



# FSP Newslink

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

**Issue 8 – Aug 2006**

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

## David's short break with The Calvert Trust

From time to time I visit exhibitions/shows where the people I meet and the information I gather might benefit the group. It was at a motability show at The Stoke Mandeville Hospital, where we had only recently held our AGM, that I came across The Calvert Trust. I think we all agree; where attainable, new goals and targets help to promote a positive mental approach, what better than to target these positives in a physical area, with the care and support of professionals. Karen Varker sat me down with a cup of tea and a biscuit, agreeing to talk about The Calvert Trust at our 2006 conference at Warwick. I later booked in on the long week I am about to précis below.

After a long journey I arrived around the booking in time of 3.00pm. The reception area was alive with scooters, walking poles, wheelchairs, tri walkers, and of course the able bodied and carers. I booked in and was introduced to the four other fearful participants in this adventure. They were two brothers for whom a weekend with The Calvert Trust was the prize (you cannot be serious) and Julie Andrews (yes, I am serious) preparing an article for the Able publication, and her husband.

After a guided trip around the site in the pope mobile (a converted golf buggy) we all enjoyed an excellent evening meal. The evening entertainment in the main bar area consisted of karaoke, disco, large screen video as per a set programme.

With teams from care homes our first task was canoeing. After kitting out; that is lots of warm clothing, waterproof and life jackets we



boarded the pope mobile and were taken to the reservoir. The hoist shown was invaluable in locating the more disabled into the canoes (two bolted together for safety. We set off, an instructor generally steered, threatening to withdraw our rum rations if a good head of steam was not maintained. We travelled the full distance round the reservoir, some 3 miles naturally set in a valley, stopping for coffee and biscuits around half way.

Over the next few days both as individuals and in various groups we took part in orienteering, swimming, kayaking in the pool, archery and mountaineering, each supervised by caring instructors. Most remarkable to see was the assistance given by the instructors in moving legs to assist climbers supported by a harness; and climbing the mountain at the same time. I have photographs showing the determination of us all to ring the bell at the top.

I will most certainly be going back to pit myself over a full week session. Does anyone want to join me doing the things they never thought possible?

*David Pearce*

### Inside this issue....

Useful information    Page 5  
Annual Report        Appendix 1

## From the Chairman

Hello everyone

From the many phone calls I have received I know a number of us all are experiencing difficulties in walking with this heat. It has been interesting however to hear how my able bodied friends are having similar difficulties, particularly the motivation to **do anything**. Let's all hope we can see some improvement when temperatures drop to something more normal.

Generally I think we have recently enjoyed our best conference ever. Thank you Debbie for your write up on page 3. Both the size available and presentation equipment available at Warwick made for a truly relaxing forum. Additionally the speakers excelled, the buffet was fit for kings and wait for it; for the first time ever we finished the AGM on time. As usual the positive interactive style of those attending flowed throughout the day. There may well be a case for us to consider retaining Warwick for the AGM with one additional meeting in say Scotland /the North and The West Country alternating annually. Give it some thought and let me have your comments. Please note that both the minutes of the AGM and our Annual Report are included in this newsletter.

Let me welcome David Harris (now Group Sec) and John Moore to the committee. They both bring additional skills, new ideas and enthusiasm to ensure the group's on-going development programme is maintained.

At the outset the activity on the e-mail site was to say the least, rather frenetic. Usage has now settled down and if you cancelled your registration at that time it may well be worth your while taking another look. It really is a golden opportunity for us to share the wealth of knowledge and experience we all hold.

Lastly can I remind you. For various reasons members do not feel able to attend AGM's. We all take for granted the positives we pick up when we all meet. How can we help those wishing to attend to get there? If you have some ideas, have a chat with your

coordinator or of course any committee member.

As usual feel free to phone me anytime

*David Pearce*

## The Secretary's Spot



I thought that now I have been elected as Group Secretary I should introduce myself. Firstly can I extend my thanks to Nigel for his work for the group during the past years - he has helped us to get on track and I fully intend to keep the momentum up.

So who is Dave Harris? - some of you will have read the Computer Column over the last year or so, but that doesn't give a lot of information about me. So here goes: Dave is married to Carolyn, who is the person with HSP. We now live in the centre of the UK's Jurassic Coast in Weymouth. We've been members of the Group for eight years or so now. I'm an active member of some organisations local to here - National Trust members group, and local Campaign for Real Ale group. Carolyn uses a stick and/or a walker and has two sizes of scooter (one in the boot of the car and a larger one for "town and country"). We recently managed to get to the top of Maiden Castle - an iron age hill fort - with this scooter and enjoyed it so much that I think we'll be looking for more such challenges!

I was the editor for our Information Booklet, and we are in the process of updating the book for another issue - which reminds me - if you think of further topics let me know soon or you'll miss the boat. On that note it's probably time for me to bring this introduction to a close, please feel free to contact me on any topic to do with the group and I'll do my best to help.

*Dave Harris*

## Annual General Meeting Warwick 17<sup>th</sup> June 2006

The morning for me commenced at 5.30 a.m. Probably like the rest of you it takes me quite some time to get ready, not only getting dressed (but being of the female gender making sure that my face looks dressed as well).

I was picked up at 7.00 a.m. by Mark Tomlinson who could be called mine and Anne Sykes “Chauffeur”. We then picked Anne up at Leeds Railway Station, her having travelled from York.

Thought that we would make an early start to give us plenty of time to get there for the Morning Coffee at 10.00am. Ian’s map was excellent but it’s a pity that the town cannot mark its roads properly. None of the smaller “A” roads travelling from the North, not too sure about the South, were marked so this made it quite difficult to find. We eventually got there at 10.45 after winding our way through the mousetrap of a car park just in time for the Meeting itself.

Anyway, let me get onto the point in question.

The meeting commenced with “top of the table”, David Pearce (Chairman) welcoming everyone and commenting about the numbers and how this had increased from last year, this was great news for everyone. He then went on to tell us what had gone on through the year and what the Group plans to do in the coming year.

Apologies were given from Christine Snow, Pattie Raven and Paul (and not forgetting her four legged friend/companion/worker “Amber”).

David thanked Richard Williams for his donation to the Group raised through sponsorship from his long and winding cycle ride from Lands End to John O’Groats (pheeewgh).

It was then time for Ian Bennett (Membership Secretary) to speak. He again mentioned how the numbers had grown this year and the Group now comprises of approximately 290 members. He suggested that he would welcome the assistance from

new committee member John Moore and Group Secretary Dave Harris. He did also mention that he had plenty of flyers on HSP/FSP that could be taken to the hospitals and GP Surgeries to add to the ones already published for the likes of Multiple Sclerosis and Parkinson’s but to mention a few, which most people have heard of and to give people a better insight into HSP/FSP (a lesser known condition). There were also leaflets on the Functional Electronic Stimulator (FES) – Odstock Stimulator. Ian uses this himself so I’m sure he would be more than willing to speak with anyone about this should they feel that it may be of help to them.

Stephanie Flower (Help-Line) then stood up and said she had spoken with a few people who had now become members of the Group, and was always there if anyone has any questions. We can’t forget her companion “Frodo”, she brought some flyers with her about him and the things he can do to help her, he’s quite an expert and believe me he is amazing (**not bad, him being male**), don’t take this too seriously will you chaps.

We then got a summary of the Group’s Accounts again brilliantly compiled by Mike Fawcett (Treasurer) and what can I say other than the funds are increasing rapidly, and as we are now a Charitable Trust these need to be spent before we can get any other help from them. “Lets get spending folks”.

The meeting then went onto a more relaxed feel with three excellent speakers who took time out of their busy schedules to speak with us.

Firstly there was Dr Jon Marsden from The National Hospital, London.

He gave an excellent talk, don’t know about you but to me he gave a very true image and the best description I have heard about HSP/FSP.

He specialises in the physical side of HSP/FSP but not the Genetics.

He went through a lot of things but the main thing he spoke about was how the neurones come from the brain to certain parts of the spine and these then control the various parts of the body but with HSP/FSP sufferers these do not reach the bottom part of the spine

that control the legs, thus causing them to become stiff and spastic.

He thanked the Group very much for their financial help with the research being carried out.

Now it was time to listen to a very experienced Physiotherapist (Gita Ramdharry who works at the same hospital as Dr Jon Marsden – The National Hospital, London. She gave an excellent talk on the various exercises we can do to enable us to get about better and easier. I'm sure some of you have visited a Physiotherapist and gone through some of the exercises yourself. She then went on to talk about the different aids that can be used, i.e. sticks, crutches and tri-walkers etc. (some of us use one or more of these already). Gita had to make her talk rather shorter than anticipated, but again thanks go out to her for giving her time to be with us.

We then retired to lunch, which was a lovely hot and cold buffet, seemingly enjoyed by all. Many thanks go out to the caterers for this.

This gave each one of us time to chat with people who we only usually get time to speak with on the telephone or through Email, meet new people and talk in general about everyday things and not only about HSP/FSP and how this is affecting us.

After lunch we had the privilege of listening to Karen Varker of The Calvert Trust who gave a very interesting talk on holidays for the disabled. This involved various activities that people enjoy doing i.e. sailing, rock climbing, bungee jumping etc. and with the help of fully trained workers disabled people can also enjoy these activities. Flyers and Brochures were available for anyone interested in this.

I think from speaking afterwards that a few people were interested (mentioning no names "MT" and "RE").

It was time again to listen to Dr Jon Marsden who once again gave a very illustrated talk summarising how people are affected by HSP/FSP. Sadly this had to also be cut short due to time running out. I'm sure that most of us could have listened to him, Gita and Karen all day had there been enough hours in

it. But he did mention that if anyone had any questions then he would be more than willing to answer people's questions either over the telephone or by Email.

Here we come to the end of another AGM, which again proved very interesting and helpful, especially to our new members being their first of many HSP/FSP Meetings to come whether it is a Regional Meeting or the next Annual General Meeting.

Hope you all had a safe journey home, and  
HERE'S TO 2006/07

*Debbie Best - Region 10*

## A Secretarial Threesome Meet

On 5 July I had lunch at a Hampshire pub with Ian Bennett and Dave & Carolyn Harris for a meeting at which we discussed my possible future involvement in Membership and other work.

As you know, Ian has been our Membership Secretary for 2 years, and Dave was elected Group Secretary at the recent AGM. I have also now been elected an Executive Committee Member, with a role which has yet to be fully determined, but my background work over the last few years, mainly assisting with the late drive for collection of outstanding subscriptions, has hinted that I could perhaps roll this into a Committee responsibility.

I came away from our meeting with the Group's own laptop computer, containing all of the Group's Membership records, with the object of "learning my way around it", and I expect to be able to determine my own offer of assistance to Ian in his role. I truly applaud Ian for his creation of this wonderful system, and I can indeed see that it will greatly assist our liaison and our records & accounting.

Thank you to the 3/4 of our members who have now already renewed their annual subscription, **and would any of you who pay by Standing Order/Bankers Order please check that, indeed, your bankers have generated the payment through your account.** If you have any queries in this respect, please contact me on 02392 592784, or

[johnmoore@drift66.fsnet.co.uk](mailto:johnmoore@drift66.fsnet.co.uk), or lan on his communication addresses.

May I conclude by saying that some Members feel that they should always make subscription payments to Treasurer Mike Fawcett. Without offence to Mike, as all forms ask for payment via Ian Bennett, and as Ian maintains all membership records, it is a degree more efficient if Ian can be the recipient.

*John Moore*

## Useful Information

<http://patientgpservices.com/> This service allows patients to submit their repeat prescriptions online without having to visit their GP. It is available to both GP Practices and patients. Saves time and is quick, easy, safe and secure to use. Use this service from home, work or away. Keeps your records in order. It's **FREE** for GP Practices and patients to use. Use it as often or as little as needed.

**Candle** offers assessments for people of all ages who have communication, movement and/or learning difficulties. We have supported the CAP project throughout its existence and work closely with some of the main CAP centres. We can advise on teaching strategies and appropriate use of technology (such as establishing a pupil's best access to communication aids and computers) as well as helping professionals and families to develop short and long term plans. Research has shown that students with even the most complex disabilities can develop literacy skills beyond what has previously been thought possible. We can help you to achieve this. Assessments cost between £350 (if you come to us) and £500 (if we come to you). To discuss your needs contact: Mick Millward on 01422 377117 or 07904693302

Or email: [contactcandle@btinternet.com](mailto:contactcandle@btinternet.com)

## Useful Websites

[www.disabledworkers.org.uk](http://www.disabledworkers.org.uk) The Disabled Workers Co-operative is a registered charity

that helps disabled people to help themselves.

[www.after16.org.uk](http://www.after16.org.uk) This website is for teenagers and young people in the UK who have an impairment or disability and are wondering what opportunities and services there should be when they leave school.

[www.sendist.gov.uk](http://www.sendist.gov.uk) Parents whose children have special educational needs can appeal to the Special Needs & Disability Tribunal against decisions made by local education authorities (LEAs) in England about their children's education.

[www.carersonline.org.uk](http://www.carersonline.org.uk) Carers UK is the voice of carers. Carers provide unpaid care by looking after ill, frail or disabled family members, friends or partners. Carers give so much to society yet experience ill health, poverty and discrimination. Top of the Document Carers UK was set up by carers to end this injustice. Our vision is for people to recognise the true value of a carer's contribution to society and where carers get practical, financial and emotional support.

<http://www.drc.org.uk/disabilitydebate/> Changing Britain for good, putting disability at the heart of public policy.

[www.skill.org.uk](http://www.skill.org.uk) Skill: National Bureau for Students With Disabilities. Skill is a national charity promoting opportunities for young people and adults with any kind of disability in post-16 education, training and employment across the UK.

[www.ilf.org.uk](http://www.ilf.org.uk) The Independent Living Funds (ILF) are two funds set up and financed by UK central government. The funds were set up as a national resource dedicated to the financial support of disabled people enabling them to choose to live in the community rather than residential care.

[www.ncil.org.uk](http://www.ncil.org.uk) This website is designed to be a resource on independent living and Direct Payments for disabled people and others working in the field.

[www.chatability.org.uk](http://www.chatability.org.uk) Chatability is a secure internet chat room and forum for disabled children and young people under the age of 18. It is a place where you can make friends online, chat to them about

whatever is on your mind. Chatability provides the opportunity for disabled children and young people to access a safe chatroom and forum.

<http://www.disabledparenting.org.uk/index.htm> There are approximately 2 million (government estimation) Disabled Parents in the UK.

<http://www.nopityshirts.com/> The best disability-related and motivational stuff in the galaxy! (Caution: some language used on this site may cause offence).

[www.freedominsure.co.uk](http://www.freedominsure.co.uk) Insurances for people with pre-existing medical conditions.

<http://www.kids.org.uk/> At Kids we help disabled children to get the most out of life. We work closely with parents and carers to give children and young people all the support they need today to fulfil their hopes and dreams tomorrow. We want to transform attitudes so that all children have the chance to be included in the play and learning of everyday life.

<http://www.disabledgo.info/> DisabledGo provides free detailed access information for disabled people across the UK. Our detailed access information will empower you to judge for yourself which hotels, cinemas, restaurants, solicitors' offices, pubs, train stations - all kinds of shops and services - are accessible to your particular needs.

## FSP Computer Help

Getting the most from what you have - this piece is aimed at making things easier or less costly while still getting the benefits.

Printer Ink. Earlier this year it was time to replace the printer on my computer. We normally don't use the printer a lot - in fact we probably print on average 5-10 sheets per day if I include drafts and test prints. What came as a bit of a surprise was that although the printer came from the same manufacturer as my previous one and was similar in its overall layout, the ink cartridges were physically similar but held only one third of the quantity of ink!!

With a new black ink cartridge costing about £11 it would cost about 10p for the ink on

one page!! I therefore have bought an ink refill kit which includes inks, disposable gloves and various little bits to help with the refilling process. Such a kit costs about £8 and will refill a cartridge four times. I had used these sometimes with my previous printer, but with the new prices I will be using them more in future. There are various UK companies which sell these by mail order and delivery is within a few days. Look on the web for "ink refill" and your printer model to find suppliers. It is prudent to choose a product which uses original manufacturers ink as this will be most suited to the cartridges you will be refilling. Another thing to remember is that although you can refill cartridges, it probably is best not to refill any one more than 4 or 5 times - they are after all designed to be disposable.

Paper - cheapest supplies. After looking around various outlets, we have settled on getting computer paper delivered with the groceries - the price was under £2.00 for 500 sheets and as we already were having the home delivery service it costs no more and saves lugging a heavy pack home!

Use of bookmarks in Browsers (called Favourites in Internet Explorer). Many people don't realise that the bookmarks in the Browser they use can be organised like files and folders to make it easier to find and use them. Usually in a browser there is an item on the pull-down menus called "Manage Bookmarks" or something similar which gives a view of all the bookmarks. Once this view is open, it is possible to drag and drop bookmarks and to create "folders" to help organise them. Each browser is slightly different, so have a try and see how yours can be "tidied up"

While I was writing this it occurred to me to mention "All in One" printers - these are now cheap to buy (under £50 new) - they can be costly for ink (unless you do refills as above). The main thing is that if you get one you can photo-copy a document at home (some models allow this independently of using the computer). You can also "scan" documents - this is making an electronic image of the document or picture which can then be sent by email so that someone else can have copy. Talk to people and see how

they have used the machines to decide if they would be any use to you.

Well, I think that's plenty for this time, I'll let you get on with reading the rest of Newslink!

Don't forget to let me have your questions and suggestions for the next items... you can send them to me at [dave@vadcar.org.uk](mailto:dave@vadcar.org.uk).

*Dave Harris*

## Members' Letters

### To Return to the Cruising Theme!!

In Issue 4 (August 2005) I submitted an article about the suitability on cruise-ships for wheelchair users. At the time of preparation of the article, my wife Carol and I were looking forward to a cruise in the Baltic on the ship "Costellation", which belongs to the American company, Celebrity Cruises.

I can confirm that everything was first rate: the ship, its facilities, its accessibility, our cabin, the entertainment, the food...and indeed the ports visited. It was in July 2005 that we sailed from Dover to Oslo, Stockholm, Helsinki, Tallinn, St Petersburg, Warnemunde (for Rostock), and Copenhagen. The weather was superb: almost unbelievably (especially in St Petersburg) at above 70F each day.

I can only really underline this as a recommendation.

I conclude by saying that

1. In November 2006 we will, for the first time, be using P&O Cruises for a visit to the Caribbean, starting with a flight to Barbados.
2. And, from the continuous mail updates on my doormat, we have already chosen another Caribbean cruise in November 2007, which also takes in Bermuda, and we're delighted that it will again be on Constellation.

I'll send an update on these 2 cruises once they've been experienced.

*John Moore*

## Regional News

### Region 4 Get Together 06/05/2006

The latest in a series of regular meetings for the South West members was for many the best yet. It certainly was the largest with 26 attendees (out of a total m'ship of 29).

The day was arranged around two speakers – Mrs Diz Leete - who gave us insights drawn from her life and two different careers - as a nurse and then as a probation officer. The talk was well received and members were attentive throughout - and demonstrated this with their questions.

A buffet lunch was then enjoyed, particularly by those who had travelled that day. Eight of us had stayed overnight due to the distances involved - for example Phil Burton had travelled from Worthing (180 miles to the East) and David and Tina Jeffries from Redruth (80 miles to the West).

Phil ran a Raffle after lunch which was a success, raising some £50 which goes towards the costs of the meeting.

The afternoon speaker was Dr Jon Marsden from the National Hospital. He gave us an explanation of the research project that he was currently undertaking into the gait of people with HSP.

Volunteers are fitted with markers on their hips and lower limbs which allow video cameras to accurately record how the limbs move during walking. Special plates in the floor also measure the forces and pressures that patients exert as they walk. The strength of the limbs and joints are then assessed by a separate set of other more conventional tests. All this information is used to build up a picture and to try to identify those factors that are common to most subjects so that eventually therapies may be developed to give the best effects.

As several members present were participating there was a lot of interest in this talk and many questions. Because of the nature of the research there is an obvious link with the FES work at Salisbury. Several members had now been provided with FES equipment and there were plans to link the

research work and the FES work to see how much could be learned through a joint effort.

After the talk and the subsequent barrage of questions, we enjoyed a few minutes more general conversation before Ian Bennett drew the meeting to a close just after 4pm - a very worthwhile day - many thanks to Ian for organising it.

## Attention all Regions

Three of our regions are currently without a coordinator and Stephanie Flower is still seeking some assistance in Region 5. If anyone is interested in assisting, please contact a committee member.

## New Members

We welcome the following new members:

Mr Andrew Sharpe  
Berkshire  
Region 3

Mrs Sheila Brett  
East Sussex  
Region 1

Miss Ann Feltham  
Hertfordshire  
Region 3

Mr Andre Wheeler  
Berkshire  
Region 3

Mrs Dianne Kirtley  
Tyne & Wear  
Region 10

Mrs Maggie Aldridge  
Swindon  
Region 3

Mrs Sally Scott  
East Sussex  
Region 1

Mazhar Ahmad Cheema  
London  
Region 1

Ms Maggie Gillson  
Berkshire  
Region 3

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.

## Useful Contacts

	<u>Email</u>	<u>Telephone No:</u>
David Pearce - Chairman 8 Brinkworth Road, Clayhall, Ilford, Essex, IG5 0JS	<a href="mailto:pearcey david@yahoo.co.uk">pearcey david@yahoo.co.uk</a>	020 85512905
Dave Harris – Secretary 18 Lodmoor Avenue, Weymouth, Dorset, DT3 5AF	<a href="mailto:dave@vadcar.org.uk">dave@vadcar.org.uk</a>	01305 772286
Sharon Gradidge - Newsletter Editor 20 Cedar Road, Eastleigh, Hampshire, SO50 9NR	<a href="mailto:gradidgefsp@aol.com">gradidgefsp@aol.com</a>	023 80612173
Mike Fawcett - Treasurer 104 Moorview Way, Skipton, North Yorkshire, BD23 2LN		01756 795480
Stephanie Flower - Help-Line 37 Alexandra Road, Great Wakering, Southend, SS3 0HN	<a href="mailto:FSPgroup@aol.com">FSPgroup@aol.com</a>	01702 218184
Ian Bennett – Memb Sec/Reg 4 co-ordinator 37 Wimborne Road West, Wimborne, Dorset BH21 2DQ	<a href="mailto:ian.bennett@tesco.net">ian.bennett@tesco.net</a>	01202 849391
John Moore – Executive Committee Member 66 Drift Road, Clanfield, Waterlooville, Hants, PO8 0NX	<a href="mailto:johnmoore@drift66.fsnet.co.uk">johnmoore@drift66.fsnet.co.uk</a>	02392 592784
Sally Langton - Group Awareness		0116 2700450
Jane Bennett - Regions 1 & 2 co-ordinator	<a href="mailto:luckyjane82@hotmail.com">luckyjane82@hotmail.com</a>	020 88534089
Isabell Quinlan - Region 6 co-ordinator		01570 471062
Kathy Chambers - Region 7 co-ordinator		01142 960619
Carol McGowan - Region 9 co-ordinator		0151 2892597
Ray Exley - Region 10 co-ordinator	<a href="mailto:rayexley@aol.com">rayexley@aol.com</a>	01904 626799
Liz Ferguson - Region 11 co-ordinator		01415 779695



# **Minutes of the Annual General Meeting**

## **Trident Technology and Business Centre**

### **Warwick 17th June 2006**

The meeting was called to order at 11:00am.

#### **Introduction**

David Pearce began by welcoming all to Warwick, and acknowledged that many of those present had made long journeys to be there. Several new members were present, and a warm welcome was extended to them.

#### **Apologies**

We had had 75 people planning to attend and apologies had been received from 15 more due to other commitments. This makes the meeting the largest we have held so far!

#### **Minutes of 2005 AGM**

The minutes were agreed to be a correct record of the last AGM.

### **Committee Reports**

#### **Help Line (Stephanie)**

Pleased to see so many people here. Plans to run “Open Forum” from 3.10pm as last year. Eric Spalding mentioned the “Expert Patient Programme”. Stephanie mentioned the “Canine Partners” organization.

#### **Secretary (Nigel Bulbeck)**

Nigel had very much enjoyed his work as Secretary for the organisation but was now in a position where he had increasing demands on his time from work and his studies. He was stepping down as Secretary with effect from this AGM.

#### **Membership Secretary (Ian Bennett)**

We now have 249 Members after “trimming out” those who (after reminders) had not renewed membership. In addition we have 20 Family Members (i.e. partners or other family members not affected by HSP) and 30 Honorary Members (mainly medical practitioners). We already have received renewals subscriptions from more than two thirds of our members.

#### **Committee Member (Dave Harris)**

Very pleased to see this very good attendance at the AGM. He had worked on Committee for a year now and was letting his name go forward for election as Secretary.

#### **Treasurer (Mike Fawcett)**

Mike said we had had a “fantastic year”. The income had been £16,500 (£5000 last year). A wide range of donations had been received from £1000 to £6,600. The final total from Richard Williams cycle ride from Lands End to John O’Groats was £5,570. Receipts from subscriptions was higher this year.

Expenditure – we had for the first time been able to provide funding (£3000) into a research project into FSP being conducted by Dr Evan Reid at Cambridge. In addition we had managed to reduce our printing costs for the Newslink by £500 by having the work done by Barnardos Printing.

Over the year we had generated a surplus of £8,600. Mike took the opportunity to remind members that grants were available from the FSP Group to help members with equipment or services related to their condition. Application forms are available from the Group Secretary.

#### **Chairman (David Pearce)**

David explained that an annual report is submitted to the Charities Commission, and copies of this report are available for members to read and take away.

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**Election of Officers**

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

Treasurer	Mike Fawcett
Secretary	Dave Harris
Membership Secretary	Ian Bennett
Executive Member	Stephanie Flower
Chairman	David Pearce
Committee Member	John Moore

**Resolutions** None

**AOB** Phil Burton thanked the committee for all their hard work put in during the year.

There being no other business the meeting was closed at 11:28am

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## **INCOME & EXPENDITURE A/C FOR YEAR ENDED 30<sup>TH</sup> APRIL 06**

	2005/2006 £	2004/2005 £
<b>Income:</b>		
Videos	5.00	262.00
Subscriptions	2669.50	2643.50
Donations	6665.45	974.99
Stoke Mandeville AGM	528.00	240.00
N.W Conference / Sheffield & Peterborough Confs	180.00	696.00
Milford Meetings	93.90	288.10
Leamington Spa AGM	450.00	-
Cycle Run	5578.18	-
Miscellaneous Income	30.00	2.50
Standard Life Bank Interest	276.07	157.80
Total Income for year	<u>£16,476.10</u>	<u>£5,264.89</u>
Balances b/f		
1-5-05 – Standard Life	4125.90	-
1-5-05 – Barclays	816.60	-
	<u>£21,418.60</u>	
<b>Less Expenditure:</b>		
Postages, Stationery & Cartridges	995.39	1468.41
Stoke Mandeville AGM	834.00	420.00
N.W Conference / Sheffield & Peterborough Confs	763.40	1131.07
Milford & Devon Meetings	171.50	182.00
Help Line	220.00	168.90
Lap Top & Software / New Printer	799.39	417.13
Donation to HSP research	3000.00	-
Grants to Members	600.00	550.00
Just Giving Collection Charge	176.20	-
Equipment Warranty	113.39	-
Miscellaneous Expenses	135.91	365.92
Total Expenditure for year	<u>£7,809.18</u>	<u>£4,703.43</u>
Transfer from Standard Life Account	11,901.97	
Transfer from Barclays Account	1,707.45	
	<u>£21,418.60</u>	
Surplus for year	8666.92	561.46
Bal b/f 1/5/05 –		
Standard Life	4125.90	3368.92
Barclays	816.60	1012.12
<b>Surplus c/f 30/04/06</b>	<u>£13,609.42</u>	<u>£4,942.50</u>

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## Trustees' Annual Report (Accompanying Receipts and Payments Accounts)

**Section 1**

**Legal and Administrative Information**

Charity name	THE FAMILIAL SPASTIC PARAPLEGIA SUPPORT GROUP
Any other name the charity is known by	
Charity Commission registered number	1 1 0 9 3 9 8
For the financial year beginning on	0 1 0 5 0 5
For the financial year ending on	3 0 0 4 0 6
Charity's principal address	<p>If including the charity's address might put any person whose name is required to be given in this report in personal danger, please contact the Disputations Officer at the Charity Commission. We can give permission for the address not to be disclosed here.</p> <div style="border: 1px solid black; padding: 2px;">                 37 WIMBORNE ROAD WEST                  WIMBORNE                  DORSET                  Postcode <span style="border: 1px solid black; padding: 0 2px;">B</span> <span style="border: 1px solid black; padding: 0 2px;">H</span> <span style="border: 1px solid black; padding: 0 2px;">2</span> <span style="border: 1px solid black; padding: 0 2px;">1</span> <span style="border: 1px solid black; padding: 0 2px;">2</span> <span style="border: 1px solid black; padding: 0 2px;">D</span> <span style="border: 1px solid black; padding: 0 2px;">Q</span> </div>
Description of the charity's trusts	<p>This should include:</p> <ul style="list-style-type: none"> <li>• details, including date if known, of the charity's governing document (eg trust deed, will, constitution etc); and</li> <li>• a brief explanation of the charity's objects.</li> </ul> <p>Where applicable, you <b>may choose</b> to give details of any specific investment powers of the charity.</p>
Governing document	MODEL CONSTITUTION FOR A CHARITABLE, UNINCORPORATED ASSOCIATION, DATED 11/9/2004
Objects of the charity	THE RELIEF OF SICKNESS AMONG THOSE SUFFERING FROM THE EFFECTS OF FAMILIAL SPASTIC PARAPLEGIA, THEIR FAMILIES AND CARERS, BY THE PROVISION OF INFORMATION, ADVICE AND SUPPORT.
Specific Investment powers	RESERVES HELD WITH THE STANDARD LIFE BANK TO EARN INTEREST ACCORDINGLY.

Please provide additional information on a separate sheet where necessary

**Section 1 Legal and Administrative Information (continued)**

Professional advisers You **may choose** to provide the names and addresses of any advisers regularly used by the charity, eg bankers, solicitors and investment advisers.

NOT APPLICABLE

**Section 2 Trustees and Governance**

Names of trustees (including the directors of corporate trustees)

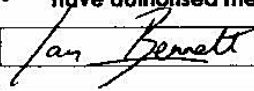
- The names of all charity trustees should be given in column (a) below. "Charity trustees" are the persons responsible for the management of the charity. Include the names of the charity trustees at the date of the report and of anyone else who acted as a charity trustee during the period covered by this report. You **may choose** to add the title of any office held (eg Chair, Treasurer, Secretary, etc) after the name.
- If any of the named charity trustees acted only for part of the period covered by the report or were appointed or resigned after the period end, the dates during which they acted as charity trustee should be given in column (b) below.
- If a body corporate is the charity trustee, or is one of the charity trustees at the date of this report, the names of the "directors" of the body corporate should be given in column (c) below.
- The name of any person or body entitled to appoint one or more new charity trustees should be given in column (d) below (eg the charity trustees themselves, the members of the charity, the settlor or founder of the charity etc).
- The maximum number of charity trustees that must be named is 50. If there are more than 50 charity trustees at the date of this report, only the names of 50 need be given, but include the trustees who are officers (Chair, Secretary, Treasurer, etc). An additional sheet may be appended to Section 2 is necessary.
- If including a particular name might put the person concerned in personal danger, please contact the Dispensation Officer at the Charity Commission who can give permission for the name(s) not to be disclosed.

Name of Trustee (details of any office held may be added after the name)	Dates during which the named trustees acted if not for whole period of this report	Names of directors of any corporate charity trustee at the date of this report	Name of person (or body) entitled to appoint any charity trustee
(a)	(b)	(c)	(d)
DAVID PEARCE - CHAIR			
MIKE FAWCETT - TREASURER			
NIGEL BULBECK - SEC			NOMINATION
IAN BENNETT - M/SEC			AT ANNUAL
DAVID HARRIS			GENERAL
STEPHANIE FLOWER			MEETING

Please provide additional information on a separate sheet where necessary

Section 2	Trustees and Governance (continued)						
Trustee selection method	<p>Please explain briefly how trustees are elected or appointed.</p> <div style="border: 1px solid black; padding: 10px; margin: 5px 0;"> <p style="text-align: center; font-size: 1.2em;">TRUSTEES ARE APPOINTED BY NOMINATION AND VOTE AT THE ANNUAL GENERAL MEETING.</p> </div>						
Names of the charity's custodian trustees	<p>Please give the name of any person who is a "trustee for the charity" at the date of the report, or at any time during the period covered by this report. "Trustee for the charity" means someone who holds the title to property belonging to the charity, without having any management responsibilities (for example a custodian trustee or other nominee).</p> <table border="1" style="width: 100%; border-collapse: collapse; margin-top: 10px;"> <thead> <tr> <th style="width: 60%; padding: 5px;">Name</th> <th style="padding: 5px;">Dates acted if not for whole period of this report</th> </tr> </thead> <tbody> <tr> <td style="text-align: center; padding: 5px;">N/A</td> <td></td> </tr> <tr> <td style="height: 20px;"></td> <td></td> </tr> </tbody> </table>	Name	Dates acted if not for whole period of this report	N/A			
Name	Dates acted if not for whole period of this report						
N/A							

Section 3	Activities and Achievements
Charity's activities and achievements during the year	<p>Explain here about what the charity is trying to do and how it is going about it. You <b>are only required</b> to provide a brief summary of the main activities and achievements of the charity during the year in relation to its objects.</p> <p>Where applicable, you <b>may choose</b> to include comments about:</p> <ul style="list-style-type: none"> <li>• the charity's organisational structure;</li> <li>• any significant changes, development and future plans;</li> <li>• any related parties, charities or other organisations with which the charity co-operates in its work;</li> <li>• the contribution of volunteers;</li> <li>• the effectiveness of any fund-raising activities; and</li> <li>• any funds in deficit, the reasons and any action being taken.</li> </ul> <p>Our total membership now stands at 298. The Group is still growing, and has many people to reach. In addition there has been a noticeable growth in members' activities with regular meetings becoming normal in several regions. The newly established e-mail "list" has got off to a great start with many members using it to discuss a wide range of the topics, which affect them.</p> <p>As an organisation we have started to increase the number of ways in which we make our presence felt. Members have volunteered as subjects for the survey/ research work being conducted by Dr Jon Marsden into the specific effects of HSP. We have also helped the FES team at Salisbury with support and feedback. This year for the first time we have provided funding for research to Dr Evan Reid's research team. Most rewarding was our invitation to contribute to the German FSP support group's survey on living with the condition.</p> <p>Now that we are a registered charity, we have seen an increase in the funds available to us. The most significant contribution to our funds last year was provided by Richard Williams' cycle trek which raised the magnificent total of £5,578.18. As a result we must ensure members are aware of the Group's ability to make grants for equipment etc. and encourage such use. In addition we must find ways to help more of our members to attend conference/local meetings.</p> <p>In the coming year we will be putting plans into effect for the following:</p> <ul style="list-style-type: none"> <li>• To distribute further mail shots to neurology consultants / departments, to increase awareness of our organisation</li> <li>• To complete a poster for circulation to neurology departments nationally</li> <li>• To update our information booklet (now almost two years old)</li> <li>• To provide increased support for our growing number of younger members</li> <li>• To reassess the role of Regional Coordinators where pertinent</li> <li>• To extend contact and cooperation with our European and World wide colleagues</li> </ul>

Section 4	Policies
	<p>Charity trustees should give in their report a description of the policies that they have adopted:</p> <ul style="list-style-type: none"> <li>• for the selection of investments for the charity;</li> <li>• for determining the level of income reserves held, stating and explaining the level of reserves held; and</li> <li>• where grants are made by the charity, for the selection of individuals and institutions who are to receive grants out of the assets of the charity.</li> </ul> <p>In addition you <b>may choose</b> to:</p> <ul style="list-style-type: none"> <li>• confirm that the trustee body has undertaken a review of the major risks to which the charity is exposed, and that systems designed to mitigate those risks have been considered; and</li> <li>• where the charity has a policy for the selection of investments, to comment on the investment performance achieved.</li> </ul>
Reserves policy	<p>THE CHARITY CURRENTLY OPERATES WITH LIMITED RESERVES BUT WE ARE ENDEAVOURING TO BUILD UP A DONOR BASE IN ORDER TO ASSIST/SUPPORT A GREATER NUMBER OF MEMBERS.</p>
Grant-making policy	<p>THE CHARITY SUPPLIES GRANTS TO PURCHASE MOBILITY AIDS/EQUIPMENT FOR ITS MEMBERS. THE CHARITY ALSO ENDEAVOURS TO PROVIDE FUNDING TO SUPPORT THE WORK OF RESEARCH TEAMS.</p>
Investments selection policy	<p>THE CHARITIES RESERVES ARE INVESTED WITH THE STANDARD LIFE BANK LIMITED</p>
Review of major risks	<p>THE TRUSTEES HAVE NOT TO DATE CONDUCTED A RISK REVIEW</p>
Section 5	Signature and Declaration
<b>Declaration</b>	<p>I declare, in my capacity of charity trustee, that:</p> <ul style="list-style-type: none"> <li>• the trustees have approved the report above; and</li> <li>• have authorised me to sign it on their behalf.</li> </ul>
Signature	
Full name	<p>IAN MICHAEL BENNETT</p>
Position (eg Secretary, Chair, etc)	<p>MEMBERSHIP SECRETARY</p>
Date	<p>1 3 0 6 0 6</p>
<p>Please provide additional information on a separate sheet where necessary</p>	