



FSP Newslink

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

Issue 11 – August 2007

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

“John Guard!”

I started fencing when I was 23 and was immediately hooked. I was never much good at ball games but fencing is a sport that combines technical skill, agility and mental determination to outwit your opponent. Rather like 3-dimensional chess but quicker. There are 3 types of weapon – foil, epee and sabre and each has its own conventions and target areas. Most people start with the foil and I fenced foil exclusively for some 25 years. Then I discovered epee which is the nearest one can get to duelling in that a valid hit can be made anywhere on the opponent.

It is rare for an injury to stop people from fencing, unlike other sports such as rugby, so it really is a sport for life. Fencers start at 8 years of age and go on till they drop. There are a growing number of 70 year olds enjoying fencing at an international level. These chaps may have slowed down but the skill and timing is still there and of course they are very experienced.

Achievements

I have always been a very enthusiastic club fencer. I don't have the mental attitude to have made a mark on the national circuit. When I was 47 I was persuaded to join the newly formed Veterans Association and that



Inside this issue....

Members Letters.....Page 5
AGM Minutes... ..Page 10

New Website:
www.hspgroup.org

was a good move. I have been on the committee now for over 15 years and helped it grow to 350 members. The Association has national championships and international fixtures and I even won my Great Britain colours at foil and at epee in the 1990's.

Present

I was competing at the European Championships in San Remo in 1997 when I realised that I was tripping over paving slabs on the long walk back to the hotel. I went to various chiropractors, osteopaths and so on and each one ended up suggesting I should go and see a doctor. Hence the eventual diagnosis of FSP.

I still fence. I still get to the club twice a week and fence solidly for an hour and a half. The tactics have changed. The mobility has steadily declined and now I am at the point where I use a walking stick to get to the piste and once there the legs hardly move. I must admit that I exaggerate the hobbling on to the piste as this lulls the opponent into a false sense of security. My hand and reactions are as fast as ever and my technique of defence has improved because it has had to. So I can fence a fit sixteen year old and stand a pretty good chance of winning the fight. And they have to think very hard about how to handle my unusual style.

Future

As the mobility declines, I get less interested in travelling to compete, it is just too much effort, although when I do turn out I still love it. So I am more involved with organising. At the club level Bath Sword is going from strength to strength and there are lots of things to do to get fencing into more local schools and to increase the membership of the club.

Last year I was one of the 4 strong Steering Group that put on a Veterans World Championships in Bath. That was a lot of work, more than a full time job for over a year. We had 340 competitors, another 100 or so partners and over 100 volunteers to make the event happen. It was very satisfying to get the compliments from all over the world saying that the event was the best they had ever attended.

John Mason

From the Chair

Hello everyone

I most certainly need to start my piece this quarter with reference to the floods in and around the Gloucester area at our conference time. When I drove up on the Friday afternoon to ensure all was okay at The Trident Business Centre I was amazed to be driving with lakes beside the road where there were fields last year. As I stopped in disbelief, locals were venturing out to take a look and in the case of some children, to have a splash. As events unfolded over the following weeks I was drawn to admire the determination and fortitude as yet another family coped with it all.....but then of course; you have to.

Let me update you on some immediate activity. With our new poster near to fruition we are hoping to send our next mail shot out aimed primarily at members of The Institute of Neurological Consultants. As I am sure you picked up at conference financially, administratively and contacts with associated bodies are all firmly established. This year we must once again ensure those encountering HSP for the first time maybe informed about us by an increased awareness with their consultant.

A copy of our Annual Report would usually be transmitted to all members with this Newslink. However, because our income last year was just below the threshold set by the Charity Commission, we are not required to produce a report.

Which brings me to the AGM. A rough headcount indicated our best turn out yet; some 84 of us in all. Considering the flooding affecting both roadways and railway networks that was remarkable. I have to say a big thank you to you all and hope those not making it, kept safe. Such was the crowd I found it difficult to circulate, particularly to those of you I didn't know too well, so my apologies. This was my ninth conference; the combination of the presentations made by Dr Stephenson and Dr Jon Marsden filled so many of the gaps in terms of my appreciation of HSP. I do hope others saw it in a similar vein. As usual we all enjoyed an

excellent buffet lunch at which time I picked up numerous new ideas, humorous stories etc from those I talked to. This “free time” is so valuable since the majority of us only meet together on this single occasion.

I mentioned a little while ago The Power Plate exercise system. My initial reaction is that it most certainly creates muscle tone. This is not necessarily beneficial however, since it is not strength but stretch that we are looking for. I am not confident in my advisor’s knowledge of the system and if in fact it can stretch, and so I have stopped my programme. I have to say my walking is very difficult at the moment, not withstanding that maybe the natural progression of HSP anyway.

As always please feel free to contact me at any time.

By the way, I’m feeling the urge for a cruise. Anyone interested let me know.

Bye for now.

David

Notes from the Treasurer

Gift Aid

Thanks to everyone who has returned the Gift Aid form and a gentle reminder to those who still intend to do so.

The Group will be able to claim back about £300 as a result and this is enough for another grant towards equipment that could make a difference to someone’s life.

Standing Orders

Another thank you to everyone who is now paying their subscription by standing order. It reduces our administration enormously. Out of 268 members, 64 are now paying by standing order, 24% of the total. I hope that with gentle reminders we can steadily increase this proportion.

John Mason

Useful Information

Associated pain experienced

On discussion with fellow-Members from time to time, I keep hearing that so many of you experience significant pain, whereas I can comfortably tell everybody that I get NO PAIN at all. (I am presently 67). Furthermore I take no prescribed medicine in relation to my FSP.

This being so, it occurs to me that perhaps I should suggest that any of you, my dear colleagues, should consider taking tablets of Glucosamine Sulphate, because its producers say that it is so effective in treating so many joint conditions, giving a positive impact on mobility, pain and swelling: this is aimed most specifically at osteoarthritis, but the product is said to stimulate the production of cartilage as well as repairing it.

Perhaps I can assume that my long-term use of Glucosamine Sulphate has kept my joints free of problem regarding pain, although I know that I can not expect any magic on the mobility front!

The Group is unable to give specific product details, as it would constitute “advertising”, but I can only suggest that you try a fairly small supply for a moderate period. Any reduction or removal of pain would probably be fairly slow and steady, rather than rapid. So, if you start to try this, make your mind up from your experience over a period of time.

You may find advertisements in the national daily or Sunday press, and from these you could apply to the supplier for a particular version of their advertised range, and obtain a booklet/catalogue. There is a range of varieties (of different sizes etc, and there are a number of possible combinations, (i.e. combining Glucosamine Sulphate with the likes of Chondroitin, Vitamin C and Calcium) and it is left to the purchaser to make his or her mind up.

For several years now I have taken 2 tablets each night. Presently I take a mixed-combination variety. My 360 tablet supply will last 6 months, and it cost me less than £12.

Maybe the Evening Primrose Oil capsules which I also take contribute in some way, but I really don't know.

I can only hope that some of you may be able to derive some benefit from this.

John Moore

Physiotherapy DVD

The German HSP Support Group has produced a DVD covering physiotherapy for different stages of HSP. The duration of the DVD is just over 20 minutes and a version has been produced in English.

If anyone is interested in acquiring a copy please let me know and I can order them from the German Group at a cost of £10 per DVD.

Ian Bennett

Mobility Roadshow Kemble Airfield 2007

I'm sure many of our members recently attended the Mobility Roadshow. Two of our members who visited the show, have put pen to paper and the following articles are their summaries of the experience:

I thoroughly enjoyed my two days at the mobility roadshow. Pity about the middle day when it just poured down for 14 hours and we didn't even get out of our caravan until 5pm. On the first day I had a half hour flying lesson in a Piper Cherokee courtesy of the Disabled Flying Association. It was a bit scary at first, up there with all that space around but I managed to get the hang of keeping the plane level and then doing a few turns. We had a very good view of the Severn and the Avon. I bet that it looked very different two days later after all that monsoon-style rain. Although I enjoyed my flight I do not yet see it as something that I would wish to take further.

The Mobility Roadshow should be a must for all disabled people who are in charge of their own destinies. One gets the chance there to see and try a huge range of mobility aids from adapted cars to powerchairs to bespoke lightweight manual chairs. There are companies specialising in accessible holidays in this country and abroad.

As well as seeing all the things there to help us it is very valuable to see what is not as suitable as one first thought. For instance a VW Caravelle conversion that I thought would be just what I wanted turned out to be quite unsuitable. The new Ford Galaxy was no where near as suitable as my 1999 model so I will stay with what I have for now and not have to try and find £30k for a new one. They still made them like mine up to early 2006.

Malcolm Palmer

We were lucky enough to visit the exhibition on a glorious sunny day amidst the recent wet weather. We spent an enjoyable day looking around at lots of ideas for the future. With my progressive situation, it was useful to see what is available to assist mobility. The highlight of the day was a trip in a light aircraft with Mark, a disabled instructor with the British Disabled Flying Association. It was an exhilarating flight around the countryside especially when I took the controls for part of flight, flying left and right and ascending and descending with the aircraft.

(I must have been OK as we landed safely !!!!)

A thought that occurred was that it would have made an excellent combination to have had an exhibition such as this along with the AGM or other meeting of the FSP group – a thought for the future perhaps!

Kind regards,

Pat and Terry Reed

Next year the Mobility Roadshow will be held at Stoneleigh Park, Coventry on 12th, 13th and 14th June. I strongly recommend that our members should visit the show.

Members' letters

Hello Ian Bennett,

It has really been interesting to read several e-mails from “your colleagues” around in Europe. I must admit that I have not been that active myself, mainly because we have had enough to do with the organizing of ourselves here in Norway. We are probably a younger group here, as we were established in spring 2004. Our group is mainly located to the areas around our capital Oslo in Eastern part of our country. But on the list of members that are connected to NASPA, there are also individuals living as separate as from Kristiansand in south, Stavanger in south west, Trond-heim in (mid-Norway) and also some living all the way up north as in Tromsø and Hammerfest (the northeast city/town on the European continent).

In addition there are probably also individuals all around that has had their handicap all their lives without exactly knowing what all this might be. I know as well that my mother and my brother all the time had the same handicap, where both of them just had to live with it as there was “nothing to do with it”, all the time from 1920 and 1949 till to day. Our mother has passed away about ten years ago, not knowing what we have learned the passed years. She also was so happy about my walking, as she used to compare mine with her own, light footed as I used to be, with a long experience for mountain climbing and cross country/mountain walking both every Summer, and also skiing during Easter.

What I miss most to day, is my yearly cross country walking in the mountains that we have a lot of here in Norway. I have a lot of slide series from all these tours around, in 1970-80-90. At least I may say that I still have all my memories in combination with all the slides.

My own HSP/FSP has become a habit to deal with. I still try to use my bicycle back and forth to my office at the University here in Oslo where I have had my residence since I ended my studies from the same department mid 1970'ies. Except for a five year term just after ended studies where I tried to be a teacher in a junior High School here in Oslo,

I ended up at this same department from beginning of 1980'es. Musicology has been my subject all these years.

Our NASPA-group that we established in March three years ago, we have now been connected to the Norwegian Handicap Association, that is a bigger organisation with much more experience that is also useful for NASPA. Not at least formally it has been for great help not having to invent all ourselves, but in stead being able to use all the expertise that NHA has developed for themselves during a much longer period than we have had ourselves for just the past years.

In two weeks now NASPA will have its yearly rounding up for the passed year, with most only social smalltalks around the tables, although probably some also for the plenum. We'll see what might be the main topics for the coming year. I have now withdrawn from the board. There might probably be between 20-30 persons/members for a semester ending like this, and many to serve for some good food as well.

Sincerely Yours,

Gunnar Flatten (Oslo)

Dear Dave,

What an excellent day the recent AGM and supporting events proved to be, we enjoyed it a lot and found it informative.

In Wrexham there is a 'Neurological Alliance Wrexham' which is a local forum established for anybody who has a neurological issue. It acts as a consultation point for statutory services and is a member of the 'Wales Neurological Alliance'. At a recent meeting, it was agreed to produce a local booklet for all GPs in the area and other health specialists, giving contact information for all of the neurological organisations they are aware of. They were not aware of FSP, therefore I have handed over a leaflet from our group to the co-ordinator so that our contact information can be included.

Obviously, the more information we disseminate to the health professionals, the more chance we have of reaching others diagnosed with FSP and letting them know that there is a support group if they require.

It may be that there are other similar Alliances in other areas, which we could use as a vehicle for spreading the word. For this reason, I am quite happy if you wish to publish this letter in the next Newslink.

Kind regards,

Terry Reed

Dear Mr. Bennett

I will not be renewing my membership for the support group as a strange thing has happened, that is, I have found out that I do not have FSP after 30 years of believing I had. In short, I requested to see a different neurology Consultant who has interestingly believed I may have a condition called Dopa Responsive Dystonia. He duly tested for this condition and found out, indeed, this is what I have. What alerted him to this possibility was the age at which I first experienced problems (10 years old) and the fact that my mobility got worse as the day wore on, i.e. I would start the day doing pretty well but would experience problems by the afternoon, severe by the ending.

I don't know whether this information is of any use to your members but I suppose there is always a chance that others have been mis-diagnosed like me. I can still hardly believe myself, but Dopa Responsive Dystonia is treatable, so, thanks to a doctor who made some connections that countless others had failed to do, I have gained a quality of life I never believed would be possible.

Kind regards,

Clare White

Dear members

I went to the group AGM at the Trident centre, Leamington and I took a fellow sufferer with me for the day. It is a great place to hold it, if a bit hard to find. I would like to thank those who organised it as it all ran very smoothly and the food was superb, as it was last year.

I was surprised to find that among all the members who attended, there were only three people in powerchairs and two of those were mine as I had lent one to my friend. I had a friendly discussion with another member about why I used a powerchair and

he could not understand why I would not want to do what he does; walk with two elbow crutches and FES. He felt that walking was absolutely essential as the best means of coping with HSP. I feel that my solution is to do as much as possible of what I did before, using as many forms of helpful devices as I need and can get. I have a one-acre garden and have help for one day a week. I recently dry lined my living room had it plastered and then painted it. I am helping my daughter to dry line and convert her garage into a spare room and toilet. All these jobs are getting much more difficult but I couldn't do any of them if I was on elbow crutches. My maxim has always been, when faced with a problem, not "can I do it?" but "how can I do it?" and I use this when dealing with my HSP. Sometimes I do not do my exercises because I have something else to do that I feel has priority. I do not intend to let my HSP rule my life. I do not "live to walk" but "live to live".

I have just heard back from the FES centre in Birmingham and have been told that I am on a 12-month waiting list.

Stop press: I contacted Birmingham with a view to having the assessment done privately to speed things up. They said that this could be done and would get back to me. When they did they said that the funding was through and they had booked me for September 3rd on the NHS. I'll let you know what the outcome is.

Malcolm Palmer

Three letters discussing our A.G.M. at Warwick:

I think that this year's event deserves huge congratulations to our organising Committee, not only from the choice of the excellent venue, but even more so for the design and conduct of the presentations.

So, enormous thanks to David Pearce (Chairman), Dave Harris (Secretary), John Mason (Treasurer), Ian Bennett (Membership Secretary) and Stephanie Flower (Helpline): everything was put forward so professionally. My own contribution for the day was the taking of the

Minutes, which I hope you will find agreeable, as presented in this issue.

For the past year, I have been working with this team, including Mike Fawcett (who has now had to stand down from his position as Treasurer after years of devoted work), and I have enjoyed every minute of it.

John Moore

Dear Ian

After attending the AGM on the 16th of June. I just would like to say after digesting all the information given from Dr Val Stevenson and Dr Jon Marsden about spasticity, and difficulties in walking with HSP it made me realize how lucky I am to have found such a brilliant support group. I have been a member for seven years, and these meetings have helped me and my three children who also suffer with HSP, to try and understand more about our condition. Also meeting new members and being able to talk to people with HSP, who understand life's difficulties that we have to cope with has helped me so much. So I would like to take this opportunity to say thank you to all the committee members, and everyone who puts so much effort in making this group so successful.

Lorraine Saupe

Dear Ian

On Sat 16th June, I left (Nailsea) at 7am, Starting my journey to the FSP AGM in Warwick, the rain was pouring down as I entered the M5 making driving very hazardous. On route I called in to Gloucester to pick up Gabrielle Cooper, Rachel Fletcher and Gabrielle's mum Angela. The rain had stopped but we were a bit concerned after hearing weather reports saying Warwickshire had been hit by heavy flooding. We set off about 8am and arrived at The Trident Technology and Business Park in Warwick at about 9.30am thankfully finding the area free from any flood water.

After coffee and cakes Christine Grimley gave us a talk about the roll of carers, which highlighted some surprising statistics about caring in the UK.

At midday Dr Val Stevenson from the National Hospital gave a talk about spasticity

which I found very interesting. I was particularly interested in learning the fact that spasticity can help with some movements and blood circulation. After Dr Stevensons presentation we had a long lunch that enabled us to meet up with old and new friends. This was really good but I was sorry that some members weren't able to attend this meeting, especially Mike Fawcett, Sally Langton and Tony Glas and family.

The afternoon was rounded off by Dr Jon Marsden who is also from the National Hospital, with an excellent presentation of "Difficulties in walking with HSP", researched from recent studies. It's always good to see Dr Marsden.

At this point I would like to say and I know I speak for the rest of the FSP Group members how much we appreciate the work that goes on behind the scenes by David Pearce, the committee and the Regional Co-ordinators to make our meetings so enjoyable. I find them really uplifting.

After Dr Marsdens presentation we had refreshments, said our goodbyes and made our way home, looking forward to the next time – we'd had a grand day out!

David Britten

Regional News

Proposed HSP Northern Meeting

**Sunday 14th October 2007 –
10am till 4pm**

Holiday Inn Preston

A meeting is arranged for October at this easy to get to place. So it is hoped that many of our 'Northern Members' will be able to come and meet together.

There will be one speaker from the sporting world

DVDs and videos will be played

Feedback from members will be gathered

Lunch and refreshments will be provided

Overnight accommodation at the hotel will be available for those that need it.

Preston, being at the hub of the motorway, rail and bus networks, is no more than one

and half hours from Manchester, Liverpool, Leeds, Newcastle, Sheffield, Stoke and North Wales.

The hotel is very close to the main rail and bus stations in Preston and parking is available close by.

The hotel has a number of disabled parking places, and has located the meeting and eats on the ground floor to allow easy access.

The scenery is wonderful and Blackpool Illuminations will be on and viewable in the early evening.

So there is no real reason why you should stay home, if you can get out!! Do come and meet us!!

Please express your interest to Mike Cain at mikeregion9@fsmail.net or phone 0161 456 7531, by September 22nd.

Expressing an interest is not an obligation to come, but we need to get some idea of numbers so as to be able to cater!!

Mike Cain Region 9

A Ramble with the Disabled Ramblers (DR)

Disabled Ramblers is a charity which facilitates rambling by disabled people. I had seen an advert for them in a magazine and joined about two years ago.



Although they had rambles during that period, I never went to any - mainly because they were “too far away”. When the list for this year arrived I was amazed to see that there were two walks arranged less than an hour’s drive from my door! I felt I must go on at least one else I would feel a fraud for joining and not participating!

I chose to go on the second of the days - which turned out to be a lovely sunny day in

mid August. The walk was around the deserted village of Tynham within a mile of the Dorset coast - it is deserted because it is now part of an Army firing range, having been taken over for that purpose during the Second World War. The village and its valley are located a few miles east of Lulworth Cove in the middle of the Jurassic Coast.

During the summer months some areas of the firing range (mainly those closest to the coast) are open to the public - but there are strict rules about not straying from marked paths. Indeed an unexploded shell had to be disposed of in the area we were walking only the previous day!

We turned up early to be sure of getting as much information as we could before the event proper began. I had booked a Trumper cross-country scooter from the DR because I felt my own might not be “beefy” enough for the job. The scooters and their vans and trailers arrived about 20 minutes after we did and were all unloaded and lined up. By then about a dozen other people had arrived with their own cross-country machines. These large machines usually were on their own trailers behind the owner’s cars, but some had larger vehicles capable of loading them inside.

Those who were loaning a scooter were then identified and given a brief guide to the set-up and controls and encouraged to get the feel of the machine on the relatively good terrain of the unpaved car park. During this time one of the trailers which had brought the machines went off to the halfway point



where we would be having lunch.

So here we were, some 17 scooters and 14 walkers ready for the off. As we set off out

of the car park there were a lot of other walkers and tourists around, and I think there was a mixture of amazement and delight on many faces to see our group all enjoying ourselves.

We were led beside the deserted village and through a farm gate onto a track normally closed to the public, but we had a Range Warden with us who made sure we had appropriate access. This track climbed fairly steeply up some 550 ft to the top of the Purbeck Hills where we saw fantastic views both inland and out to sea.

After the climb we travelled for half a mile or so along the hilltop ridge to an iron-age fort where we had lunch overlooking Worbarrow Bay - a beautiful and secluded beach with views of the isle of Portland in the distance. At lunch we found that the trailer which was parked nearby contained a Portaloo, and was fitted with a privacy curtain. There was enough space for even the largest scooters to drive right inside. This made the day very civilised.

After lunch we retraced our steps and returned to the village - it was even more exciting descending the steep path with 17 vehicles!! We then made our way along another path to the beach (a further mile).

The views were superb - someone commented that you might be in the Greek Islands with the scenery and the colours of the cliffs and the sea. Some brave souls made the final steep descent to the beach, but came back saying it was difficult to get back up as the scooters were skidding on loose scree. I was glad I decided to leave that bit out!

That mini excursion allowed some of the helpers to go for a short swim. After that we all returned to the car park and gave our scooters back. After saying our farewells to new friends we'd met on the day it was time to set off home, resolving to go on another of these excellent events soon!

The Disabled Ramblers are open to anyone with a disability and rambles are organised all over the country. The daily "hire charge" for a Trampler is £10 for members (suggested donation).

Their web site is www.disabledramblers.co.uk, their vice-chairman is Robin Helby who can be contacted on 01483 893 159. The postal address is:

Rosie Norris - Membership Secretary

The Disabled Ramblers
Orchard Cottage
Uplands
Ashted
Surrey
KT21 2TN

Carolyn Harris Region 4

Forthcoming Events:

Mobility Roadshow

Stoneleigh Park, Coventry
12th, 13th and 14th June 2008.

Region 4 get together

October 27th 2 pm – 5 pm
The Dartmoor Lodge Hotel – Ashburton
All members welcome. For further details contact Ian Bennett on 01202 849391

Afternoon tea Regions 1 and 2

Saturday 21st April 3 – 6 pm
Milford Day centre
Contact Jane Bennett on 020 8853 4089
for further details

New Members

We welcome the following new member:

Mr James Connor
Chorley
Region 9

Minutes of Annual General Meeting

Trident Technology and Business Park, Warwick, Saturday 16 June 2007.

Present:

Committee seeking election, David Pearce, David Harris, John Mason, Ian Bennett, Stephanie Flower, John Moore, being part of a total of **85 attendees**..... indeed a record, including a good number of new members.

Introduction by Chairman.

David Pearce welcomed and thanked everybody for their attendance, including new members; this being particularly acclaimed at a time of widespread poor weather and flooding. He gave thanks to the Committee for their past year of service, and, in particular to Mike Fawcett who is now standing-down from his position of Treasurer: he has served the Group for 17 years since 1990. David sought a collection from attendees in recognition of his outstanding support.

Apologies for Absence:

None received.

Minutes of 2006 AGM

Accepted as a true record. Proposed for adoption by Petula Baker and seconded by Phil Burton.

Matters Arising

There were none.

Committee Reports

New Committee Member (John Moore) expressed his duties since his adoption to Committee at last year's AGM. These have included the "chasing" of outstanding subscriptions, various word-processing efforts, regular entries into Newslink, and the production of Minutes for Committee Meetings.

Help-line (Stephanie Flower) reminded everybody of her ever-willing wish to consider people's queries and problems, and recommended sight, at the end of the meeting's business, of the DVD which she and husband John had produced on holiday in Spain, which duly shows how "disabled-friendly" so many sites and facilities are.

Chairman (David Pearce) had already given comments in his introduction, but wanted to add his particular thanks to John Mason, who had so willingly and efficiently stood-in as interim Treasurer.

Acting Treasurer (John Mason) ran through and explained the Treasurer's Report, duly thanking a) his wife, Sonya for all of her pre-audit supportive work, b) Mike Fawcett for his great help in the past and in the hand-over and c) to Mr W T R White for auditing the account. The account showed a balance of £12,454.05. John also stressed how beneficial it is to the Group a) to receive payment of subscriptions by Standing Order (thereby avoiding renewal correspondence) and b) to be able to increase the amount of standard subscriptions by 28p in the £, where tax-paying Members declare payment under the Gift Aid basis.

Secretary (David Harris) explained items of expenditure on the Account, and various new features in our operations. The item of Grants included that made to Dr Jon Marsden towards his research on our shared medical condition, and also those granted to, so far, 8 Members, for the likes of mobility aids, and FES assessment. A poster has been designed, with the aim of its being displayable in Neurological Departments' Notice Boards, or other medical waiting-rooms. Two websites have been produced: one for UK information and one by our European friends.....the

UK site is considering the creation of a Forum. Finally, David drew attention to our aims to foster Young Member inter-communication.

Membership Secretary (Ian Bennett) outlined our membership status, summarising that the overall count of 323 members contained 270 standard members, plus 20 Family Members and 33 Honorary Members (i.e. doctors, research fellows, etc.) Ian then displayed the national map-site, showing a spot where each member lives, indicating the concentration of those in the Southern Home-Counties, with the secondly most packed area being in the North-West, around Manchester and Liverpool (i.e. Region 9). Ian mentioned the interest of Mike Cain in possibly wishing to take the role of Regional Co-ordinator. He then summarised cost-cutting aspects a) via Gift Aid payments and b) via use of email for transmission of Newslink. Finally, could we hear of specialists' details within the aim of increasing the medical profession's awareness of our condition? Ian then offered purchase of leather holders suitable for the FES control unit (to be worn on a belt) as he had a few with him.

Election of Committee for the year ahead. All of the existing committee members and John Mason as the interim acting Treasurer had stated their willingness to stand for re-election, so it was just a case of Proposal and Secondment. Hands were duly raised as and where appropriate, and the following have been resultingly elected:

Position	Officer	Proposed By:	Seconded by:
Chairman	David Pearce	Caroline Begg	Debbie Best
Treasurer	John Mason	Ron Hamblin	Phil Burton
Secretary	David Harris	Carol Moore	Caroline Begg
Membership Secretary	Ian Bennett	Andy Barrett	Debbie Best
Helpline	Stephanie Flower	Jane Bennett	Pat Leigh
Exec Committee Member	John Moore	Barbara Kevan	Phil Burton

The AGM business was then followed by three presentations, Christine Grimley of The Guide Post Trust on the subject of the role of Carers, Dr Val Stevenson of the National Hospital on the subject of spasticity, its impact and its management, and by Dr Jon Marsden of the National Hospital on the subject of the difficulties of walking with FSP and any mechanisms and aids to rehabilitation.

Contacts

	Email	Telephone No:
David Pearce - Chairman 8 Brinkworth Road, Clayhall, Ilford, Essex, IG5 0JS	pearcey david@yahoo.co.uk	020 85512905
David Harris – Secretary 18 Lodmoor Ave, Weymouth, DT3 5AF	david18lod@hotmail.com	01305 772286
John Mason - Treasurer 18 Sandringham Road, Trowbridge, BA14 0JU	john@jrmason.demon.co.uk	01225 761788
Stephanie Flower - Help-Line 37 Alexandra Road, Great Wakering, Southend, SS3 0HN	FSPgroup@aol.com	01702 218184
Ian Bennett – Membership Sec 37 Wimborne Road West, Wimborne, Dorset BH21 2DQ	ian.bennett@tesco.net	01202 849391
John Moore – Committee Member 66 Drift Road, Clanfield, Waterlooville, PO8 0NX	johnmoore@drift66.fsnet.co.uk	02392 592784

FSP Group Accounts 01/05/06 to 30/04/07

Statement of Income and Expenditure				
Income			Expenditure	
SO Subscriptions	355.00		Administration	846.20
Cash Subscriptions	2477.50		Newsletter	744.16
Donations	1062.67		Grants to members	2440.00
Conferences	225.00		Helpline	220.00
Fund Raising	307.36		Conference expenses	1702.65
			Bank charges	1.43
Income from operations	4427.53			
Bank Interest Received	371.54			
TOTAL INCOME	4799.07		TOTAL EXPENDITURE	5954.44
Deficit for the year	1155.37			
	5954.44			
Assets				
Assets at 1st May 2006			Assets as at 30th April 2007	
Current account	1707.45		Current account	1850.36
Deposit account	11901.97		Less cheques not presented	103.39
			Deposit account	10772.08
TOTAL	13609.42		TOTAL	12519.05
Less deficit for year	1155.37		Less prepaid subscriptions	65.00
	12454.05		TOTAL	12454.05
Accounts prepared	25/05/2007		by John Mason	
Accounts audited	13/06/2007		by WTR White ACIB	