have had before. What a difference! I'm still not sure why but they just do not trip me at all. I think it's probably the composition of the sole and the extremely good flexibility. So I thought I would mention it in case it would be of help to anyone out there. If you click on to 'Padders' in Google you will find lots of places that sell them. The new factory shop in Kettering sells them at about £30 per pair.

*Malcolm Palmer*

Hello,

I am Bruce Stuart (42) and I was diagnosed with HSP in 1997. I took ill in 1994 with a

severe stomach bug (not nice) and became very weak and had problems with my balance and walking, this was diagnosed as Chronic Fatigue Syndrome. I had had problems with stiffness and sudden spasms in my muscles since I was in my late teens but, I thought I was just overdoing things a bit (as you do at 18) and ignored these problems.

After a period of rest I started gentle exercise and short walks. While I was doing this exercise I was getting severe spasms in my muscles (all over) and I assumed it was because the muscle was weak after six months of rest. I was crossing a busy road in the summer of '96 when the muscles in my lower back and back of my legs went into rapid spasm. When the rapid spasm stopped I was completely weak and I fell just short of the kerb. When I tried to get up the muscles in my arms and legs were like jelly and just flopped. Thankfully 2 men lifted me to the pavement and made sure I was alright before they left. When I told my GP about this he referred me to the Southern General Hospital in Glasgow (Neurology).

After many tests and scans and 3 days in hospital I was diagnosed with HSP. When I was talking with the consultant when I was in hospital I mentioned my oldest brother has something called Strumpell's disease. The consultant told me that is an old name for HSP. My brother was diagnosed in 1992 and his symptoms are very different from mine.

Although I have severe problems with my legs and have to use 2 walking sticks and ankle/foot splints, I have a lot of other upper body problems. These are mainly to do with control of my arms and hands and I tire very quickly. Some days I put on the PC and I can hardly use the mouse. The consultant I had seen for the last 8 years has just left and the new consultant has decided to redo a lot of the original tests and some more. As Ursula said in an earlier e-mail, I was told that the diagnosis of HSP was arrived at by a process of elimination.

Neither of my parents have this condition, or anything like this and we were told that we have a recessive form of the condition. Like Ursula, we were told that each of my parents

would have passed one copy of the gene and each child would have a 1 in 4 chance of having HSP. I never liked probabilities or statistics, but I am the youngest of 3 children. My oldest brother has HSP, my other brother may have it (complicated by measles encephalitis at 13 months) and (although I am having further tests) I have it. Three out of three.

Misdiagnosis? Sods Law? Just our luck?

Best Wishes

*Bruce Stuart*

Well, hello everyone!

Liz and Ronnie Ferguson here.

Ronnie is the one with HSP, I am the one with the fastest typing so got delegated to this task! We returned this evening from a week's holiday in Spain to two surprises; the first is that having left temperatures of 28 deg in Spain this morning, we arrived home in Glasgow four hours later and had to dig our car out of the snow! The second is that I switched on the pc and found 22 emails from HSP folk!

This is a great idea and we are delighted to join in. Do I take it that this is just a general chat forum between us all? If so I'd like to share some info and also ask advice.

1. On our recent trip to Spain we arranged before-hand to hire a mobility scooter while we were there. It was delivered to our apartment the day we arrived and collected again the day we left - it was brilliant. If you want more info about that please let me know.

2. This is more of a problem and we don't know what to do next. Ronnie works for (I won't name them here) the largest supplier of Electricity and also now gas in Scotland. He has been driving round the country in one of their vans for the last 10 years. In December 2004, we advised his employer, HR department, Trade Union etc, that it was no longer safe for him to drive using his legs, that we had hand controls fitted to our own car and we asked them to supply Ronnie with a hand-control van so that he can continue to do his job. They agreed immediately and said there would be no problem. His work's

doctor agreed also that that was required. Well we are still waiting for the van - they keep on telling us that it is all in hand, but there is no van. Ronnie now spends his time sitting as a passenger in his colleague's van, doing nothing other than just going along for the ride! As a result he is not walking nearly so much, not driving nearly so much and his weight is increasing, none of which is very good for him. Here are our questions - any ideas on the correct course of action we should take now, how do we get them moving, and does anyone know of a make and model of automatic van which can be fitted with hand controls. Many thanks for your advice and we look forward to the next 22 emails!

## Information via our website

I recently received the following communication via our website, which could be of interest to some of our members:

Dear Ian:

I have had HSP since I was 11 or 12 years of age. I am now 51, but for the last 10 years or so I have been taking a daily dose of Siberian Gingseng of 1000mg and have found this to help greatly combat the oncoming fatigue in my legs that I was beginning to experience. Before doing this I consulted with my doctor, who was supportive in this "experiment", as he was of the opinion that if it helped then great. (I live in Nova Scotia, Canada).

He was the one who informed me that there was no miracle cure or treatment for this disease, and only could recommend physiotherapy.

I don't know if anyone else has tried this but it has worked for me. I'm still able to walk quite well for most of the day, which is good as my job is that of an Educational Assistant at a local high school. I need to change classes and floors during the day.

I hope this may give someone else a possibility for help.

Cheers:

Claude Balesdent

## Forthcoming events

### Mobility Roadshow:

8th, 9th & 10th June Kemble Airfield near Swindon from 10 am daily. A chance for anyone with a mobility problem to see what is available. For more details Tel: 0870 770 3222 Email [choice@gtnet.gov.uk](mailto:choice@gtnet.gov.uk) or visit [www.mobilityroadshow.co.uk](http://www.mobilityroadshow.co.uk)

### FSP Support Group AGM

Saturday 17<sup>th</sup> June 10-15 am – 4-30 pm  
Trident Technology and Business Centre at Royal Leamington Spa.

## New Members

We welcome the following new members:

Mr Colin Preston  
Manchester  
Region 9

Mrs Jackie Morgan  
Dunfermline  
Region 11

Mr Henry Marcuzzi  
Surrey  
Region 1

Mr Tim Fitzmaurice  
Leeds  
Region 10

Mr Watson Fenwick  
Rutland  
Region 8

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.

## FSP Support Group AGM Saturday 17<sup>th</sup> June

This will be held at the Trident Technology and Business Centre near Royal Leamington Spa and Warwick. We are occupying a large conference room at the top of the building reached by a lift. There is also a separate dining room for our buffet lunch. The building is only 2 years old and has ample car parking.

If you are looking for some overnight accommodation whilst attending the AGM, listed below are some local hotels, guest

houses and B & B's. I have details of further accommodation in the area, so please call for information if required.

### The Best Western Falstaff Hotel

16-20 Warwick New Road  
Leamington Spa  
Tel: 01926 312024

The Best Western  
64 Upper Holly Walk  
Leamington Spa  
Tel: 01926 883777

Buckland Lodge Hotel  
35 Avenue Road  
Leamington Spa  
Tel: 01926 423843

Victoria Park Hotel  
12 Adelaide Road  
Leamington Spa  
Tel: 01926 424195

Avenue Lodge Guest House  
61 Avenue Road  
Leamington Spa  
Tel: 01926 338555

Hedley Villa Guest House  
Tel: 01926 424504

Courtyard by Marriott  
Olympus Avenue  
Tachbrook Pk  
Leamington Spa  
Tel: 01926 425522

Dell Guest House  
8 Warwick Place  
Leamington Spa  
Tel: 01926 422784

Maps will be despatched shortly for members attending the AGM

## Dave Sparling: A great member and a great friend

We need to share just a few sad words with you all. On 5th April, Dave Sparling from Shepperton in Region 2 passed away. Dave and his wife Val have been regular attendees at the Region 1 & 2 afternoon tea sessions. Dave always took an active part in the open forum discussions and was also very keen to offer help and advice on an individual basis. Dave will be missed but his enthusiastic input to the group will always be remembered.



# HSP Annual General Meeting and Conference.

**Saturday 17<sup>th</sup> June 2006.**

Venue: Trident Technology and Business Centre  
Trident Park  
Poseidon Way  
Warwick  
CV34 6SW

- 10.15 Coffee and welcome.  
11.00 AGM  
11.30 There will be a short break  
11.40 **THE NATIONAL HOSPITAL**  
**Dr Jon Marsden: Factors affecting Walking, Standing and Sitting with HSP.** A new look at some of the coping strategies we have all adopted with HSP with particular reference to the study project in which we are involved.
- 12.25 **Gita Rampharry:** We are pleased to welcome Gita once again. She will talk us through the physiotherapists view on HSP and the importance of exercise in a mobility maintenance programme.
- 1.00 Lunch  
2.30 **THE CALVERT TRUST**  
**Karen Varker: Challenging Disability through outdoor adventure.** Situated right on the edge of glorious Exmoor, The Calvert Trust offer activity holidays including sailing, horse riding, archery and much more. In fact, just the opportunity to do the things you never dreamed possible.
- 3.10 **Dr Jon Marsden: Feedback and discussion from Focus Groups.** Follow on from this morning's session but aimed more at the mutual exchange of our experiences and how treatments can target those factors to be developed and assessed in the future.  
**And running in tandem, Open Forum for our younger member's to talk through issues in dealing with HSP with Stephanie Flower**
- 4.10 Coffee and farewells  
4.30 Close

## Agenda for AGM

1. Apologies for absence.
  2. Approval of minutes for AGM June 2005.
  3. Matters arising.
  4. Annual reports.
  5. Financial accounts and approval.
  6. Election of committee members for the year 2006/2007.
  7. Any other business.
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## Nomination Form for 2006 AGM

If you wish to nominate anyone for election as a committee member, please use the form below and get the agreement of your nominee. Please return the form to Nigel Bulbeck, not later than 3<sup>rd</sup> June.

Officer	Present	Nominee	Signature of Nominee
Chairman	D Pearce		
Secretary	N Bulbeck		
Treasurer	M Fawcett		
Membership Sec	I Bennett		
Committee Member	D Harris		
Committee Member	Stephanie Flower		
Committee Member			
Committee Member			

Return to: Nigel Bulbeck, 38 Middlefield, Farnham, Surrey, GU9 8QA

## Useful Contacts

	Email	Telephone No:
David Pearce - Chairman 8 Brinkworth Road, Clayhall, Ilford, Essex, IG5 0JS	<a href="mailto:pearcey david@yahoo.co.uk">pearcey david@yahoo.co.uk</a>	020 85512905
Nigel Bulbeck – Secretary 38 Middlefield, Farnham, Surrey, GU9 8QA	<a href="mailto:nigel.bulbeck@allianzcornhill.co.uk">nigel.bulbeck@allianzcornhill.co.uk</a>	01252 728095
Sharon Gradidge - Newsletter Editor 20 Cedar Road, Eastleigh, Hampshire, SO50 9NR	<a href="mailto:gradidgefsp@aol.com">gradidgefsp@aol.com</a>	023 80612173
Mike Fawcett - Treasurer 104 Moorview Way, Skipton, North Yorkshire, BD23 2LN		01756 795480
Stephanie Flower - Help-Line 37 Alexandra Road, Great Wakering, Southend, SS3 0HN	<a href="mailto:FSPgroup@aol.com">FSPgroup@aol.com</a>	01702 218184
Ian Bennett – Memb Sec/Reg 4 co-ordinator 37 Wimborne Road West, Wimborne, Dorset BH21 2DQ	<a href="mailto:ian.bennett@tesco.net">ian.bennett@tesco.net</a>	01202 849391
Sally Langton - Group Awareness		0116 2700450
Jane Bennett - Regions 1 & 2 co-ordinator	<a href="mailto:luckyjane82@hotmail.com">luckyjane82@hotmail.com</a>	020 88534089
Isabell Quinlan - Region 6 co-ordinator		01570 471062
Kathy Chambers - Region 7 co-ordinator		01142 960619
Carol McGowan - Region 9 co-ordinator		0151 2892597
Ray Exley - Region 10 co-ordinator	<a href="mailto:rayexley@aol.com">rayexley@aol.com</a>	01904 626799
Liz Ferguson - Region 11 co-ordinator		01415 779695
David Harris – Committee Member	<a href="mailto:david18lod@hotmail.com">david18lod@hotmail.com</a>	01305 772286