



FSP Newslink

The Newsletter of the Familial Spastic Paraplegia Support Group

Issue 1 – November 2004

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

Under the sea with Philly B

Well hello to you all. My name is Phil Burton. Five years ago I was diagnosed with HSP and it is getting in the way a little more as time goes by, as it is for all of us! I consider that I have been very lucky to have had 40 years ish of good health although sports wasn't very good, my walking/balance and carrying weighty items was not very good but it was just put down to me being me.

Within myself physiologically I feel really good and accept the limits I now have, I have immense support and guidance from my wife Ann who is my 'rock'.

When I joined the association some of the paperwork said that if there was any way we could raise some funds then please try.

So I decided to try something out. Four years ago Ann and I went to Cyprus and on the second day of our holiday a Scuba diving school came to the hotel, carried out a demonstration and then invited any guests to have a try – I did and I was hooked. I then went on one of their "Discover Scuba" dives with the highlight feeding the fishes six



metres down!! Over the following years we have been back to the same hotel and I have taken a few more dips!!!

Last September I intended to take the PADI Open Water Diving Course but my legs were being quite a bother so was not able to

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do it. I decided that I really wanted to do it so over the winter I had swimming lessons to try to improve my technique. I have been a reasonable swimmer but as you all know our legs screw the process up somewhat (which is stupid as I have my half mile swimming certificate from my school days !!).

Raising funds

With our May hols approaching I approached a lot of friends and a few businesses saying that if I passed the diving course would they make a donation to our society. I also spoke with the hotel manager who let me put up a sheet about me and I gave a presentation on stage one evening to let every one know what it was about plus the fact that they had seen me at breakfast with my wires and pads + a funny walk!!! and boy did I get some funny looks. During my little talk I emphasised that I looked upon my problem as “I have spastic paraplegia but it doesn’t have me”.

The course was for four days (which would have meant less sun but I could bear it!!) and I would then be able to dive to 18 metres. Steve the instructor would only let me take the first two days of the course as he said that the second part of the course would be physically too demanding and even if I passed it I would be leaving myself and others I dive with in possible danger if they or I needed help, but to see in the future if my physical strength improved.

Some of the things I had to do were: Swim 200 metres and tread water for 10 minutes (which I still don’t know how I did these) – guests at the hotel were spurring me on.

Under water, both in a swimming pool and the sea, half fill my facemask and then blow air into it as I breathed out, to clear it. Then fully fill my mask with water and clear it and then take my mask off, leaving it off for a minute or so!!! Before putting it back on (with a lot of relief! especially in the sea as my eyes stung a lot). There were some other

skills to carryout as well as a lot of paperwork.

I passed with flying colours and have to date raised £507 for our association – I may have a little more to come but it is like trying to get blood out of a stone!! £80 of it came from fellow guests, which was really nice of them.

Brilliant experience

Steve and his staff at the dive centre have every year been brilliant with me. When you go for a dive, you are driven to a bay, then “kit up” at the back of the car and walk down into the sea with your gear on minus the fins, which you put on when in the water. For me (or you) this would be impossible so they carry all the gear into the water as well as helping me into the water to kit me up.

With every dive I take I find myself getting more confident, relaxed and seeing more of the life below the waves – it is truly amazing and I will endeavour to increase my qualifications so that I can go far deeper as in Cyprus there is a freighter about 50 metres down which sank with a load of lorries on board and is now forming into a reef with lots of life in and around it so I am told.

From now on every year while I can physically do it I am going to set myself a challenge and raise funds at the same time for our association.

I am calling it the Philly B Challenge.

If any of you would like to help by getting sponsors and collect their monies for me then drop me an email to philburton@fsbdial.co.uk and I will add you to my list so that I can keep you posted as to my forthcoming endeavours.

Take care all of you and if this has encouraged any of you to try something then good luck.

Phil and Ann Burton

Editor's Column

By Sharon Gradidge

Welcome to the “nearly” Christmas edition of your FSP newsletter, which I do hope you will agree has got to be our best yet!



We have been very fortunate in that as a group in our entirety we have members from vast areas of proficiency in the workplace which has, enabled myself, with assistance from our very own Ian Bennett, (who I must thank profusely for all his help & support, not just with regard to me but his commitment to the group as a whole) to produce what we hope to be an informative professional publication as we look forward to charitable status.

I must emphasise how nice it is to see so many area co-ordinators arranging meetings in their own respective regions.

Furthermore, as you read through your newslink you will notice that two of our members are not letting their FSP get the better of them, and are daringly going ahead with very ambitious projects.

I trust you will all join me in wishing them the best of luck in their adventures & if you can support them in any way, I'm sure they will be immensely grateful.

With Halloween and Guy Fawkes parties & displays now over, I do hope you are all in good health & getting prepared for the festive season that is so very near upon us. I know I am, the excitement of the forthcoming celebrations spreads like bubbles to the end of my fingers.

As always, please keep in touch, & take care over those uncomfortable winter months. If you have any news or articles for the February Newslink you would like to share with other members please send direct to myself via Royal Mail or e-mail. A merry Christmas & a happy new year to you all xxx

From the Chairman

Hello everyone

No doubt we have all put our heavy duvets on our beds and turned up the central heating now the nights are drawing in. I know the rockets shake me up so I do hope we all looked after our pets on that certain night.



I really couldn't start my few words this quarter without a sincere thank you To Phil Burton (**have you seen that front page?**). He has most certainly made me think differently about fish fingers. Those of us who have met Phil at the Milford socials must have first hand knowledge of the positive approach he has to absolutely everything in life. We must consider ourselves fortunate to have Phil (amongst others not named) as a friend who conveys the very style by which the group will continue to flourish.

And so to Peterborough. Let me thank you all for finding the time, and for so positively supporting us, not only on the day but also throughout the year. Prof Wood very kindly agreed for us to video his presentation enabling us to update our FSP literature and better still; for it to be available on video or DVD. Ian Bennett has a few words on page 10 on how these are available. What a major success the four brain storming groups proved to be in the open forum session. Most certainly these smaller numbers made it easier for ideas to be offered; the Information Brochure being the best. I have to thank David Harris for his input here and draw you to his words on page 10 giving details on this.

For the current year I have already started collecting information with regard to securing grants. Primarily it would be nice to generate funds to assist in transport provision. The benefits taken from our group meetings must

be opened to those where this may be a problem.

It gets even better. I do hope you have had a chance to read *A Challenging Cycle Ride*. This has to be the golden opportunity for us to announce our charitable status, exploit the publicity and of course, to raise funds.

Needless to say, we must all actively ensure the group gives Richard our maximum help.

I am now the proud possessor of a disabled persons railcard. By the time you read this I will have enjoyed Ray Exley's social in York and will report back on how the journey went. I mentioned in my annual report the race between Ray and my region on who would get their social together first. YAR BOO SACKS he beat me.....well done Ray!

There are funds available. Please get in touch with any committee member if you would like financial help with mobility aids.

I very much look forward to meeting up with the southern members who will be attending Jane Bennett's Milford meeting on November 13th.

As always don't hesitate to give me a ring or drop me a line at any time.

David Pearce

Useful Information

R.E.M.A.P.

"Alleviating a disability often demands novel solutions matched to the precise needs of an individual. That's where R.E.M.A.P. comes in".

R.E.M.A.P. is a unique charity which for more than 30 years has designed, manufactured and supplied technical aids to disabled persons where there is no suitable commercial item. REMAP will also modify commercial equipment to suit the needs of the individual. Most importantly there is no charge made to the client.

This is possible because REMAP members work for nothing, often use unwanted or discarded industrial materials and sometimes get help from private and Government engineering workshops, apprentice schools, colleges of further education, polytechnics and similar organisations.

Remap is one of the UK's most cost effective charities and its engineers also think 'green' when it comes to choosing materials for the job. A lawn mower, defunct dishwasher or car parts will, in skilled hands, often become components of aids that open up new horizons for many hundreds of disabled people.

Many people with disabilities encounter problems in their daily lives, which cannot be solved with standard commercial equipment despite the increasing range available. It is this gap that REMAP fills, bringing engineering and other skills to bear on one off problems.

Please note, REMAP panels meet regularly to consider referrals which usually will have been notified to them by occupational therapists, charities concerned with disablement, people with disabilities or family members on their behalf.

There are REMAP panels all over the country, if you require more information you can contact the REMAP head office at:

Hazeldene
Igtham
Sevenoaks
Kent
TN15 9AD

Alternatively, you can visit them online at info@remap.org.uk

Radar Key

Radar (The Royal Association for Disability and Rehabilitation)

If you are not already aware, and you are registered as being disabled, you are entitled to a Radar key. This key entitles the holder

to use disabled toilet conveniences, throughout the world. As many of us are probably aware, central town centre communal toilet facilities are not always clean, tidy, or by all means appropriate for our needs. This key is available from Radar or your local council (I was advised that the reason for these keys being issued was because of the increase in the vandalism of public conveniences). I found the staff to be very helpful and informative, and all they will require from you is identification confirming your disability. I have found this key invaluable, especially when travelling long distances, as unless you have a Radar key you will find almost all disabled toilets are inaccessible (especially at night). You can contact Radar at:

12 City Forum,
250 City Road,
London
EC1V 8AF

Tel: (020) 7250 3222
textphone Tel: (020) 7250 4119
fax (020) 7250 0212
To order a key online e-mail:
radar@radar.org.uk

How Will You Keep Warm At Home This Winter?

The Warm Front Team is a Government funded scheme managed by Powergen Warm Front to help people in receipt of income or disability related benefits to improve the insulation and heating in their home.

To keep well during the winter, it's essential to keep warm. As the weather gets colder, we are all more likely to catch colds or flu; and if your body temperature drops then the risk of a heart attack, stroke or breathing difficulties increase. This is especially true if you are vulnerable as most of us are to a physical disability. Moving around generates extra body heat, so any kind of activity will help to keep you warm.

- *Don't stay sitting for long periods.*
- *Spread chores out through the day so you can alternate between rest and activity.*
- *Moderate exercise, such as walking (even around the house), has real health benefits. Try to keep your exercise up in winter, without taking risks in wet or icy weather.*

The Warm Front Team Grant Scheme (WFS) was launched on 1st June 2000 and is available to households in England in receipt of a qualifying income-related or disability benefit. Grants are available from the Government's WFS scheme to help people with the cost of making their homes warmer.

Warm Front Plus Grant

Grants of up to £2,500 are available to cover the cost of insulation measures such as loft, cavity wall and draught proofing and where appropriate installing a central heating system in the main living areas. To be eligible, you must be aged 60 or over and in receipt of an income related benefit, own your own home or live in private rented accommodation.

Warm Front Grant

Grants of up to £1,500 are also available for households if you are in receipt of a qualifying disability related benefit; or if you have a child under 16 living with you, or are pregnant, and the householder receives a qualifying benefit. Please note that Scotland, Wales and Northern Ireland have their own separately funded schemes. The scheme is run by two managers from the Warm Front Team and the Eaga Partnership who can help make your application, and arrange for the work to be done.

Local Council Grants

If you have a low income, your local council may be able to offer financial help for:

- House renovation and improvement, including insulation.

- Installing disabled facilities that help people to live independently in their own home.
- Home repair assistance for small work.

The grant will vary according to the cost of the work and your own financial circumstances. If you are successful in qualifying for any of the above grants you will also receive practical energy efficiency advice from Powergen's Home Energy Advisor who will give you information on how to help you reduce your energy bills. If you apply for a grant, please note, do not start any work before your grant is approved, as this will not be refundable if your application is denied.

To Apply

Phone the Warm Front grant line **free** on 0800 952 1555.

Write to the Warm Front Team **free** at:

Powergen Warm Front Ltd,
Freeport
ANG20756
Milton Keynes
MK9 1BR.

Online at:

www.powergen-warmfront.co.uk

Please note, if you rent your home from your Local Authority or Housing Association you are not eligible for free heating or insulation measures from the Warm Front Team.

Prescriptions

Pre-Payment Certificates

If you are not entitled to free NHS prescriptions on age, medical, maternity, low income, or benefit grounds Prescription pre-payment certificates can help you with health costs. The PPC covers any item prescribed by a doctor on a NHS prescription, including elastic hosiery (as well as support tights supplied by a hospital).

They last for

- 4 months, costing £33.40 or
- 12 months, costing £91.80

There are no provisions to pay in installments; the full fee must be paid in a lump sum. The prices usually increase on 1st April each year, therefore, all applications received before 1st April will be charged at the old rate, and those received after the 1st April will be charged at the new rate.

You can apply either:

- Over the internet. To order a PPC via the website visit www.ppa.org.uk
- By having your credit or debit card details ready and ringing the order line on 0845 850 0030; or
- By completing form FP95, which is available from pharmacies and doctors surgeries or by going to <http://www.dh.gov.uk/assetRoot/04/05/02/72/04050272.pdf>

and sending the completed form to:

Prescription Pricing Authority
PPC Issue Office
PO Box 854
Newcastle Upon Tyne
NE99 2DE

At a pharmacy registered to sell PPCs. A list of all the pharmacies that are registered can be found via the website home page.

Anyone who needs more than 5 items on prescription in a 4 month period will save money with a 4 month PPC. Anyone who needs more than 14 items on prescription in a 12 month period will save money with a 12 month PPC.

Exemption Certificates

Anyone with a specific medical condition should apply for an exemption certificate on Form FP92A, available from pharmacists, hospitals or G.P's. This form should be completed and handed to your G.P who will then send it off.

A client not in this category may still qualify for free prescriptions and dental treatment

on low income grounds, this is for people who are just above the income support level. HC1 forms can be obtained from post offices, doctors and Health Helpline tel: 0845 850 1166.

Disability Living Allowance

Disability Living Allowance is a tax free social security benefit that you may be able to claim if you are under 65 and have a long term health problem, mental or physical, that affects your everyday activities. Disability Living Allowance is for people who may need help with getting around, or help with personal care, or help with both of these.

Vital

Do get assistance with completing D.L.A application forms from your local Citizens Advice Bureau (some bureaux have a home visiting service). D.I.A.L (Disability Information Advice Line) is another organization who may be able to assist with the completion of the application form.

Disability Living Allowance is not means tested at all, however there is a disability premium attached to Income Support. To claim, you have to send a copy of your award to Income Support and D.W.P should back date any extra money to the D.L.A award date. Recipients of child tax credits should inform the Inland Revenue of their D.L.A award as they should be entitled to a higher premium.

Normally, you can only get Disability Living Allowance if you have needed help for 3 months, and you must be likely to need help for at least 6 months after you claim. You can still claim Disability Living Allowance even if you do not actually get the help you need. You can claim even if you live alone. And you can claim even if you are working. You must normally be living in Great Britain and have lived there for 26 weeks in the 52

weeks before you claim. Great Britain is England, Scotland and Wales.

You may be able to get Disability Living Allowance instead of Attendance Allowance for personal care if you claim anytime before your 65th birthday. After the age of 65 you will need to be claiming Attendance Allowance. However, if you are already in receipt of Disability Living Allowance before the age of 65 you do not need to make a claim for Attendance Allowance. If you are claiming for someone under 16, there is a special claim pack for children.

Carer's Allowance

If you are claiming the middle or high rate of the care component of Disability Living Allowance and there is someone looking after you for 35 hours or more a week, they may be able to get Carer's Allowance. See form DS700 for more information which you can get from your Jobcentre Plus or social security office. If someone thinks they may qualify for Carer's Allowance they should not delay putting in their claim, even if your claim for Disability Living Allowance has not been decided.

Many people, including some doctors, care workers and Department of work and Pensions staff, pass on information and opinions about Disability Living Allowance that aren't correct. So, no matter what you've been told before, here are 12 things that don't affect your right to claim Disability Living Allowance.

- You're getting any other benefits - Disability Living Allowance will be paid on top.
- You're working.
- Your partner works.
- You have savings.
- You have not paid any national insurance contributions.
- You don't consider yourself to be disabled - Disability Living Allowance is for people with long term health

problems which affect their everyday activities.

- You've been told by a doctor, nurse, care worker - or anyone other than a welfare rights worker - that you won't get Disability Living Allowance. Eligibility for Disability Living Allowance is a legal question, not a matter of medical - or any other - opinion.
- You live alone and no-one is providing care for you.
- You already have someone, a partner for example, providing care for you.
- You don't want anyone to provide care for you.
- You've been turned down before. Once you've looked at the information in our guides about completing the claim pack and providing supporting evidence, you may decide you could put forward a stronger case if you applied again.
- You do not want to spend money on personal care: you can spend Disability Living Allowance on anything you wish.

How Much Will I Get?

Only use the amounts shown as a guide. The rules for benefits mean that your individual circumstances may affect the amount you can get. This means you will not always be able to work out exactly how much you will get by using the figures detailed below.

Weekly amounts:

Paid because you need looking after (care component)

Highest rate:	£58.80
Middle rate:	£39.35
Lowest rate:	£15.55

Paid to help you get around (mobility component)

Higher Level	£41-05
Lower Level	£15-55

I am already getting it so what happens if:

I go into hospital or someone I claim for goes into hospital?

You must tell your social security office as soon as you go into or come out of hospital. You must also tell them if someone you get benefit for goes into or comes out of hospital.

Nothing will usually happen to your DLA straight away.

After 4 weeks

If DLA is paid for someone aged 16 or over, it will usually stop.

If you go into hospital and benefit from the Motability scheme, the part of your DLA that allows you to get Motability may continue until your Motability agreement ends.

After 12 weeks

If DLA is paid for a child under 16, it will usually stop.

Disability Living Allowance renewal claims

Some disability living allowance awards are for an indefinite period, but most last for a fixed period: three years for example. However, most neurological conditions get an indefinite award. The letter you receive informing you that you have been awarded DLA also tells you what period the award covers. Before your award runs out you should receive a renewal claim pack to complete and return, if you don't do so your award will not be renewed. When completing renewal claims, always ask D.W.P for a copy of your previous award papers. A brief guide to DLA renewal claims is available from:

www.benefitsandwork.co.uk/benefits/detailed/renewals.htm

To get more information or leaflets, get in touch with [your social security office](#).

A confidential telephone service is available for people with disabilities, their representatives and their carers. Ring the Benefit Enquiry Line (BEL) on:

0800 88 22 00.

People with speech or hearing problems using a textphone can dial:

0800 24 33 55.

The person taking your call will not have your personal papers but will be able to give you general advice. This advice must not be taken as a decision on any matter about which you are making an enquiry.

You can also get leaflets and forms from the Benefit Enquiry Line.

Any queries regarding D.L.A please contact Stephanie Flower (Helpline) who works in this field at her local C.A.B office.

Directgov

The government is making it easier for you to access information and services through a website called Directgov. It provides information for disabled people and carers of all ages in areas such as employment, independent living and rights.

Trains and Trams

Rail Pass

British Rail has a Disabled Person's Railcard. It costs £14 a year.

To get the railcard you must be blind or visually impaired, deaf or have epilepsy, or you must get Attendance Allowance, Severe Disablement Allowance, War Pension Mobility Allowance or DLA (higher or middle rate). With the Railcard, you can get 1/3 off the cost of a standard train fare.

To apply fill in the form "Rail Travel for Disabled Passengers" which is obtainable at railway stations nationwide.

A senior Rail card for the over 60's is also available holders of which receive 1/3 off the cost of the standard rail fare.

Disability Bus Pass

You can get application forms for the Disability Bus Pass from travel information centres (at the bus station), libraries, doctors' surgeries and from Centro. The form is also available in Large Print and audio tape.

These bus passes give you half-price travel on the bus from 9.30 am to the end of daytime service Mondays to Fridays, and all day on weekends and bank holidays.

There are 2 new *Extra tickets* that can be used with the new pass:

The first allows free travel on bus, train and Metro in the West Midlands from 9.30am. - This will cost £21.30 for four weeks or £232 for 52 weeks.

The second *extra ticket*, the 'Extra Plus' allows travel at all times, seven days a week, and will cost £24.40 for four weeks or £265 for 52 weeks.

There is a Centro helpline to tell you about the new scheme or to get an application form telephone 0121 214 7979.

Shop Mobility

Shop Mobility is a scheme to make shopping easier for people with mobility problems. When you register you must take a simple test. Once you register, you can park your car and rent an electric wheelchair or scooter, to shop around town.

The cost is 50 pence for the first hour, and 25 pence for each hour afterwards.

To register you must have i.d. including your address and a photo, and evidence of your exact weight.

For more information contact:

Shopmobility
12 Cleveland St.
Wolverhampton

Telephone/Minicom (01902) 556021 who will advise you of your nearest outlet.

FSP Information Booklet

At our recent AGM a suggestion was made by one of the workgroups that we collect all the tips and information from the Newsletters and publish it as a single source of information. We've taken up that idea and the booklet is already well into production and will be published in the next few weeks - so look out for it dropping through your door!!

David Harris

FSP Presentation available on Video/DVD

The FSP presentation delivered by Professor Nick Wood at this years AGM is now available to members on video or DVD. The cost is £5 per copy, £4 of which will be donated to group funds, and anyone requiring a copy should send a cheque made payable to "The FSP Group" to: Ian Bennett, 37 Wimborne Road West, Wimborne, Dorset, BH21 2DQ. Please remember to state whether you require a video or DVD.

A challenging cycle ride

As a recently discovered nearly fifty years old FSP affected gentleman, I was pleased to learn that the FSP Group is trying to become a charity. I am very fortunate to be very mobile and reasonably fit and think it would be an interesting fundraising idea to Cycle the length of the country from Land's End to John O'Groats!

This is something that I've wanted to do since my childhood but, since now I have FSP, I need to do this soon. My plan is to build up my fitness, so that, in early Summer 2005, I complete this sponsored cycle trip for the FSP Group. I hope our Group will have succeeded in becoming a Charity by then and this could assist in bringing in funds and publicity for a newly formed Charity. It

will also give me the opportunity to visit many members up and down the country.

A great way to exercise

For the last forty years or so I have enjoyed cycling and now that late onset FSP has started, I find cycling my best and easiest way of exercising. My late father used to say to me, as an undiagnosed FSP sufferer, "As I get older I get stiffer and stiffer" and I am now beginning to fully understand the magnitude of what he meant! I find that strapless toe clips help me keep my feet on the pedals and the only issue I have is that my back can ache when I climb up steeper hills. I hope this can be reduced by me raising my fitness and to assist this further I am looking towards using a different bicycle design that will enable me to cycle with a straighter back. My current thoughts are to use a Dursley Pedersen (a hundred year old upright design with a slung saddle (<http://www.dursley-pedersen.net/>) or a recumbent tricycle, perhaps the German AnthroTech machine (http://www.anthrotech.de/Info_e/index_e.html). The tricycle will have better capacity for carrying bags but, my primary concern for this long trip is comfort and I will need to test the effect of a long day of cycling on both sorts of cycle.

Can you help

Would you as an FSP Group member be able to help me during this trip? No route has been planned yet and my route could be adjusted so that I could visit you on the journey. I hope to be able to travel at least fifty miles a day with an occasional day of rest during this expedition. An outline route might take me via Penzance, Truro, Padstow, Bodmin, Bude, Barnstable, Tiverton, Wells, Bristol, Gloucester, Cheltenham, Worcester, Kidderminster, Wolverhampton, Stafford, Stoke-on-Trent, Congleton, Cheadle, Worsley (my parental home), Haslingden, Nelson, Skipton, Kirkby Stephen, Penrith, Carlisle, Moffat, Glasgow, Callander,

Pitlochry, Aviemore, Inverness, Thurso and Kirkwall.

This is a flexible route outline that is only a first draft and not intended to indicate the overnight stops but will give you an idea of where I could be travelling. If you would like to meet me or offer me accommodation next summer, please contact me as this could alter my route planning. If you live like me in the East or Wales I apologise that I won't be passing but please if you can any sponsorship would be gratefully received.

I can be emailed at: rushour@gn.apc.org or alternatively call me on my mobile: 07748111868.

FSP Support Group Committee

During the AGM, the committee was both restructured in accordance with charity commission requirements, and new appointments were made. The new committee structure is shown below.

Group Secretary

Nigel Bulbeck

Nigel was nominated as secretary at the AGM, a role that is not unfamiliar to him, as for much of last year Nigel has been assisting David Pearce with certain secretarial duties. Nigel is very keen that the group expands and makes positive moves that will help future generations with FSP. In addition to financially helping members with equipment purchases, he is very keen on funds being raised for research.

Nigel lives in Farnham, Surrey (region 1), and can be contacted on 01252 728095.



Chairman

David Pearce

David has been Group Secretary since 2000, but has now been elected as our Chairman. In addition to his duties as Group chairman, David is also concentrating on supporting area coordinators with their duties in increasing Group awareness, and conducting local meetings. Investigating methods of fundraising is another area David is focusing on. David lives in Ilford, Essex (region 2), and can be contacted on 0208 551 2905.



Treasurer

Mike Fawcett

It was no surprise when Mike was reelected as Group treasurer. Mike was a founder member of the group back in 1991, and has made a meticulous job of being our treasurer ever since. Along with David Pearce, Mike has been a key figure in organising Group meetings. Mike lives in Skipton, North Yorkshire (region 10) and can be contacted on 01756 795480.



Membership Secretary

Ian Bennett

Ian has been assisting the committee for much of last year. He was nominated for the role of membership secretary on account of these efforts. Ian is to be the first point of contact for any member issues, and consequently is very happy to be called at any time. Ian lives in Wimborne, Dorset (region 4), and can be contacted on 01202 849391.



Regional News

Region 4

On Saturday October 2nd, 11 members from region 4 got together for the 3rd West Country members meeting. As before, we were well accommodated by the Barn Owl public house, on the outskirts of Exeter. Region 4 members are now beginning to get to know each other, and I can happily reflect that the afternoon's proceedings now have more of a social flavour to them than in the past. When I drive west to Devon for, what I now hope will be a regular 6 monthly occurrence, I now feel I'm off to meet a group of friends. Yes, FSP and some of its associated problems are still discussed in detail, but there is also some general social discussion and banter. We were privileged on this occasion to have the company of our treasurer Mike Fawcett, from as far north as Skipton. Unfortunately Mike wasn't quite 100% on the day, and we consequently shortened the meeting slightly so that Mike could get back to his B&B for some rest. It was however great for region 4 members to have the opportunity to meet Mike, so thank you Mike for taking the trouble to attend.

Thanks to all who attended, and I look forward to meeting up again probably in early April.

Ian Bennett

Region 5

Following the request in the August newsletter for a volunteer to come forward and relieve Stephanie Flower of her role as temporary coordinator for region 5, Richard Williams has very kindly offered his assistance. From now on, Richard is to assist Stephanie with area coordinator tasks. Thank you very much Richard for offering your support.

Members' Letters

Gabrielle Cooper from Gloucestershire (region 3) wanted to share the following with us, regarding her attendance at the recent AGM in Peterborough.

Dear Friends,

I feel I must write to thank everybody who attended the meeting and made my journey so worthwhile. I learnt so much, and managed to meet some new faces as well as old friends. The meeting was opened by David who welcomed everyone who had attended, and apologised for members of the committee who had previous engagements or who were unable to travel to the venue.

As the group is applying for charity status, David explained that the structure of the meeting needed to be based on a more formal footing and after official committee business we all settled down to listen to the guest speakers.

First speaker of the day was Professor Nick Wood (our medical advisor) from the National Hospital. I was particularly looking forward to hearing what he had to say as when talking to others about the condition his name often cropped up. I was not disappointed! He updated us on how research about the condition is progressing and how its reoccurrence in future generations happens and what can be done to help alleviate the condition. He spoke clearly and concisely, explaining in layman's terms so that we could understand.

How refreshing not to be bombarded with scientific and baffling gene types!! Furthermore, Ian Bennett videoed the whole thing which members can now order and revisit at their own leisure.

The second speaker was Richard Sealey from the Wolfson Neurorehab Centre. He offered us a further chance to tell us about the role neuro-physio can play in maintaining mobility. He showed us a video in which one of our members, Eric, had been greatly

helped in improving his mobility by assisted exercise and the use of orthopaedic – type supports. The results were amazing and the difference to his gait quite dramatic!! Richard also asked us questions on how we keep ourselves mobile at home so he could pass on any valuable information to other physios who have had little experience with dealing with F.S.P.

Lunchtime provided the perfect opportunity to talk to other members about their condition and how they dealt with it in their everyday lives.

The final speaker was Karen Sullivan who talked about support available for the disabled in the workplace. This was followed by a very useful open forum where we discussed ideas on how to move the group forward. Suggestions included producing a simple but informative booklet on F.S.P., which detailed useful addresses and contacts to help us in everyday life. Also, a list of carers was initiated so that a support network maybe set up to help those looking after F.S.P. sufferers.

I left the meeting feeling positive and encouraged. I wish to thank everybody who made it possible and to Richard, (not Sealey) who gave myself and my mother a lift to the train station. I look forward to seeing you all at the next conference. Best wishes,

Gabrielle Cooper (region 3)

Mike Fawcett writes:

Early in the summer, Ian Bennett said that he would like to come to Skipton with a view to meeting my son, Ian, who had set up our web-site. I said that if he came up here for four days, I would then organise a little holiday for him showing him the attractions of Skipton and the nearby Yorkshire Dales. By the time our plans had materialised, the school holidays had begun, so Ian decided he would like to bring his wife Shirley, and two young daughters, Jade and Cara with him. After a bit of research, I was able to find the

best bargain in town for a family room, only £45 for the four of them to have bed and breakfast. It would not have been the place for me to stay however, as it had two flights of stairs to get up to the room.

Unfortunately, this B & B was full on the Saturday night, so what did Ian and his family do on a rainy August day? Camp! The mad so and so's.

The following day we went on a 1½ hour cruise along the Leeds – Liverpool canal. We had good views of the surrounding countryside accompanied by coffees and other refreshments. In the afternoon the two Ian's had their meeting discussing the web-site, whilst Shirley and the girls went swimming in Skipton's new pool and played in the nearby park.

On the final day we all went to Bolton Abbey where amidst the Abbey ruins, there is an 850 year old priory church, virtually on the banks of the river Wharfe. Having had a picnic lunch, we noticed the approaching black clouds, and the subsequent downpour made us think our Dales visitation was over. Fortunately, as quick as the weather deteriorated, it brightened up again, and we were able to continue with our planned activities.

We drove a couple of miles upstream, and parked in an area right by the riverbank, where there was a tearoom and visitor centre. I was able to hire an electric scooter to convey me along the footpath, which ran parallel with the river. Our destination was the Strid, which is a narrow gorge that the river rages through, and after ¾ hour of walking/scootering, we arrived, and found that our efforts had been very worthwhile.

While in Skipton, Ian and his family also managed to explore Skipton Castle, and experience the hustle and bustle of Skipton market.

So we had a wonderful weekend. It shows that friendships and experiences can be developed thanks to our Support Group.

New Members

We welcome the following new members:

Allyson Gibbs Mr Brian Lanham
Burgess Hill Alderholt
Region 1 Region 4

Emma Wyatt Mr Mark Pengelly
Eastwood Southend On Sea
Region 5 Region 5

Mr Tony Grogan Mr Terence Reed
Liverpool Wrexham
Region 9 Region 9

Miss Deborah Best Mr Colin Dodd
Leeds Bradford
Region 10 Region 10

Miss Frances Williams
London
Region 2

If any members are interested in contacting one or more of the above new members, please contact the relevant area coordinator, who will be happy to supply their contact details.

Useful Contacts

	Email	Telephone No:
David Pearce - Chairman 8 Brinkworth Road, Clayhall, Ilford, Essex, IG5 0JS	pearcey david@yahoo.co.uk	020 85512905
Nigel Bulbeck – Secretary 38 Middlefield, Farnham, Surrey, GU9 8QA	nigel.bulbeck@allianzcornhill.co.uk	01252 728095
Sharon Gradidge - Newsletter Editor 20 Cedar Road, Eastleigh, Hampshire, SO50 9NR	gradidgefsp@aol.com	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	FSPgroup@aol.com	01702 218184
Ian Bennett – Memb Sec/Reg 4 co-ordinator 37 Wimborne Road West, Wimborne, Dorset BH21 2DQ	ian.bennett@tesco.net	01202 849391
Sally Langton - Group Awareness		0116 2700450
Audrey Town - Family Records		01484 861668
Jane Bennett - Regions 1 & 2 co-ordinator	luckyjane82@hotmail.com	020 88534089
Isabell Quinlan - Region 6 co-ordinator		01570 471062
Kathy Chambers - Region 7 co-ordinator		01142 960619
Pattie-Raven Chapman–Region 8 co-ordinator	pattieraven@chapman406.fsnet.co.uk	01427 728495
Carol McGowan - Region 9 co-ordinator		0151 2892597
Ray Exley - Region 10 co-ordinator	rayexley@aol.com	01904 626799
Liz Ferguson - Region 11 co-ordinator		01415 779695
Rachel Taylor - Genetics Nurse (Nat'l Hospital)		0207 6762196

Minutes 2004 Annual General Meeting - Peterborough

The meeting began at 10 50am.

David began by welcoming everyone to Peterborough and especially those who had travelled some distance to attend. The following new members were especially acknowledged as those present could well remember their own feelings when attending a first group meeting; Terry Reed, Colin Dodd, Deborah Best, Joy Utting, Keith Hargreaves and Pattie-Raven Chapman.

In line with Charities Commission procedures Mike Fawcett asked that a temporary chairman be selected (the meeting could not proceed further without one) and for this to operate only until the formal appointment of 2004/2005 posts as indicated in the meeting agenda. David Pearce was appointed.

Apologies for absence were received from the following committee members: Stephanie Flower and Sharon Gradidge.

Apologies for absence were also received from the following: Jane & Michael Bennett, Iris & Ron Hamblin, John Flower, Martine Ashford, Carolyn Crawford, John Moore, Lynne, Steve & Alice Parsley.

The total attendees would have exceeded 80 (our largest number yet) had circumstances not intervened.

A show of hands was asked in order to adopt a new constitution in readiness for our initial approach to The Charities Commission. A basic model enabling us to fine tune our specific current needs and modify as experience dictates, was made available for all to view. Ray Exley asked how this new constitution varied from its predecessor. David advised the new constitution simple echoed our existing structures but added additional aspects in terms of accounting and management controls of a small company. The committee now have clearly defined and accountable responsibilities, essential for the expansive programme ahead.

The Minutes of the September 2003 AGM were available in The Annual Report & Accounts document given on arrival. It was accepted these were an accurate and true account and agreed as thus. There were no matters arising.

Group Secretary's Report

David highlighted just how busy the year had been. The input made by Ian Bennett in new members' activity was now freeing David's time for other activities. More of the holistic values within the group's sphere of activity could now be addressed. David confirmed the plan to increase those members involved was coming on stream. There are now 16 individuals either on the committee, area Coordinators and their helpers, and those on special projects ensuring a very positive future.

David very much hoped to be spending more time on grant applications. Where availability of suitable transport had prevented attendance to meetings by members we could encourage contact with local community transport schemes for which funding could be made available. The special benefits of our meetings must be made more accessible.

Suggested projects for the coming year were detailed in the Annual report for which time had been made for discussion in Open Forum later. As always we must ensure our activities are needs led

The role of coordinators is becoming more clearly defined. Operating proactively they are helping members' integration, feeding back useful information and most certainly increasing our awareness whenever possible. Two or three people all working together would seem to be ideal.

The first approach to the Charities Commission is planned within the near future. This will most certainly open up many doors for the groups' future plans. We can most certainly look with pride at our present position; however it's where we are in two/three years' time that is going to be interesting.

David thanked Sharon Gradidge for her dedicated input as our newsletter editor. David also expressed his gratitude to Vanessa Lanham (daughter of new members' Brian & Betty Lanham) for her generosity in volunteering her professional experience and skills in improving the newsletter. His appreciation was also expressed to everyone for their continued encouragement and help throughout the year. Attention was drawn to the relevant sections in the Annual Report which could be read at leisure.

Financial Approvals

- 1) It was approved there would be no change in subscription levels in 2004/2005.
- 2) As there is a reasonable surplus of funds it was decided that the group would purchase some suitable computer hardware to assist in the more efficient production of the Group's publications.
- 3) Our aim this year is to reduce administrative costs.

Mike Fawcett - Treasurer

Treasurer's full report can be seen on page 9 of the Annual Report

Helpline & Newsletter Editors reports are shown on page 11 of the Annual Report

Appointment of Committee Members

Nominations were received as follows:

Chairman	David Pearce	(seconded by Richard Williams)
Secretary	Nigel Bulbeck	(seconded by Carolyn Harris)
Treasurer	Mike Fawcett	(seconded by Petula Baker)
Mem Secretary	Ian Bennett	(seconded by Eric Spalding)

The above posts stand for one year.

There were no proposed resolutions.

There was no other business.

THE MEETING CLOSED AT 11.40AM