



FSP Newslink

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

Issue 5 – November 2005

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

Flying Scholarships for the Disabled

Perhaps I should begin by explaining why I, a widow from a small Cotswold village, who until recently hadn't heard of FSP, should be publishing an article about "Flying Scholarships for the Disabled" within your newsletter. It is wholly due to my husband Paul who died 16 months ago, and your membership secretary, Ian Bennett (all will become obvious).

Paul's energy, vision and love of aviation, was instrumental in the creation of IAT (International Air Tattoo). Who would have thought that an idea of two friends could have grown into the largest military aviation show in the world, and in so doing led to the birth of the Flying Scholarships scheme?

It was back in 1971 North Weald just outside London that Paul and a fellow Air Traffic Controller, Tim Prince, decided to put on an air show to remember the barnstorming era of early aviation. Paul and Tim would attract famous acts and display teams from around the world, by their charm, wit and a good deal of bluff and of course persuasion. This led to the International Air Tattoo moving to RAF Greenham Common in 1973 – a much larger base used by the Americans. IAT became a huge hit with the public because it was never a trade fair with



Still up in the clouds! On completion of his first solo, Ian attempts to come back down to earth

the focus on selling aircraft or weapons – it was pure family entertainment with more than 9 hours of flying displays each day, as well as lots of static aircraft where people could meet the crews. I believe 5 of the current Red Arrows Display Team attribute their desire to join the RAF to attending an IAT as a child and the chance to meet RAF pilots. Ever more popular IAT moved further west to Fairford in Gloucestershire with a huge runway and a two mile static display line. Paul received from the Queen, Royal patronage and the title Royal International

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Air Tattoo of which he was extremely proud. Few aviators could fail to have heard of one of the RAF's heroes and how a man who had lost both of his legs could overcome not just his own disability, but more importantly the perception by others of himself as (in his own words) a stubborn cripple. Sir Douglas Bader fought through every prejudice and constant setbacks to keep flying with his tin legs.

I have to say that I always enjoy the true story of how, after being shot down and his tin legs badly broken in the crash landing, he was taken prisoner by the Germans. It was arranged between the two opposing Air Ministries for a replacement pair of legs to be parachuted into his prison camp in Germany. With his new legs, he escaped twice, before finally being moved to Colditz the most secure POW camp.

The night before Douglas Bader died in 1982 he was still giving inspiration to others in an address to the Guild of Air Pilots and Navigators. He was passionate in his belief that disability can be, if not overcome, at least challenged by the strength of character of the individual.

Douglas Bader had been the president of the IAT since 1976 and in that role he had inspired the many volunteers to raise funds for the RAF charities to relieve hardship and distress amongst past and present members. That function continues with the Royal International Air Tattoo today.

On Bader's death Paul and Tim felt that no garden, painting or sculpture would be a fitting memorial to such a man. He deserved a living memorial and thus was born the Flying Scholarships for the Disabled.

There could of course be no scholarships without the money to support the project. And for that the FSD owes a huge debt of gratitude to the late King Hussein of Jordan who provided the financial backing to the scheme, subsequently taken on by his widow Queen Noor, our Patron today, and King Hussein's sons King Abdullah and Prince Faisal.

Many, many others contribute towards the scholarships but I must single out the work of Polly Vacher. She has flown solo around the globe east to west and pole to pole to raise

funds and also the profile of this noble charity. She inspires many through her own courage determination and love of aviation. BA crewing, Guild of Air Pilots and the Red Arrows each fund a scholarship and this is the first year of a scholarship being awarded in memory of my husband Paul. Ian Bennett was the beneficiary of this particular scholarship.

Earlier this year I felt I had to visit Ian and the talented team who realise people's dreams, so on 7th September I flew down to Port Alfred, South Africa to meet up with all at 43 Air school. On behalf of Paul, the sponsors, fundraisers and the public who donate towards this project, I can't express enough thanks to all involved for their courage, dedication, skill and love of flying.

Janet Bowen

The Flying Experience

Flying had always been an ambition of mine ever since my childhood days, so when I came across a magazine article headed "Opportunities in Aviation for Disabled People" I carefully read the details and without hesitation made an application.

I'll avoid going into all the details regarding the selection process other than to say that the eight successful applicants for 2005 were selected at RAF Cranwell (Lincolnshire, UK) back in April 2005. I was delighted to find that I was one of the lucky eight, and consequently would be travelling to 43 Air School, Port Alfred, South Africa at the end of July for a six week, 40 hour flying scholarship.

As 30th July drew closer a little anxiety crept in as I had no clear idea of what the six weeks would entail, not to mention the fact that I was leaving my wife and two daughters behind.

I needn't have worried! Following an exhausting journey that actually took 36 hours from door to door, I arrived at 43 Air School late on Sunday evening with three other disabled scholars; Louise Scotter, Andy Thomson and Mark Salter. We were immediately shown to our rooms but I was too tired at the time to appreciate the high standard of accommodation. However, it

didn't take me long to appreciate just how lucky I was. Of the 175 bedrooms on site (it was a surprise to me what a large organization it is), mine was the closest to the bar, so naturally I felt it was politically correct to make full use of this facility throughout my stay.

From day one, we were introduced to our instructors and the flying began. Those early flights are something I'll never forget. Myself, regularly piloting an aircraft over stunning coastal scenery in the Eastern Cape is dream material, and yet here it was really happening.

However there was a part of the flying syllabus that I hadn't fully anticipated. Ground school! On the first Monday morning we discovered that we had to attend two hours of ground school every day, and in the very first of these sessions we were each confronted by a pile of books at least a foot high. It suddenly dawned on me that there was some serious work to be done here and it was then explained that there were eight exams to sit. This may sound daunting and initially it was, but it turned out that our ground school lecturer was one in a million. Not only is he a gifted teacher, but he also spent much of his own time with us, demonstrating endless patience going over any problems and misunderstandings we had. In fact this attitude typified many of the staff.

I decided to work hard, but also to have some fun, and although I got my head into the books during my free time, I also spent a few hours and a few South African Rand in the bar in the evenings. It wasn't uncommon for the FSD scholars to be the last to vacate the bar, but bottled lager at 60 pence a go had to be taken advantage of.

As the days and weeks passed by and we got deeper into the syllabus we all experienced highs and lows. Days when safe landings seemed impossible, navigation exercises that went hopelessly wrong, problems learning the technical theory and a "runway widening exercise" are just a few examples of some of the lows. Nevertheless, we supported each other when the chips were down, as indeed did all our fellow students and instructors.

The 4 of us bonded well from day one and have become very close friends. We have also made many new friends from around the globe and can't thank the other students enough for interacting with us as they did. I have happy memories of people taking it in turns in giving Louise a piggy back to ground school and carrying heavy bags for us. Our instructors and lecturers deserve immeasurable thanks for their hard work and patience with us throughout the six weeks. In fact we received help and support from the cleaners' right up to senior management. For me, going solo was simply unforgettable but the icing on the cake was achieving my pilot's license. When I made my application to 'Flying Scholarships for the Disabled' I could never have imagined that a life time ambition was to be achieved within the nine months that followed.

I can't thank FSD enough for giving me this opportunity of a lifetime which I shall never forget.

Anybody who may be interested in applying for a scholarship can access full information and an application form on the FSD website: www.toreachforthesky.org

alternatively Email:

info@toreachforthesky.org

or telephone 0870 800 1942

Ian Bennett

Editors Column

Hi everyone, it's that time of the year again, and I wish you all a happy and prosperous Christmas, and a happy new year. It's hectic for me at the moment. I had expected to have had my operation by now ready for my move early January. I am moving from a large 3 bedroom house which I have lived in for 25 years, into a 2 bedroom disabled flat. Don't get me wrong it's going to benefit me in the long run being on one level, as I only have one son at home now who is 14 and I have to face the fact that in a few years he will not be home as in addition to attending school, he's also attending college doing a public service course as he is intent on becoming a police officer, I do hope he succeeds as he has learning difficulties, it has

been his ambition for a considerable amount of years now and I am really proud of him.

Anyway, hopefully next time I speak to you I would have had my operation and will give you feedback on how successful it has been. Many thanks to all of you who have contacted me wanting information on this and I hope the advice I have given you all has helped you. Take care, bye for now, look forward to speaking to all of you again in the new year, Sharon x

Mike's Miscellanea

Unfortunately David Pearce has had a bad attack of cellulites and has been hospitalised so I am filling in for him for this edition only. I'm sure that I speak on behalf of all our members when I wish David the very best and a speedy recovery.

We held our North-Western conference on October 15th at Holland Hall Country Hotel at Up Holland, conveniently only 3 miles from the M6. 26 attended, and besides the expected attendees from Manchester and Liverpool we had 7 people from Yorkshire and also folks from the Lakes, North Wales and Cheshire. The hotel amenities were superb and they provided us with a splendid cooked lunch in addition to the usual cold buffet.

I hope that now members from this area have met that this will give rise to future get-togethers.

Just a word about our finances which have been doing very well this year. The Lands End to John O'Groats cycle marathon has eventually raised the magnificent figure of £5300, for which we must thank Richard Williams very much.

The other thing is that our newly achieved charity status has seen a great increase on the level of our received donations. We have had recent contributions from sponsored sports events, a line dancing event, funeral and birthday collections. These extra funds have amounted to £2500. I wish to thank you all for your generosity, for which we are very grateful.

How are we going to spend our additional funds? We are now in a position to make a substantial grant towards FSP research and

Ian Bennett is currently in communication with Professor Nick Wood concerning this. We are also extremely keen to continue to support our members by providing grants to assist them in increasing their mobility by financing scooters or wheelchairs. Members who can't get funding for the FES scheme should also contact us as we are keen to help with this. Anyone wanting assistance generally at a level of £300 per individual, please let me know and we will forward you the necessary application form.

Finally we are going to provide extra support to our growing number of regional meetings. One new idea will be to sponsor some extra activities. Why don't we undertake some visits, coach outings etc?

My final paragraph is on the topic of outstanding subscriptions. There are still 80 outstanding, around 1/3 of our total membership. Will members who have not yet contributed please get their cheque books out. This particularly applies to the N.W and the S.E. if you have discovered that you are not affected by FSP please let us know and we will remove you from our lists.

All the very best.

Mike Fawcett

From the Group Sec

I would like to advise all our members (friends) that it is with regret that I have to announce my decision to stand down as the Group's Secretary at the next Annual General Meeting in 2006. Working full time, together with business career study and exams, plus family and personal life has left very little time for my role as the Group's Secretary. So now is your chance. Please bear this in mind when the AGM comes around next year.

Nigel Bulbeck

Helpline news

Hi Everyone, I hope you are all keeping well and have all had the Flu Jab done! Very important for those of us that have limited mobility.

John and myself have had 3 weeks holiday in Canada, it was absolutely wonderful. We went from 3rd Sept-22nd, the leaves were turning towards the end of our stay.

It was a 9hr flight to Calgary Airport, spent the first night in The Palliser Hotel, real 5*luxury, staff on the door in top hat + tails! Next day we looked round the Calgary Tower, which has a revolving restaurant at the top. Then we got a hire car and drove to Banff. We went up to Sulphur Mountain in a Gondola, also any others we could find. Such a fantastic view from them, who needs to go skiing?

We stayed in a place called Chateau Lake Louise, I have never stayed in such a wonderful hotel in my life, it included an upgrade to a Junior Suite.

We travelled from Banff to Jasper and then back to Calgary to fly home, I could go on for pages about it, but suffice to say it was awesome!!

There were a few places that were really not accessible, my husband has come home with muscles like popeye!! Please contact me if you are thinking of going and need some advice about what is accessible.

Love Steph

Useful Information

Gowrings Mobility UK Road Atlas

If you are a disabled motorist, you will know it is vital to have access to information to make your journey smoother, such as which petrol stations are accessible, where you can park when you reach your destination, and how accessible the accommodation is.

'The Gowrings Mobility UK Road Atlas: the essential parking and motoring guide for Blue Badge holders' is a unique road atlas covering all of the UK, incorporating useful information for disabled people such as parking for Blue Badge holders, accessible car parks and petrol stations, tourist information, Shopmobility locations, accessible beaches, toilets and accommodation.

The atlas will be available from **January 2006** and has a **RRP of £12-99**. Gowrings Mobility is offering a special rate of **£12.00 including P&P**. To order your copy, **Lo-call 0845 608 8020**.

Beyond Boundaries II

The Beyond Boundaries series on BBC2 documented 11 disabled people crossing Central America from the Atlantic Ocean to the Pacific Ocean.

Diverse Bristol TV are now looking for applicants willing to go one stage further in the second series of Beyond Boundaries; an expedition through the African wilderness.

They are looking for amazing people to take on an amazing task. If you feel you are up to the challenge, 18 or over and can make yourself available for four weeks in January/February 2006 then please contact Belinda, Gareth or Katie for more details. They can be contacted by phone 0117 9858750/ 0117 9858748, Email Africa@diversebristol.tv or write to them at:

Beyond Boundaries Africa

Diverse Bristol

West Point

78 Queens Road

Bristol

BS8 1QX

Starting a Local Group

As I understand it, approximately half of the FSP regions have a Local Group.

And so I have made a few notes here, to help encourage others to think about starting up their own local group.

Perhaps the first consideration - is which geographical area to represent?

To some extent, this has already been decided.

The UK has been split up into 'regions' by THE FSP GROUP.

Secondly - one has to decide whether one has the time: inclination or resources to be a representative (I prefer the term 'co-coordinator') of the FSP group?

It would be no good starting the group if one knew that one couldn't continue with it, for at least a year (say).

Letting people know that you intend to start a group?

The Membership Secretary might be able to help here. He will know how many people

are in your region, their address details and contact numbers.

Contact these people and see what response you get! You will need a rough idea of numbers before you can proceed further.

And then there is the consideration of a suitable venue.

An ideal venue is one that is fairly central to your region, accessible to all, and has plenty of parking. The venue should be: easily identified, on a main road, and easily reached. If people are likely to be coming from a great distance, then some refreshments might be in order. Access to loos is important too!

And of course, at the right price!

The first meeting?

Fix a date, several weeks in advance, and stick to it (where possible).

Changing dates can cause confusion.

The meeting itself?

Determine, (from those present) exactly what the local group's aims are!

- To be a social gathering, and provide peer support.
- To raise funds for FSP.
- To raise funds for the local members.
- To raise awareness of FSP.
- To provide a bit of each.

In any event, the local group might evolve into something that you hadn't considered.

It's a steep learning curve, things change!

What applies in one area, doesn't always apply in another.

Be clear in your own mind, what it is that you are prepared to do. (in a previous life, I had allowed myself to become: Chairman, Secretary, Treasurer, Publicist and Events organiser, PHEW!)

Ray Exley, Region 10

Members Letters

Dear Sharon,

Sorry for the delay. I hope you are all well and coping with every thing in general, I have been busy having hydrotherapy sessions, recommended after my hip fracture, and

then also going to the local swimming pool to try to do the exercises again. They have a really useful hoist to help disabled people into the water and I am really benefiting from the exercise.

In the May newsletter I noticed you were talking about holidays and also the letter from Petula Baker about cruising holidays caught my attention. I have been on four cruise holidays with P & O Cruises and really found they gave excellent help and service. They do have a limited number of disabled cabins with wheelchair accessible bathrooms but if you have some mobility and are able to step over the edge of a shower lip or even into a bath well most cabins would be suitable. I do think that if you do need a disabled cabin, then it does have to be booked early, as I have heard that as the disabled cabins on the newer ships are quite large and they are quickly filled, sadly at times by quite mobile people. I took my rollator on to the ship and had no real problems; the staff were so helpful. Many times they would explain to me if I go to the deck below, in the lift then I could leave the ship via the ramp and not the stairs. Very often the staff there would push my rollator for me while I used the rails on the ramp. P & O do say in their literature that on the occasions that they cannot stay in a harbour and the tender has to be used to get to the port, passengers need to be able to step on to the tender themselves, they cannot transfer a wheelchair bound person.

Transferring from the ship to the tender was no real problem for me I found, as there was always some one there ready to help. My friends were a little miffed at this I was at times assisted by a rather handsome officer. Also another I found very encouraging; you know sometimes a person can be in a wheelchair and the companion is always asked questions like "does she take sugar?" while the person involved is more than capable of answering. Well the crew or staff of P & O did not show that attitude at all. One passenger was wheelchair bound and also had great difficulty in communication but I noticed that one day in the shop the assistant was really helpful with her and did not talk down to her at all. Sadly though the

ship we spent 3 holidays on has now left the fleet, but there is another namesake now to take its place and we are going on a weekend sample party cruise next year, so I may be able to give some more highlights.

Well I think that is about all for now. My friend telephoned earlier this year and invited me to visit her and also extended the invitation to another friend we both know. So I am in the process of trying to arrange flights to New York, so I may be able to give highlights of the Big Apple next time I write. Take care.

Best Wishes

Linda Bernard

Dear Sharon

It was nice talking to you on the telephone the other night; you believed that maybe other members would like to hear about my botox experience. Well, on arrival for my usual appointment, I wasn't aware that this was planned. After we had had a chat about how things were, he just decided to do it. He injected the inside of both legs into the muscles from the knees upwards, it didn't hurt, he assured me he was trying this for the stiffness, and to give it about 10 days before I would notice any change. Well up to the present date I have not noticed any difference. I will go back in November for a further clinical review with the same doctor, so whether he decides to give me any more botox injections or not, I just don't know.

I went to see another doctor in April this year at our local hospital (Hope Hospital) and he asked me if I would like a visit from the CNRT team, this stands for: **COMMUNITY NEUROLOGICAL REHABILITATION TEAM**. I said why not, anything that may help me was worth a try. Two ladies came to assess me, from then on I have had another lady calling in at home showing me exercises. Another lady calls in to advise me on exercise that may help my bladder problems. I now go to the swimming pool in the hospital on a regular basis, I can't swim but they give me leg exercises, I have also had new insoles put inside both my shoes and these botox injections, and not forgetting I also got a four wheel walker from them, with a basket on.

But apart from all this, I am sorry to say I am just getting worse. I get up from sitting now and I can't move! It gets me down because I am really trying my best at everything, and now both my arms are starting to trouble me.

Anyway enough of my problems, all the best for your operation (which in the long run I will think about getting). I have just received my invitation to the meeting in the North West (Up Holland) FSP support group, I will get my husband to take me. It is on the 15th October, too far for you to come I should imagine.

Take care.

Dorothy Slavin

FSP Computer Help

Introduction

The FSP group contains a wide range of people from different backgrounds and age groups. There are widely differing levels of physical disability. The use of computers in homes is spreading and many people are finding them an invaluable way of finding out new information or just keeping in touch.

In any varied group, the range of skills that any individual has will differ from person to person. For example a person who has been in an office job is more likely to be familiar with the use of keyboards than someone who has had a job which is mainly based outdoors. Someone who has worked with electrical or electronic machinery may be more confident with connecting and setting up computers and printers etc.

A person's background and experience will to a large extent influence the ease and confidence with which they "get to grips" with computers.

This series of occasional articles about using PCs at home will set out to help members in the group to make a little more use of their computers. The main purpose is to improve levels of knowledge and confidence a little bit and as the series develops, perhaps to provide some points of contact who are prepared to try and help members who run into difficulties.

There are a few topics I have in mind to develop over the coming months, but I would be happy to receive questions and suggestions for future topics - such feedback may well help me to decide what topics are of most importance to you - the members!!

Having said that - let's move on to the first topic - this is about the Internet - and is aimed at giving a simple description of some general aspects of the web together with some pointers to how to use it more effectively.

Aspects of the Internet:

1. Finding Information

Most people now have a basic understanding of how to use a "Search Engine". This is what you do whenever you fill in a search box and click the "search" button within a web browser.

Often, a large amount of information is presented in response to a search which is not relevant to your enquiry. There are some simple ways to make a search more relevant which are common to most Search Engines. I will mention just three here which when used can make searches much better.

The first is the use of quotes around two or more words. This forces the Search Engine to look for pages which contain those words *in that sequence* instead of pages which contain the words anywhere in any sequence. For example while writing this I typed in *green frog warts* into Google and it located 103,000 pages. Putting quotes around the three words and searching again gave a list of just two pages!!

The second is the use of the signs "+" and "-" immediately in front of words in your search. A plus (e.g. +frog) forces the search engine to only include pages if that word is present - similarly a minus (e.g. -frog) forces the search engine to omit pages which contain that word from the search.

OK that's enough for this time - lets have your questions and suggestions for the next items... you can send them to me at dave@vadcar.org.uk.

Dave Harris

Regional News

North West Meeting

Saturday 15th October 2005

New Holland Hotel, Upholland,
Nr. Wigan

The meeting commenced at 10.30, and believe it or not some of us arrived before the Committee surprise surprise.

I would like to start by saying how much I enjoyed this (*"not a bad turnout from Region 10, even if I say it myself"*) meeting with new members and exchanging telephone numbers to enable the friendship to continue.

A big thank you goes out to the Staff at the Hotel, for putting on such a wonderful spread of food (both hot and cold). I think this suited everyone's needs, and especially for the help they gave in carrying the food to the table for anyone who was unable to do this themselves.

I was really interested in the talk given by Carol's Physiotherapist and I think quite a lot of us were "flabbergasted/gob-smacked" to hear what she had to say (a little different to what I and a few more us have been told to do).

I personally was a bit disappointed with the talk given by the guy from Access Holidays. I was under the impression he was going to talk more about how going on holiday can be made easier for disabled people.

On glancing through the brochure when I got home, the thing that stood out most to me was the cost, it was rather "expensive", especially for anyone who is not able to work and relies on Disability Living Allowance and other possible benefits to live.

Can I just say though that it is good to know that there is a Company out there for us if we do get that we are unable to go on holiday as usual and require it.

It was then time for afternoon tea and time for us all to get together and have a chat and talk about ourselves, the jobs we do, the hobbies and past times etc. we have, and

believe it or not I think that "FSP" was mentioned!

The meeting finished at approximately 4.30 and we all went our own sweet ways and hopefully got home safely.

Here's to many more Meetings, whether they be Regional, North West, South or the AGM.

"It is always good to know that we have each other for support if needed".

Debbie Best

Region 4 Get Together

On Saturday 1st October, 20 members from the West Country met at the Dartmoor Lodge Hotel in Ashburton Devon.

It was excellent to see both new faces and faces that hadn't been seen for a while. The proceedings were very much as per usual, just a social gathering. Members from region 4 are getting to know one another and happily mingle and chat with each other throughout the afternoon. It amazes me what information can be picked up just through chatting to others in the same boat. For example, during discussions with a couple of members of similar age to me, it came to light that it is possible that the fatigue I suffer from could actually be a sign of depression. Certainly not conclusive, but nevertheless very interesting. I'll certainly put this possibility to Nick Wood on my next visit to the National.

As with our previous meeting half a dozen stayed the night at the hotel, and in doing so had a very pleasant evening meal together followed of course by a drink or two at the bar in the evening.

Before driving back to Dorset on the Sunday, David and Carolyn Harris and I had a pleasant tour of deepest Dartmoor culminating with a cream tea at Widecombe in the Moor.

Once again we had a very worthwhile region 4 meeting, but I feel that maybe the time has come to try something a bit different. The emphasis will always be on getting together as a group, but perhaps some kind of activity could be incorporated within our afternoon.

Any suggestions will be appreciated, but be warned! I may just have something up my sleeve.

I look forward to seeing you all again probably next April.

Ian Bennett

German HSP Support Group

We have been contacted by the German HSP Support Group asking us for our assistance. They have created an HSP survey consisting of a list of 43 questions. This has already been dispatched to all the members in Germany and the majority of them have returned the completed questionnaires.

Rudolf Kleinsorge, the secretary of the German Group has asked me if I can distribute this survey amongst our members to complete anonymously. If you are interested in assisting, please complete the enclosed survey and return it to Ian Bennett. Please do not put your name on the form.

I understand that the main purpose of the survey is to give newly diagnosed HSP people a clearer picture of what their future may entail and maybe help them plan accordingly.

The German group will share full results with us which will give us a statistical picture of how we are all affected.

The German Group can be found on the internet at the following address:

www.hsp-selbsthilfegruppe.de

Please try to find the time to help with this survey. Surely international support groups interacting and assisting each other can only help to create more knowledge and understanding for us all.

Forthcoming events

Region 10 get together

November 26th Midday

The Doormouse Public House - York

Contact Ray Exley on 01904 626799 for further details.

New Members

We welcome the following new members:

Mr Andrew Rutherford
Durham
Region 10

Mrs Maria Kane
Trowbridge
Region 4

Mrs Janet Woods
Ipswich
Region 5

Mrs Sandra Williams
Manchester
Region 9

Mrs Diana Moussa
Stockport
Region 9

Mr Michael Booth
Betchworth
Region 1

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.

Mr Ian Clarke
Longfield Kent
Region 1

Mrs Susan Simmons
Sheffield
Region 10

Useful Contacts

	Email	Telephone No:
David Pearce - Chairman 8 Brinkworth Road, Clayhall, Ilford, Essex, IG5 0JS	pearcey david@yahoo.co.uk	020 85512905
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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
Audrey Town - Family Records		01484 861668
Jane Bennett - Regions 1 & 2 co-ordinator	luckyjane82@hotmail.com	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	rayexley@aol.com	01904 626799
Liz Ferguson - Region 11 co-ordinator		01415 779695
Rachel Taylor - Genetics Nurse (Nat'l Hospital)		0207 6762196
David Harris – Committee Member	david18lod@hotmail.com	01305 772286