



HSP Newslink

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

Issue 14 – April 2008

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

HOME SWEET HOME



My name is Michael Want and I have had HSP since birth. I used to wear callipers when I was a young boy, which I absolutely hated with a passion. I just wanted to go and play with the rest of the local lads and have a game football, but this just wasn't to be.

I went to a boarding school, which was very much against the wishes of my parents as, at the time, I was an only child of who they could not bear to be away from. I went to a boarding school due to my hyperactivity and the requirement of lots of attention.

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I can only describe as an early version of ADHD (Attention-deficit hyperactivity disorder).

To cut a long story, they just thought I was a clumsy child and would grow out of it! (Oh how ignorant and wrong they were).

After firstly being diagnosed with another type of muscle wasting condition, I was then diagnosed with HSP. I suffer with this in my legs and along with my younger sister, mother and grandmother (mother's mum).

I had been living with my parents and younger sister in a 3 bedroom house with a garden in Greenwich, SE London until four and a half years ago, when I started to fall on a regular basis and even down the stairs leading from my bedroom which was on the 1st floor.

Upon climbing back up the banisters to a vertical position and dusting myself off (So to speak), I decided to do something about it.

I contacted the disability housing team at my local council, who through an occupational therapist found me a two bedroom ground floor flat in Blackheath, South East London, where I had been living for the last four and a half years. (Two bedrooms, as although I had no dependants, I was working from home at the time).

The last property was a standard property with a bath and no adaptations, until I contacted the council who then with the help of the same occupational therapist, removed the bath and replaced it with a wheelchair accessible shower and bathroom which was great.

Approximately six months ago, I once again contacted the council's housing disability team at the council to ask for some building work to be done at the property to widen the doors and kitchen etc to allow access for a wheelchair.

An occupational therapist from the housing adaptations section visited me and to sum up in words the sort of help I was about to receive was "Sorry the property cannot be adapted any further" we will need to move you to a different property.

This came as a bit of a shock, but pleasing at the same time as I knew it meant a move to hopefully a larger property.

The disability housing team contacted Quadrant Housing Group about this, and the fantastic news is that at the beginning of December 2007, I was offered to view a property just a stone's throw from the hospital where my consultant neurologist is based (Queen Elizabeth Hospital, Woolwich, SE London).

We then received an offer to view a two bedroom ground floor flat with a garden, so excitedly we went to view the property where was presented a brand new purpose built wheelchair accessible property.

In fact, it was so new, that we had to wait about two weeks for the developers to finish off the build.

The property has everything a disabled person could wish for or need, as listed below:

- Wide access doors (Internal and external)
- Two separate doors leading to our own large garden
- Separate front door (Through the communal entrance)
- Full wheelchair accessible bathroom with a wet room style shower.
- Full open plan kitchen with fully height adjustable kitchen units and sink.
- Hob built into worktop with full wheelchair access (Legs fit underneath the hob)
- Oven at wheelchair height.
- Hand operated worktop surface mounted kitchen window opener
- An abundance of tilted double sockets mounted on the worktop (In case height adjustment is needed)
- All walls strengthened including bathroom to support hoists and handrails etc.
- Handrails and grab rails fitted in every room
- Very spacious rooms which are large enough for full wheelchair access even with furniture in, such as the bed and wardrobes etc.

- The list is endless.

The rent of the property is £90.00 per week plus bills etc.

I realise there are many people with all kinds of disabilities who need housing/re-housing. But I just wanted to share my bit of good fortune, and to say “Never give up”.

I now live in our new home along with my wife.

Micky Want - Region 2

Editor's comments

You may have begun to wonder whether this newsletter was ever going to arrive. I've deliberately delayed it simply because of lack of content. If you have anything interesting that you'd like to share with other members, please don't hesitate to put pen to paper in time for the next issue. I have decided not to religiously produce a newsletter every 3 months. This will always remain my target, but if however I am lacking in material, I'll delay things until I have suitable content. Please send any articles directly to me either by mail or email.

Sorry to moan, but **please, please, please contribute to your newsletter**. Maybe we can make the next issue the best ever!

For members wishing to use a communication forum, there is now a facility available on the European HSP website. Please visit www.hsp-info.eu and then click on “The HSP forum Europe”. Please use this facility as it's the one thing we don't have available on our website, and our German friends have gone to a lot of trouble to set this up for our use. Many Europeans speak English, so you may find you receive replies from not just the British, but also from other nationalities. There is also a European HSP chat room available on this site.

Ian Bennett

From the Chair

Hello everyone

I hope you are all keeping okay. After those few hot days didn't that snow just catch us all out. I suppose it proves how unpredictable our weather pattern now seems to be. Global warming, carbon emissions, or

Gordon Brown ; who can we blame it on? No doubt it will still catch us all out with frost one morning and the heavy coats will have to come out again.

Firstly let me update you on Mike Fawcett. He is now recovering from his hip operation and after a recovery period he is due to return home on Monday 1st April. I am sure he would welcome a call. His phone number is 01756 795480.

As events unravel and I need to adjust to the increased stiffness in my legs I am reminded so much of my friends in a similar situation. We seem to accumulate wheelchairs, walkers and scooters willy nilly. Five or six seems to be the average. I mention all this because I am finding my walker so tiring I am seeking a lightweight self-propelling wheelchair myself. You wouldn't believe the weight variances in **lightweight**. Once I get it I'm wondering if there will still be room for me in my car. C'est la vie.

Although we have signed up a few new members recently, generally our new member intake has reduced from previous years. I have accessed an updated hospitals list from which we hope to target the neurology units with a mail shot. Which reminds me, do try to get your posters presented on your next clinic appointment.

Our AGM has been booked for Saturday 21st June, and again we will be at **The Trident Technology and Business Centre** in Leamington Spa. Please have a good look through the AGM section included, particularly nominations and attendance forms. I look forward to seeing you all again and of course extend a very special welcome to first timers. Just a reminder, if you need transport or can offer a lift, let us know.

I could not close this column without a thank you to all of you who responded to Dr Crosby's research programme. He was overwhelmed with the response; to such a degree they have had to rethink on just how best to move it forward. Can I draw your attention to his article on page 4. HSP is a rare condition and consequently it takes with it the responsibility to engage in research programmes as needed. Well done everyone.

As always I look forward to hearing from you, but especially meeting up with you all again at Warwick.

David Pearce

Secretary's Spot

Now that we're well into 2008 it's time to start planning for the AGM. The formal invite to this years AGM is on page 10 together with all the AGM details. For the third year in a row we will be using the Trident Technology and Business Park, Leamington Spa. As a group we want to help as many people as possible to get to the AGM. We have two policies which are useful here: members who provide transport for two or more other members can claim a mileage allowance for their journey; also, we would like to arrange specialised transport to and from the meeting (e.g. for those who are wheelchair bound). Obviously this will work best if we can get two or three people brought by a single vehicle. Such arrangements take time to make, so if you are interested please let a committee member know before the end of April so that we can see if it can be done.

On another topic, we think that there are still many more people "out there" with HSP/FSP who don't know our Group exists and we are trying to spread the word. Our present approach is to introduce the Group to Neurologists and Physiotherapists by means of a short piece in their professional newsletters and by letter if we can get a suitable address list. Other ways which have had good effect in the past have been getting articles into Magazines or Newspapers. This usually needs to be formed around someone's own story to get coverage. Any volunteers to try this or other ideas to help others to find us are most welcome – so put your thinking caps on!!

Dave Harris

Useful Information

I would like to draw the attention of the group members to a couple of things that have improved my walking recently. Members may be forgiven for thinking that I only use a powerchair and have given up the

idea of walking but this is not so as I do realise the need to keep the calf muscles working at pumping the blood up from the legs etc.

After I was told that I was not suitable for FES the consultant suggested that I try walking sticks with Fischer handles. For those of you who do not know them they are ergonomically designed handles that fit the whole hand and are different for each hand. I put red and green bits of insulating tape on each handle for port and starboard.

I was given adjustable Fischer sticks by the OT but quickly realised that I wanted solid ones of my own so I bought a pair each of black and brown ones from:

www.youreableshop.co.uk

Whilst browsing their pages I came across Flexible ferrules and decided to try them. They have been a revelation! No matter what angle the stick is at, the base of the ferrule remains parallel to the floor and it is so non-slip that one can have complete confidence, even on wet, smooth surfaces.

Indoors I am now using a trolley with brakes made by **Days** and it has cut the number of falls drastically and I can transport so much stuff compared with heretofore.

The numbers for these items on the Youreable website are:

WA4250	Flexible ferrules
WA4224	Fischer handle sticks
TT2060	Adjustable height walking trolley

Malcolm Palmer

Research

At St George's Hospital (University of London) we have been studying the hereditary spastic paraplegias (HSPs) for the past 10 years. Thanks to the generous help and co-operation of a great many families of the FSP group in particular, our department has over this time discovered the genes for a number of forms of the condition. The identification of the causative gene is the first main goal of our research as this provides an initial insight into the cause of the condition and permits the development of diagnostic

gene tests. However it is also very important to understand how a gene mutation actually leads to the clinical features of HSP, and to do this scientists must undertake more detailed studies of the biology of cells. As with my research group at St George's, many other groups studying HSP and related conditions are now undertaking these studies.

Most recently our work at St. George's has led to the discovery of a new gene which is responsible for HSP in some patients. The identification of this gene has highlighted a new mechanism that leads to nerve cell death in HSP. There is now much research that must be done to investigate how widespread this mechanism may be amongst the many other genetic forms of HSP, and this work is well underway.

We are very grateful to all those patients and families who have previously and continue to help us with our research. Without your generous cooperation and support, we would not be able to do any of this work. Many thanks indeed.

Dr. A. Crosby

Members' Letters

The following two letters were written by sisters from Bristol. Karen is HSP affected and Debbie is able bodied.

My sister Debbie invited me and her mother - in- law (more on her later!) to have a full body massage. This I gladly accepted!

We went to our local college, Brunel, Ashley Down, Bristol. We always go to the college as it uses supervised trainees who are interested and give 100% and our college only charges £9.90 which makes it very affordable.

I went expecting a lovely pampering time but wow did I get much more!

I went in and the college student asked me relevant questions about my health. These are standard questions to ascertain which type of oils will suit you best. The student and I decided that a massage oil mixture for aches, pains and spasms would be beneficial.

The full body massage consisted of the body and the face. The massage itself was relaxing and therapeutic. Total ME time.

When my session was finished I cannot highlight enough the benefits. The pain relief was very noticeable and my walking was improved for at least 3 days. I found it so beneficial I will fit this into my financial budget once a month.

Also my 72 year old mother-in-law was quite apprehensive about going, never having this done before and worried about her wrinkles and being the oldest one there (she certainly was not) etc. Well she was so glad she went she came out full of the wonders of massage also. If you are apprehensive then book and go as a couple, with a family member or friend but try it and go.

My message is and this includes all you guys, GO FOR IT. Treat yourself. We all know all our bodies respond in different ways and if nothing else you could end up with a pleasant experience and good relaxation. I will see/meet some of you at the Devon meeting April 26th. Bye for now

Karen J. Bristol.

(If any-one would like to know, in Karen's massage oil was lavender, Rosemary, Clarysage and Marjoram. This you can also make up yourself with a 15ml base carrier oil then adding 5 drops of the 4 essential oils).

The wonders of a walking stick

It had to be said, "Sorry Karen but you look a little drunk when you walk". Not a nice thing to have to point out to some-one but none the less the truth. Did Karen whinge, moan, berate, cry, become angry or go into denial? Well yes a little of some of the list but just for a very short time. Knowing Karen her realistic practical head would come into play and great stuff it did.

We discussed why she needed a walking stick, the benefits to her health on using a walking stick and the best way to maintain her dignity. We did a little research, got the info and yes a walking stick was the way forward. Now the tricky part. When you're new at the game who the hell wants to acknowledge they need a stick then go out and buy one.

Karen's way: She decided we would make a date in a week to go and buy one. This gave Karen breathing space and a week to get

used to the idea she was having to get a stick. She also told people in conversation we were off to buy one.

We kept the date, no reasons or excuses why she could not go. We went to a shop which I had found and knew the staff were helpful. Karen went in and chose one that she sort of liked. Now the big test. Yes going outside. I held the door open for her and said come on show me how you use it. She was nervous and yes felt basically stupid. She then went to walk towards the car. Now my plan. Oh no not straight in the car, come on Karen use it. Karen's response: "I feel stupid and people are all looking at me". My response "So what if people are looking", show them what your made of and use it. Good on Karen! She did, she walked across the pavement, she walked up and down the kerbs, she walked up and down a step and then walked over to the car. As her sister I felt very proud of her because she is attractive, young in attitude, very independent, has always taken care of her appearance and has had to deal with much in her life. To me, Karen having the stick shows that she fully understands and acknowledges she has a condition and wants to stay mobile and independent. Karen now has made sure she uses her walking stick. She does not need to lean on anyone and is respecting and taking care of her body by using the stick. To date Karen has been using her stick for nearly a year. Her attitude towards it is positive and fun. This is Karen. She has quite a few different sticks, this is to colour co-ordinate to accessorize with her clothing. She has even asked a lady in the street, "where did you get your stick as it's just the colour I want"? She smiles and says she feels so much more dignified and independent, she looks younger and has a more relaxed look on her face and best of all, her positive attitude has turned her walking stick into a friend. When she grabs her stick she says come on CHICK STICK off we go.

So please people in need of a walking stick but are fighting not to have one, give up the unnecessary fight, smile, take courage and go get yourself a walking stick friend.

Debbie W Bristol

Dear Members,

I recently took my daughter to Queen Mary's Hospital in Roehampton, West London to have a new pair of splints made, and was delighted when they offered to make her a custom pair of trainers to fit over her splints. They let us choose from a catalogue a good selection of shoes and trainers whilst they measured her feet, we had to wait about three weeks before returning to check they fitted and to have any adjustments that may be needed, before being sent back to have the soles put on.

I thought I would write to let other members know that maybe their local hospitals might offer this service. I have always had trouble trying to find shoes to fit over splints resulting in having to buy trainers two sizes larger to enable a good fit, which caused my daughter to catch her toes and trip. My daughter is so pleased with her new footwear and is now wearing her splints much more frequently, she used to be so self conscious about her feet looking so big.

Lorraine Saupé - Region 1

Dear Ian,

During my last visit to my local neurological physiotherapist she thought I had a bit more muscle wastage on my left quad muscle so she used the TES. This is a battery unit attached to two pads which stimulate the muscle. This is supposed to strengthen the muscle and, in turn, improve the ham strings. My therapist uses this on horses, she treats more animals than humans!! The next day I felt it had improved my walking, and have agreed to try this treatment for the next two months.

The name of the clinic supplying the TES, is Diana Farragher and can be found on the internet. It is being suggested by my physio. I rent the stimulator for two months and see how I get on with it. It will have a chip for my condition.

My question is, have you heard of this clinic? Has anyone else in our FSP Group tried the TES? It is not a cure, naturally but it may help.

Best regards,

Fergus Palmer - Region 4

Flying

It is with a huge smile on my face that I can announce that Caroline Begg has been awarded a flying scholarship from Flying Scholarships for the Disabled (FSD). After a stressful and meticulous selection process over a three day period at RAF Cranwell, Caroline came through with flying colours. Caroline will be jetting off to South Africa later this summer for a six week, 40 hour flight training programme. I'm sure I speak for all of us when I say:

CONGRATULATIONS Caroline.

Whilst on the subject of flying, I couldn't resist including the following article, written by a good friend of mine who has multiple sclerosis. He describes his first aerobatic experience with the **British Disabled Flying Association**. Any members interested in such fun should visit www.bdfa.net for further information.

M.S Aerobatics

Lasham Open Day this summer. For the first time in a long while I was in the right place at the right time, and just for once, I knew it...

The Bulldog was just creeping to a halt, Alex and Ben beaming alarmingly big schoolboy grins, as they set the brake and switched off. They had clearly been playing. Now luck had made it my turn - my first flight in the Bulldog.

The first thing that struck me when I sat down was the stick rather than yoke - very much more Biggles, I thought, looking around and trying to take it all in. Having only before been in PA28s, the adjustable pedals, rather than adjustable seat, were another new diversion for me, and I spent a little while soaking in the fantastic visibility the Bulldog affords. I was missing the point. What should have struck me first was the five point harness...

After a few hiccups caused by an entrenched reluctance to start from hot, the 200hp Lycoming popped and shuddered, crackling into life.

It was a day of big clouds. Lasham quickly slipped from view behind us as we turned

and headed north, was momentarily glimpsed again, then hidden by the shifting, billowing, scenery. In **'The Wind In The Willows'**, **Ratty said that there was nothing - absolutely nothing - half so much worth doing as simply messing about in boats. That morning I knew that Ratty had never flown.**

Alex reckoned it would be a waste to go flying in such a delightfully agile aircraft without giving it some work to do, and asked me if I felt up to taking part in, rather than looking up at, some aerobatics. I have seen plenty of aerobatic displays - I've never missed RIAT, my wife works there as volunteer airside medical staff - so I was hardly going to refuse. That alarming grin crept back over Alex's face, and we went off to find some clear space between the clouds, climbing as we went.

First a loop. Picking up speed in a shallow dive, then back hard with the stick... I didn't know what to expect, but that didn't last for long, as my head was squeezed down, chin against chest, the most extraordinary feeling of heaviness I've ever experienced. With my head fighting hard to pour itself down my neck, I thought I'd have to open a couple of shirt buttons to be able to see out. Then, over the top of the loop my headset gave up the fight, lost its tenuous grip on my ears, flew off and scuttled across the canopy...

...I looked up, and saw the peculiar sight of Basingstoke 4,000 feet above me. Very, very odd.

I don't suppose that anyone will forget their first experience of aerobatics. I knew even then that I wouldn't, and that there was more to come. The Bulldog has a g meter, to show you how frightened you ought to be, which indicated that we had pulled 3.5g as we entered the loop. I now knew the quick way to weigh 42 stones. At 3.5g your eyebrows feel heavy. However modest this would sound to a fast jet pilot, as a new experience, it was astonishing.

Next, after recovering my headset and giving a comforting extra tug to each part of my harness, a stall turn. Plain eerie. It simply isn't right for an aircraft to come to a complete standstill, pointed straight up, but it made an interesting contrast to be

momentarily weightless as, with the last breath of wind over the wings, we yawed to fall into a vertical dive with the prop clawing at the air...

...before climbing again to search for an open passage in the languidly boiling cloud, to spiral into a lengthy, smoothly elegant barrel roll, and watch the horizon move completely round the clock. Amazing.

My son Rob had beaten me to it by some years, performing his own aileron roll in a Yak 52, hidden amongst a bewilderingly skilful display by the pilot/owner. Now I could remember, and much better appreciate, the excitement in his voice when he told me about it, as we built up speed to enter our own... to roll tightly around our axis, peel off and head south for home.

Throughout, because MS has stolen my sense of balance, I didn't feel even slightly queasy. It felt perfectly natural to be tearing about all over the sky inside a cement mixer, really quite normal. They say that every cloud has a silver lining, and we looked at quite a few just to make sure.

It was a great experience that I am truly grateful for, but I'll be perfectly happy to make do with learning to fly straight and level, and leave the lively bits to people better adapted to grinning than I am. Come to think of it, my son does a lot of grinning...

Emrys Harries

Any crazy volunteers?

A truly impressive but bizarre BDFA event that is currently in the early planning stages is towing a DHL Boeing 757 on the runway at Lasham - **with our manual wheelchairs!** We don't expect to make V1, but we do expect to make quite an impact with the press and TV, have a load of fun, and raise a significant amount in sponsorship for BDFA funds. Planned to take place on 6th September this year, with a trial and practice in May, we'll need quite a number to take part – a 757 is a large aeroplane. Calculations on the BDFA beer mat show that we'll need 30 to pull it (relatively!) comfortably, and we'd like to have some arm power in reserve too. This hasn't been tried by anyone, so we'll be

boldly going where no one has been before... setting World records as we go.

What we need first are VOLUNTEERS to sign up for this amazing project, who can commit to raising sponsorship money, having a pretty rigorous workout, and enjoying an incredibly rewarding day out for themselves, friends and family. There will be gliders and powered aircraft aerobatic displays, and plenty of other action on the day. Please register at www.aerobilitydhl757.net if you are interested in helping with this crazy scheme.

Regional News

Region 4

Community Research Awards

Plymouth University are very keen to support and help their local community and particularly voluntary organisations within this community. For this reason, they have a new initiative, and invite applications for a "community research award". We have recently applied for one of these awards, and if successful, we will be provided with a specialist research team who will look into the healthcare services the HSP affected community in the South West currently receive. There will be meetings set up with this local HSP community, and following discussions, methods of improving services will be sought and implemented.

If successful we will be awarded a budget maximum of £10,000 and this funding will be available from 1 June 2008 to 31 July 2009. All funds will be used to finance the project. We will know if we have been successful with this application by April 28th.

If you live in the South West (Region 4), be prepared to be asked to attend local discussion groups. I believe travel expenses will be covered within the budget.

I apologise that no one is aware of this but when we found out about this opportunity we literally only had one day to apply for it.

Fingers crossed!

Ian Bennett

Regions 1 & 2

Being a Regional Co-ordinator has many pleasures, which include communicating with members. I say communicating as so often some of our members are unable to travel to local meetings or AGM's so telephone calls, letters and e-mails are the main contact.

As much as there is joy in knowing members there is also sadness at our members' demise. At these times those attending our Afternoon Teas at Milford are told. Some members have often attended AGM's and are known by a wider audience. Unfortunately, when Brian McCloy died a few years ago I was unable to tell more members, as I did not have a picture of him at one of the AGMs that he and his wife Liz had attended.

Before Christmas I was sad to hear of Julia Richardson's death. Julia and her friend, Francis, were regular attendees at the Milford meeting and were there at the first meeting back in December 2000. Unfortunately, due to Julia's health problems we had not seen them for a while.

For those that have attended the Birmingham AGMs and the Milford meetings you might like to see the lady in question. (Thanks to David Britton for sending the photo).



I am sure she will be sadly missed by all who met her.

Best wishes,

Jane Bennett

Forthcoming Events:

Mobility Roadshow

Stoneleigh Park, Coventry
12th, 13th and 14th June 2008.
Visit: www.mobilityroadshow.co.uk

Region 4 get together

Saturday April 26th 2pm onwards
The Dartmoor Lodge Hotel – Ashburton
All members welcome. For further details contact Ian Bennett on 01202 849391

Afternoon tea Regions 1 and 2

Saturday 19th April 3 – 6 pm
Milford Day centre
Anyone interested in attending, please contact Jane Bennett on 020 8853 4089

FSP Support Group AGM

Saturday 21st June 2008
Trident Technology and Business Centre at
Royal Leamington Spa
Full details on page 10

New Members

We welcome the following new members:

Mr Adam Hardwick Andover Region 3	Mrs Irena Pritchard Lancaster Region 9
Mr Andrew Christie Chatham Region 1	Mrs Jane Hoyle Exmouth Region 4
Mr Jack Wilson Edinburgh Region 11	Mrs Jean Howard Filey Region 10
Mr John Greaves Darlington Region 10	Mr Robert Turner York Region 10
Mr Amofa Owusu-Sekyere Sheffield Region 10	

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.

THE HSP SUPPORT GROUP

Annual General Meeting & Conference 2008

Saturday 21st June

This note is formal notice that our AGM for 2008 will take place as shown below. There are two forms also set out on page 13 for you to use. The first is for you to use to nominate anyone to a committee position. The second is to let us know who will be attending so that we can tell the caterers. All organisations need to have a broad range of skills and it is important that we have enough people on our committee to cope with the unexpected - so please use the form if you know someone who would join. You will also notice that last years AGM minutes are included on page 11. This is so that all members get the chance to view them, and at this years conference they can be approved as accurate.

I look forward to seeing you at this year's AGM.

Dave Harris -- Secretary

Venue: The Trident Technology and Business Centre
Poseidon Way
Leamington Spa
CV34 6SW

Agenda

- | | |
|-------|--|
| 10.15 | Coffee & Welcome |
| 11.00 | AGM |
| 11.30 | A short break |
| 11.40 | Dr Christopher Mc Dermott :
School of Medicine & Biomedical Sciences – University of Sheffield
A Summary of research developments examining supportive and symptomatic treatments for HSP. Would you believe there are mouse and zebrafish models of HSP?
Sounds interesting? Question and answer session. |
| 12.40 | Relax before lunch. The opportunity for us all to make new friends and chat with old friends, or to simply wind down. |
| 1.15 | Buffet lunch |
| 2.40 | Martyn Collis - RYA Sailability:
I'm disabled on land.....but everything changes on water.
Getting out on the water can be a liberating experience. Sounds a bit like an HSP meeting doesn't it?. Martyn will advise on instructors, where to sail and via a short DVD let us see the potential round the world racing trialists for the future. |
| 3.30 | Coffee & Open Forum: The chance to continue ideas discussed before lunch or to relax for the journey home, |
| 4.15 | Close |

Minutes of 2007 Annual General Meeting

Trident Technology and Business Centre, Leamington Spa - Saturday 16th June

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

Duly 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) 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) 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.

Committee nominations

If you wish to nominate anyone for election, please use the form below and get the agreement of your nominee. Please return the form to Dave Harris, 18 Lodmoor Avenue, WEYMOUTH, Dorset, DT3 5AF, not later than 7th June.

Officer	Current	Nominee	Signature of Nominee
Chairman	D Pearce		
Secretary	D. Harris		
Treasurer	J. Mason		
Membership Sec	I Bennett		
Exec Committee Member	S. Flower		
Exec Committee Member	J. Moore		
Exec Committee Member	Vacant		
Exec Committee Member	Vacant		



If you are attending the AGM, please detach and return the form below before 31st May.

**ANNUAL GENERAL MEETING
TRIDENT TECHNOLOGY AND BUSINESS CENTRE
LEAMINGTON SPA
JUNE 21st 2008**

Name:

I will be attending the 2008 AGM. I shall be accompanied by family members / friends including children. There will be wheelchair users.

I **will** / **will not** be able to assist with transport, should any member in my locality require a lift. The cost per person will be £7.50. This will include a buffet lunch and refreshments throughout the day.

I / we enclose a cheque payable to “**The FSP Group**” for: £

For further information, please contact, or return completed form and payment to:
Dave Harris, 18 Lodmoor Avenue, WEYMOUTH, Dorset, DT3 5AF

If you are interested in attending, but transport is a problem, please let us know. Should you need to cancel, any payment will be refunded in full

