



# FSP Newslink

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

**Issue 4 – August 2005**

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

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## Hello everyone, what an undulating experience

From the 9th to 23rd June I traveled by bicycle from one end of England to the furthest bit of Scotland. Here is a huge 'thank you' to all those who supported me on this long trip which ended up as 1002 miles! If all the pledges are met I will raise £5000+ that is a large portion of the £10,000 target we hoped for.

The members of the FSP Support Group whom I have seen and heard from are overjoyed and delighted by this. This was a long trip that took 6 months in training and planning with two weeks of hard cycling! During the trip I had some critical support from members of the FSP Support Group, many friends and family who all contributed in making this trip a great success. I was also encouraged and supported at many B&Bs and hostelrys on the journey where food and accommodation I required was offered! Special places that I will hopefully revisit as they were very special were the Clinton Arms in Frithelstock in Devon and the most remote B&Bs in the country at 1 Macleod Crescent, Altnahara which is 20 miles away from anywhere else down a single track a road!

If I was to do this again I would have taken much longer! I would suggest a more

leisurely pace with an absolute maximum of seventy miles every day.

Pre-booking with pre-planned stops was essential for me to get the trip completed as looking for both food and accommodation every night would have been difficult and problematic! I managed 102 miles on my last day that took me until 22:10 and it rained and exhausted me almost completely!

I also hope to produce a personal account of the trip on my own WEB site with a few photographs. There will only be a few pictures as I didn't have time most days to stop and take photographs! Please do send or give me your money if you haven't done so already.

<http://www.justgiving.com/fspgroupprwcycle>  
All donations are secure and sent electronically to The Familial Spastic Paraplegia Support Group. If you are a UK taxpayer, just giving will add an automatic 28% bonus to your donation at no cost to you, making it worth even more.

Please join us in supporting The Familial Spastic Paraplegia Support Group and a fabulous cause! Please contact me if you want to know any more about the trip. My email address is:-rushour@onetel.com Best wishes,

*Richard Williams*

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## Mike and David's visit to the Mobility Road Show at Donnington Park, Derbyshire

and their 3 day stay in the locality – July 2005.

I have a Strider maxi scooter and my intention was to find a smaller and collapsible version, which could be adapted for easier travel on trains and planes for my trip to Brazil later this year. David was looking ahead to the renewal of his Motability vehicle early next year with particular reference to scooter sizes, hoists or ramps.

The main exhibition hall houses some 144 stands displaying everything you could seek and a lot more. There are charities, travel and leisure services and of course those handy little gadgets we all use. In the open area each dealership had on display their most popular vehicles with hand controls, hoists, lifts and other adaptations. Scooters were available to hire, without one David would not have been able to see the whole show. We spent the whole day there coming away with a much better idea of what we needed.

If you are interested next year's show is changing to Kemble Airfield near Swindon from 8<sup>th</sup> – 10<sup>th</sup> June 2006. As there were some interesting places to visit we booked ourselves into a nearby hotel in Melbourne. Very conveniently they had two ground floor rooms and at only £32 per night.

The next day we visited a National Trust property, Calke Abbey. This consisted of a 300 year old stately home with extensive gardens, stables and a church. The ascent to the gardens was steep but fortunately David was able to fit his manual chair to the Abbey's vehicle and be transported up; and so very worth it.

Initially the house seemed to be a problem as there was not much to view on the ground floor. To really enjoy the most worthwhile rooms you needed to ascend quite a big staircase. However the treads were shallow and we both managed it – no problem.

Self-propelling wheelchairs were available for us to use on this floor level. In the side corridors the interior had been untouched since the late 19<sup>th</sup> century demonstrating the effect neglect and time can make.

Rooms that had been sympathetically restored were astonishing with cases of stuffed birds, animals, silver, carpets and furniture. On occasions there had been a need for both wallpaper and curtains of the period to be produced. We found the staff there very knowledgeable, enthusiastic and helpful to the disabled.

On our final day we visited The National Forest Conkers Discovery Centre at Moira. This tells how the forest is being created over 200 square miles covering Leicestershire, Derbyshire and Staffordshire. Inside there is a museum of many interactive exhibits. Outside there are woodland trails viewing lakes culminating in a mega assault course guaranteed to occupy the children for hours.

I found I was able to help David get around on his wheelchair by giving him a tow with my scooter. One of the Burton brewery horses was giving people lifts in a cart. It is certainly worth a visit as in addition to the Discovery Centre there is a Waterside Centre which is inter connected by a miniature railway.

We dispersed after lunch at the centre having had a very enjoyable holiday in glorious sunshine.

*Mike Fawcett and David Pearce*

## Editor's Column

**By Sharon Gradidge**

Hi everyone , hope you all had a great summer and enjoyed that gorgeous weather, although at times it was too hot to want to do anything. Just a reminder that subscriptions are now due. Could you please make them payable to Mike Fawcett due to Ian Bennett's absence.

We would appreciate when you complete the membership renewal form; please ask for your subscription to be treated as a Gift Aid

donation the reason being we will be able to reclaim tax thereon.

I would also like to bring to your attention that we are intending to hold a Northern Conference in October. Will those interested in attending please make a speedy response to Mike Fawcett, Carol McGowan or Ray Exley as two years ago we lost a substantial amount of money booking the conference room and unfortunately members who had alleged they were going to attend the meeting changed their minds at the last minute.

Regrettably we had to still pay for the venue with a minimal amount of member's attendance. On a lighter note, In October I am due to go into hospital to have a bladder operation incorporating a 4 day stay. It's going to change my life completely no more pads, commodes, and being able to go out for the day not having to worry about needing to go to the toilet and sometimes not getting there on time, it's going to be so lovely.

There are four operations available to male or female patients. If any one would like further information, feel free to contact me. Enjoy the rest of the summer, take care,

*Sharon*

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## From the Chairman

Hi Everyone,

Wow, is it hot (or is it hot) I'm putting this together under sun shade in the garden with a large lemonade and ice.

I couldn't possibly complete this article without reference to the events on the morning of Thursday 7<sup>th</sup> July. What a changing world we live in; from the elation of securing the 2012 Olympics in London to having our heart so seriously bruised. I'm sure a great number of us have put out thoughts to assist those affected on the day and thereafter.

So what did you think of conference then? Didn't the quality of the venue set the tone of the day, especially in the tricky area of accessible toilets? We were entertained and

informed by two magical speakers, enjoyed a sumptuous buffet, shared in Richard William's cycle trek experiences and talked the hind leg off a donkey in the free time period in the later part of the day. How nice it was to see new friendships developing with phone numbers being exchanged on the day, and afterwards I believe, though not without prior agreement of course.

I have to thank Stephanie Flower for her impromptu gathering of our younger adult members in attendance. Clearly one or better still, two people working together could encourage the pooling of information and ideas here. A similar situation also arises where families have children with HSP and Stephanie Flower has developed this further in her article on page 7.

In excess of 100 flyers were taken away from conference and so a big thank to those who have offered honorary membership to their consultant and presented flyers. I know Debbie Best, Sharon Gradidge and Gabrielle Cooper have all been successful. Prior to your next visit to clinic please check with Ian Bennett re flyers and the approach.

Let me welcome the new trustees and thank them for their input over the coming exciting and busy year. One of our prime goals is to enable a greater number to enjoy the positives of our membership at meetings. A questionnaire may well be the best way to identify just how to bring this to fruition.

They say end the show on a high. I'm sure you'd all like to give Ian Bennett our best wishes throughout his six week adventure in Port Elizabeth, South Africa ending around 11<sup>th</sup> September. After stumbling across a charity in the Motability magazine called Flying Scholarships for the Disabled (FSD), Ian decided to apply for a scholarship.

Following a comprehensive vetting exercise he secured a flying scholarship, on completion of which he will have completed 40 hours flying and flown solo. This incredible opportunity is open to everyone and to find out more, the website is [www.toreachforthesky.org](http://www.toreachforthesky.org)

As always please keep up the constructive ideas and suggestions (let's keep it clean, eh? Stay well,

*David*

## Motability Customers:

### Options available for next of kin following death of a customer

New arrangements for the use of Motability cars mean there is one less worry for family or friends in the unfortunate event that a customer passes away. Previously there were fixed rules about the number of days the car could be driven following the date the customer passed away.

Motability now offer a more flexible approach, meaning the car will be available for family use until such time as they agree to collect it. Should the proposed driver not already be one of the nominated drivers on the Contract Hire lease, all

Motability will require is that the deceased's family contact them. The reason being it is then possible that they can then ensure that the appropriate insurance, loss and damage protection is provided until they arrange to collect the car. When a request is received checks are carried out to ensure that the proposed driver can legally drive and has no previous convictions.

Alternately, the deceased customer's family can buy the car, or another member of the family can buy the car, or another member of the family receiving the higher rate disability allowance can take over the lease.

The Motability Customer Helpline advisors will be happy to deal with each case individually. For further information you can call them on 0845 456 4566.

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## Forthcoming Events:

### Region 4 Get Together

Our Region 4 get together will be held at The Dartmoor Lodge Hotel, Ashburton, Devon on Saturday 1<sup>st</sup> October. We aim to start at 2.30pm and bring to a close at 5pm.

For further details, please contact Ian Bennett on 01202 849391.

## Region 10 Get Together

The next Group 10 meeting, will be held on Saturday August 20<sup>th</sup>, at The Dormouse Pub. We hope to meet at 12noon. The pub is on the A19 in York. I chose this venue because it has good disabled facilities.

If anyone needs directions: please ring me (Ray) on 01904 626799.

## Afternoon tea Regions 1 and 2

This years November's Afternoon Tea will be held on Saturday 12<sup>th</sup> November 2005, at our usual venue, The Milford Day Centre, Godalming, Surrey. Further details will be sent out to you soon. This year we have Dr Jon Marsden joining us to enlighten us on how far research into FSP has evolved.

The Afternoon Teas are very social events. There is no Agenda. More importantly, there is time for members and carers to have time to talk. Furthermore, there is also time for an Open Forum. To bring the afternoon to a close the last hour is available to take refreshments and socialize. We are always delighted to meet members who venture out to attend our Afternoon Teas. We are both looking forward to the afternoon and hope to see you there.

*Mike and Jane*

## Essex Meeting

The date for the Essex meeting is on the 22/10/05 at the Old Rectory Court, Southchurch Rectory Chase, Southend-on-Sea, Essex, SS2 4XE. Time: 2pm-5pm. For more details, please contact Stephanie Flower on 01702 218184 or Richard Williams via phone or e-mail if you would like to attend. It is a large venue able to hold up to 40 people. It is just going to be an informal social afternoon, with light refreshments. You can contact Richard on 01799 550534 or via e-mail at [rushour@onetel.com](mailto:rushour@onetel.com)

## Region 11 Scottish meeting

Well, we are delighted to say that at last the Scottish members have had their first meeting. It took a wee while to get it arranged but now we can put faces to names.

We met on Saturday 14<sup>th</sup> May in the beautiful Glasgow Royal Concert Hall and it was a scorching sunny day. It was really nice for everyone to meet up at last as although Liz had previously spoken to every Scottish Member by 'phone, none of us had actually met each other before.

There are 13 Scottish members and 7 of them made the journey mostly bringing friends or family with them. A 50% turn-out is absolutely fantastic and we thank you all for making the effort, especially Alison and her husband who traveled all the way from Fife on public transport!

We were all delighted that Mike Fawcett also made the journey up to attend our first meeting, and he was able to give us an insight into the origins of the FSP (HSP?) Group. (Although it has to be said that Mike traveling to Glasgow is small fry when you consider all the exotic countries he has visited recently – nothing stops that man!)

We sat around a circular table and were supplied with tea, coffee and pastries. We had deliberately not formed an agenda as we wanted the chat to be friendly and informal so that people could discuss whatever they liked.

We all get different things from the meetings; some people find it quite an emotional time, some are very nervous about making that first contact, but hopefully we all benefited in some way. Judging by the complimentary phone calls we received afterwards, it seems that we did. Hopefully, some of the folks who were unable to attend this meeting might feel able to join us next time and we all look forward to that. Best Wishes,

*Liz and Ronnie Ferguson*

## Members' Letters:

### Cruising for Disabled People.

In response to Petula Baker's article in May, I thought I should offer details of my cruising experiences.

My wife and I started cruising 12 years ago, and have been on 6 sea cruises and 2 river cruises. Flights were necessary for 4 of them (i.e. 2 to the Caribbean, one to the Nile, the other to Venice). For the other 4 we have been able to sail from Southampton and Dover, and, in fact, we sail from Dover again this year, heading for the Baltic.

It is only in the past 5 years that consideration of wheelchair usage has been critical for me (i.e. after I broke my leg: tibia and fibula). Before that, the chair was only vital for journeys ashore, but, now that I have to walk with a frame (a folding concoction of a Zimmer frame) and therefore the 'chair becomes a fairly regular necessity on board, I do have to enquire on the scope and width of gangways, etc on board.

Only once, so far, have we booked a "disabled cabin". This was on a cruise to the Med with Page and Moy. On an earlier cruise with them we had no difficulty, but we thought we would give the special room a try.

On other cruises, including one last year on the QE2, we have carefully ensured that either the door of the cabin is accessible to wheelchairs (no matter how little the chair may be needed inside the cabin) or the 'chair can be left in the corridor outside the cabin, (in which respect it may be necessary that the cabin is at the end of the corridor, so that the 'chair will not be in the way of crew or passenger activity).

I had read in a magazine, the Disabled Motorist that the Constellation was a particularly good ship for disabled access, and that is why we have chosen that very ship this year. It is one of the Celebrity Cruises fleet.

In conclusion, I think it fair to say that the more modern and larger ships are likely to have better access, but it all comes down to full and specific enquiry. So, Petula, good luck with your future efforts. If you are able, as you sound, to use a stick for occasional walking, you may be free to utilize a standard cabin rather than necessarily a disabled cabin. The question of disembarkation at the ports of call is not usually a problem for me. There may be a potential difficulty when the ship can not enter the port and everybody has to get down into special tenders to be taken ashore.

Until last September this had not been a problem for me, but then I did experience difficulty in walking on the ship's pontoon outside Dubrovnik, and the crew members told me that they were not allowed to lift me at all, due to "Health and Safety" Regulations....I eventually managed it, holding arms, but with some difficulty. Again, therefore, it's as well to find out whether and where the ship will be unable to enter port.

I hope this has been of some use. I offer my phone number, should you wish to enquire further: 02392 592784

*John Moore*

## **Active mind, disabled body**

Here is a bit of a story about my 5yrs old rescued Golden Retriever called Amber. She is that good she been training by a lady who works voluntary for DOG AID. She is going to be doing a good companion course in September and then she will start her training for an assistance dog. She will be able to help me do tasks in my daily life.

My first recognition of having a disability is I was wearing calipers. No one told me then or since why I had to wear calipers. During my childhood I remember that I was always falling. This happened through my teenage years. This was never investigated, I was always told to stop being clumsy and to pick my feet up. In my early 20s things seemed to get a little better.

Then I met my future husband Paul who showed me love and trust. We got married in 1977 and had two children. It was after this time that I started falling again. Over the years this was investigated and was given many names; peripheral neuritis and hereditary paraplegia, among them. It was not until I went to the hospital with high blood pressure that the doctor told me that I had spastic paraplegia as my disability. I use a wheelchair but this has not stopped me from doing things as I am also a qualified sports leader.

I have done many course such as typing which I achieved a distinction. Additionally I have achieved a level 1 pass in counseling and also a computer course. I used to do art which I liked.

I have also done wheelchair racing including The London Marathon and The Great North Run which is a half marathon. I became blind in my 40s which stopped my racing and art but I still carry on with my courses.

To help me I have a screen reader and thanks to The F S P group I now have a scanner reader so I can read my own mail, books and the news letter. The course I am doing at the moment is called emotional intelligence. This is about self-awareness and how to manage your emotions using various techniques. I am half way through the course and I have passed 22 assignments. It is proving to be very interesting and useful as I am learning not to get stressed but think things out calmly; which makes me feel better.

My husband Paul is my carer, he has arthritis, in February this year he suffered a heart attack; but we still keep going on with our daily life and still keep cheerful.

*Pattie- Raven Chapman*

Hi to you all, I would like to thank all on the committee for all their hard work over the last year & for a really good & enjoyable AGM. I thought it might be of interest to some of you.

Three months ago I saw a rehabilitation consultant as I had been off work for 4 months as my balance had gone really bad. I

had to use 2 sticks. She prescribed me 300mg, 3 times a day a drug called Gabapentin which is a nerve inhibitor – this has eased the tightness of my legs, my knees are no longer pressing tightly against each other – still quite wobbly but my legs are feeling easier.

This consultant in her report said that she couldn't see me ever working again and when my wife and I read this we looked at each other and said that we would show her how wrong she was. I have since restarted work although slower & needing some help but I urge all of you not to give in.

We need to show everyone around us that we can still do well – so please be positive.

*Phil Burton*

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## **Annual General Meeting Saturday 25<sup>th</sup> June 2005 The Olympic Lodge, Stoke Mandeville Stadium.**

I would like to start by saying a very big thank you to everyone concerned for arranging yet again another successful AGM, (bearing in mind that this was only the second one for me). Even though it was a long way for us Yorkshire folk to travel, (but not as far as some of you, I hasten to add), it really was worth it. Great appreciation also goes out to the caterers for a lovely spread of food.

It was great to meet once again with people I had already met in Peterborough (2004) and more than that, to meet with others that I had only spoken with on the telephone. Speaking for myself (and no doubt many more of you), I would also like to say a big thank you to the two Speakers. Both very different, but specialists in their own field

The first being Dr Tom Warner a Neurologist from The Royal Free Hospital in London. This was very interesting in that he went into some depth about the condition e.g. the various types and the different genes which make up FSP, without making me and probably the rest of you feel, oh no, not FSP

again. Then came a talk about the “FES Machine” by Paul Taylor from Salisbury Hospital. This was of great interest to me because since first meeting and speaking with Ian Bennett about this, some time ago now, I felt that it might be a useful gadget for me.

The only worry I had though was I also suffer from Epilepsy (aren't I the lucky one eh!), and when speaking with my Neurologist and Physiotherapist about FES I was advised not to try this as it can trigger off seizures. So after being told at the meeting that it would only really be hazardous to anyone who's Epilepsy is not controlled, this made me feel great, as mine has now (hopefully) been under control for approximately 4 years with drugs.

Good news then came when I last visited my Physiotherapist and mentioned what had been said at the AGM, she told me that they have an FES Clinic (so I do not have to make the “long and winding road” to Salisbury), which, of course, I would have done had it not been available on my doorstep, and she would put my name on the list to see someone. Watch this space and I'll let you know how I get on.

One thing though that really did shine was when Stephanie got a small group together in the afternoon (this being the younger members of the Support Group, and not forgetting her “four legged friend (“FRODO”).

It was lovely to watch them and they seemed to be having a really good chin wag, which is what life is all about. As we all know, there is plenty to talk about other than FSP. “YOU NEVER KNOW - THEY COULD BE THE “UP AND COMING” COMMITTEE”.

It was then time for Richard Williams to get up and tell us all about this cycle ride from “Lands End to John O'Groats” (completed in 14 days!!!). He really was pleased with the whole experience, but not as much I don't think as the group was with him.

He did a great job and once all the Sponsor Money is received, I'm sure it will be put to great use. “WELL DONE RICHARD AND MANY THANKS”.

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I was really pleased though when Andy Barrett – Region 4, (one of the newer members of the group) came to me and mentioned that he had read my letter in the February Newsletter – Issue 2.

After having a chat with him, he, like the rest of us, seemed quite relieved to hear that other people were experiencing similar problems. I am now in contact with Andy on the telephone “another one to add to my long list”. Good to know that we are not alone isn’t it.

But, finally, I cannot go without saying a very big thank you to Mark Tomlinson (mine and Anne Sykes’s chauffeur for the day, there would have been three of us but sadly Christine Snow was unable to attend). Without him neither of us would have been there, so what more can I say but. Thanks Mark, “Here’s to more Friendships”

*Deborah Best Region 10.*

## **Review of FSP patients who use a dropped-foot stimulator**

Presented by Peter Axten, Phil Burton, John Mason and John Moore.

We attended Salisbury District Hospital at their invitation on 21 July for the purpose of their FES team finding out more about FSP and what they could do to improve the service they provide to us. Peter and John Moore attended the morning session. Phil and John Mason were joined by a man from Dorking in the afternoon, who has indicated that he wishes to join FSP Group. Each session lasted approx 4 hours.

We were reviewed by Carol McFadden (Research Physiotherapist) and Paul Taylor, who is head of the FES clinical service (and who was met by so many of us at our recent AGM). Another gentleman patiently recorded our walking efforts on video (one camera from the front and another to the side) for gait analysis, and evidence of walking-improvement, with the aim of comparison of our styles without wearing the FES and then after re-fitting of the FES.

In addition to the video recordings, we all underwent a joint and muscle assessment, in which Carol manipulated our lower limbs with active and passive exercises. She also made recommendations concerning stretching exercises that would aid our mobility.

We also completed some fairly detailed Questionnaires.

Part of the review included the wearing of an additional set of stimulator pads on other parts of our legs and hips and lower back, in trying to judge any different effect, or improvement in our walking abilities.

Whilst the stimuli were indeed different, time prevented us judging any real gain, and it was decided, except in Phil’s case, that we should continue to wear our existing equipment. For Phil, a positional adjustment showed more significant signs, and is now to be maintained: this will be reviewed again on Phil at Salisbury in 6 months’ time.

Phil also has gluteal stimulation sittings for 20-25 minutes most nights, and Carol asked him to maintain this, but to sit on a chair, and use his sticks to move off from the chair every time that the stimulators switch on.

Overall, it was a good review, both by Salisbury in learning our problems, and by us individually in assessing our weaknesses and methods to minimize their effect.

We were thanked by Carol and Paul for attending, and, in return, we thanked them for their efforts, not only on the day, but for all of their determined attention into research and fuller understanding of FSP, for the benefit of all of our fellow sufferers.

Let us indeed hope that this will have contributed positively to the Salisbury team’s research and knowledge of the illness.

*Peter, Phil, John and John*

## **Helpline Column**

Hi Everyone

I must say how wonderful it was to see so many of you at A.G.M. in Stoke Mandeville in June. I hope I managed to speak to most of you at some point during the day. If not, I



am usually available to chat by phone or email. Where the cost of the call is an issue I can always call you back, so please tell me when you call or leave me a message on the answer-phone.

We had a number of young people at our A.G.M this year, and I thought it would be a good idea if they had some time together in the afternoon. This proved to be very successful once everyone had been introduced to each other, and broken the ice.

One of the important issues they discussed was how they had all coped with dealing with the condition, the school situation and how they all felt about growing up with F.S.P.

This includes all the problems that arose as well. I'm sure they will all agree what a useful meeting it was. A fabulous idea would be, for the young people to co-ordinate a young persons group, this could especially deal with ideas related to when they leave education and independent living as examples.

I am very aware that these young people are our group of the future and therefore they are vitally important to us all.

Also can I add, that we have a lot of parents with young children being diagnosed at the moment, many of who are distressed and a lot have complicated forms of F.S.P. This also brings with it an awful lot of stress, education itself can be a complete nightmare, without the obvious practicality issues surrounding.

A co-ordinator to help this particular group also would be of great benefit to the group.

Please feel free to call me if you have anything you would like to discuss.

Take Care everyone.

*Stephanie*

## **Minutes of the A G M Stoke Mandeville 25th June 2005**

The meeting was called to order at 10:50am.

### **Introduction**

David Pearce began by welcoming all to Stoke Mandeville, and acknowledged that many of those present had made long journeys to be there. There were several new members present, and a warm welcome was given to them.

### **Apologies**

Nigel Bulbeck had had a car crash in the last few days and was consequently unable to attend. Apologies were also given by Christine Snow and the wives of John Moore and Phil Burton.

### **Reports**

#### **Newsletter Editor - Sharon Gradidge**

The Newsletter (now FSP Newslink) had been improved a great deal over the year and was now giving a more professional image which Sharon was pleased with. She acknowledged help received from Ian Bennett and from the Group which had provided a new printer which helped the production process a lot.

#### **Secretary - (given by David Pearce in the absence of Nigel Bulbeck)**

Nigel had very much enjoyed his work as Secretary for the organization during the year. Some of the work had involved him in making contact with other organizations, and this had been fruitful in getting the knowledge about the existence of the Group out to these organizations (in particular in getting links to our web-site from theirs).

He strongly felt that promoting awareness of the condition and of our existence was very important for the coming year.

#### **Help Line - Stephanie Flower**

The Help Line was being used more than ever - not surprising in view of growing numbers and growing public awareness. A theme that she wanted to stress to all

members is that of dealing with the “guilt” of passing the condition on to children.

She urged members to be positive about this and to accept that there was no “blame” here because in most cases it was not possible to recognize that a person had FSP until after children had been born.

For this meeting Stephanie noted that there were many younger members attending this meeting, and she urged them to make use of the breaks and the informal area to meet and to get to know a bit more about each other

### **Treasurer - Mike Fawcett**

Mike was pleased with this year - we were now in a stronger position with a surplus of £560. Some new sources of income had occurred with additional donations of some £350 and sales from the video of Prof. Wood's presentation at the last AGM bringing in some £260 - thanks to Ian Bennett!

As a result, Mike was not recommending subscription increases, particularly in view of the large increase in membership.

There were new opportunities now for fund raising - sponsorship can help, Gift Aid for which we have applied can help and there will also be contributions from Richard Williams' cycle ride.

We have recently had two generous donations amounting to £900. Members approved the accounts by a show of hands.

### **Membership Secretary – Ian Bennett**

Since the last AGM an average of one new member per week had joined our group. The Web Site is a main contributor - some 50% of new members found out about the group from the Web Site. Public and medical awareness is improving; this increases the number of diagnoses.

There are two key ways in which this can be further improved - we need to develop the web site so that it can be found more easily more often by those making appropriate searches - we need to get consultants to help in letting local specialists know more, and we can help by offering those who express an

interest in honorary membership so they can get the Newslink regularly.

Ian was very pleased with the information which we are now able to give to new members as they join. As well as the welcome letter, we can now give them the Information Booklet, details of the Web Site and Help Line, and information about Regional coordinators and regular meetings nearer their homes. Ian said that he wanted to highlight a couple of recent benefits relating to our charitable status.

Firstly, on account of the Cycle Ride which Richard Williams had recently completed, we registered with an internet based organization called “justgiving.com” (only possible since we became a Registered Charity).

This facility alone has now generated over £2000 for us (which will be recorded as part of next year's accounts). Secondly, we had only just been donated three software packages by Microsoft to the value of £750.

Ian said that he hoped these two issues highlight the sort of benefits associated with our charity status. In closing, Ian said he had had a lot of pleasure from doing the work for the group. He had made new friends and he could also see that others in the group were making friends as well.

### **Chairman – David Pearce**

There had been dramatic changes since the last AGM (only nine months ago). We had achieved charity status, our first regional meeting in had occurred, we had produced the Information Booklet, which had been sent to every member, we had improved both the Newslink and Web Site and had registered a big growth in Membership.

Much of this had been achieved through Teamwork - he could remember attending his first meeting after joining the group six years ago and it had changed his life dramatically (for the better).

He felt that for the coming year we needed to get more consultants “on-board” to ensure that newly diagnosed people get to know about the group quickly. In the longer

term we should be aiming to find ways of financing further research into the condition and ways of treating it or ameliorating its effect.

It was also important for the organisation to start to increase the people on the “top table”, and this could include the able bodied, as more needs to be done as we grow and further skills will be needed.

An important role for the coming year is to help less mobile members with transport to meetings. A number of volunteer roles still open were highlighted by David. David closed by thanking Richard Williams for his cycle trek endeavors.

### **Election of Executive Committee Members**

The election was conducted by formal nomination and then by show of hands. Results as follows:

Chairman - David Pearce

Treasurer - Mike Fawcett

Secretary - Nigel Bulbeck

Membership Secretary - Ian Bennett

Help Line - Stephanie Flowers

David Harris

### **Resolutions – None**

### **Any Other Business**

Ronald Hamblin from the floor expressed thanks on behalf of the meeting to the Committee and everyone who had contributed to the gaining of Charitable Status for the organization.

There being no other business the meeting was closed at 11:45am

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### **Trustees' annual report:**

For those members who were unable to attend the recent A.G.M. a copy of this report was sent out. If for some reason there is any member who did not receive this document and would like a copy please contact myself and I will forward one onto you promptly, regards, Sharon.

### **Additions to our funds: Between May- July 2005**

We are very grateful for the following contributions.

Cycle Run: From Giving Com Ltd £227

Donations: From Members. £355

From two individual Members £920

A total of £1502. I am expecting more direct credits from the cycle run when I get the July bank statement and I will update you on this in due course. Mike Fawcett.

### **Can you help with genetic research for Familial Spastic Paraplegia?**

**From Dr Tom Warner**, Reader in Clinical Neurosciences at the Royal Free Hospital London. Doctor Warner presented the HSP segment at this year's conference.

There is a lot of work going on both in the United Kingdom and abroad trying to identify genes, which cause familial or hereditary spastic paraplegia.

In London there is collaboration between Dr Tom Warner at the Department of Clinical Neurosciences, Royal Free University College Medical School, Dr Andrew Crosby at St George's Hospital Medical School, Department of Genetics and Prof. Nick Wood at The institute of Neurology.

The team has been mapping and studying genes for a number of years to try and work out what genes are involved and how, when genes go wrong, they cause FSP (HSP).

Over the years many of the families from the UK FSP support group have helped with the research, for which they are grateful, and are always on the look out for new families who have not been involved.

If you are part of a family with a number of other people who have HSP and would like to be involved, please write to Dr Tom Warner, Department of Clinical Neurosciences, Royal Free and University College Medical School, Rowland Hill Street, London, NW3 2PF with details, and he can

get back to you to describe the research and what it might involve.

*Dr Tom Warner*

## Proposed Conference in the N.W. on either 15<sup>th</sup> or 22<sup>nd</sup> October 2005

The committee wants to hold a conference in a suitable venue to attract members, particularly from the N.W. and Cheshire and Yorkshire.

At present I am enquiring about sites to the South and West of Manchester, such as Quarry Bank Mill, Tatton Park, Haigh Hall in Bolton and Wigan Pier.

I have also been investigating sites in Crewe. Before we book any accommodation we would like to get a rough idea of the possible attendance to expect.

When we held our first Northern conference in Wigan there were only a dozen or so turned up, and naturally this was very disappointing.

I would ask of you that members who would like to attend please contact me or their regional coordinators, Carol McGowan or Ray Exley within the next two weeks. The committee is all hoping there will be a positive response. All the best,

*Mike Fawcett*

## Committee Contacts

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|---|--|---------------|
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