



FSP Newslink

The Newsletter of the Familial Spastic Paraplegia Support Group

Issue 2 – February 2005

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

Learning to live again

I'd like to start my story with memories of my school years. Sports sessions were a dread for me. I was no good at sport and had weak ankles, as simple as that. Leaving school, employment, nights out with friends, I began the next stage of my life.

I experienced falling down; over a match stick it seemed, in a swift movement, but strange as it was that was me. I was pretty normal I thought and at the age of 25 I was married with the loveliest daughter. After her birth my life began a new route, roller coaster style. My legs became stiff making walking difficult, with this my marriage broke up, there was no connection, it was a very traumatic split. My walking deteriorated further to which I was then involved with Doctors, Specialists, and test after test.

Natalie was 3 years old when I was finally diagnosed with FSP. What the hell was FSP I thought, I no longer felt normal, and became a freak. I have been blessed with the support from my parents and my older brother Stephen. Such a lovely daughter I have, but my world had now turned upside down. I felt alone with this progressive thing.



Good friends, Christine Snow (left) and Deborah Best from region 10. Christine wrote this article and Deborah has written an article on page 6.

I attended my first AGM in Birmingham and I learnt a lot about FSP, it was a brilliant meeting. However, I saw a very bleak picture of how my life could become. I became terrified therefore I didn't attend another meeting for a number of years. I hated myself and so with depression, went into a shell. Bringing up my daughter, trying to be positive for her was difficult. I struggled on until I then went to some more AGM meetings. This is in the last four years.

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With 2004, came the Sheffield meeting where I met Ian. He was so very helpful, full of support and advice. At the Peterborough AGM I met Debbie. We had a bond almost instantly. We were totally in tune and on the same wavelength. I suppose you could say I woke up, or it was a kick up the bum. I felt my shell opening up, what a relief and a shock.

My friends and family look at me, not my wobbly walk. I'm not happy to have FSP, but things could be worse. I laugh as I write this, but I treasure Ian and Debbie and wouldn't have met them if it weren't for this FSP thing. AGM and regional meetings have allowed me to meet new friends with wonderful personalities. All sharing the same traumas, dreams, shocks and reality that FSP brings, and it's this sharing that has enabled me to live again.

Christine Snow

Editor's Column

By Sharon Gradidge

Well as we are now into February, can I be the last person to wish you a happy New Year! For any of you stuck with no New Years resolutions, please consider writing an article for the newsletter, no matter what you want to talk about, it would be great to hear from you (especially if you have a humorous tale to tell). I hope you all had a lovely Christmas, enjoyed lots of seasonable nibbles & didn't put on too much weight. We ate out again for the second year running. It was nice especially with regard to having mobility problems and get up in the morning and just relax and let someone else spoil you.

I do apologise for my column not being so long and cheerful as normal but my Christmas was very saddening as I lost my darling mum the day after Boxing day. I would just like to say a immense thank you to all my fellow committee members especially Steph Flower and Jane Bennett but likewise Ian Bennett for helping me with

producing the Feb Newslink at this difficult time in my life along with region coordinators who have always been there for me when I have needed to talk and needed a listening ear. Sometimes it's more amiable to talk with people who are not directly involved in the circumstances, and I thank you all for your support from the bottom of my heart God bless you all.

Take care, and best wishes to you all x

From the Chairman

Hello everyone and belated as it may be let me wish you all a happy and a prosperous New Year.

In last quarter's newsletter I promised I would update you on my first assisted railway journey. It helped to have a very specific purpose (Ray Exley's social in York and what a great time we had) for making this journey not withstanding some considerable ear bashing and encouragement from Mike Fawcett. The benefit of firstly registering as a disabled traveller and using the assisted travel service, is that your presence is monitored by staff throughout the extent of the journey. I deliberately used my wheelchair as a clear indicator of a disability but would still have received the same care had I used my normal aid, my tri-walker. Well, everyone met and transported me on lifts to platforms, with ramps to get me to my next train exactly on time with both efficiency and courtesy. Mike and I enjoyed a lovely day at the National Trust site at Fountains Abbey prompting me to join and most certainly to visit other sites throughout the coming year, especially as I no longer have concerns on using the railway network.

Having produced our first formal Annual Report in September last year, it became evident that the distance between our year-end on the 30th April and the AGM held in September is too distant. Consequently it has become necessary for us to move our AGM date forward to June. I do hope this

will not inconvenience too many of you. Indeed there may be a benefit for some of you where commitments in September have previously prevented your attending. After a most rewarding day I have chosen The Conference Suite within the Sports Stadium on The Stoke Mandeville Hospital site for **Saturday 25th June**. The stadium is the national centre for wheelchair sports. Their facilities include a gym, sports hall, swimming pool and athletics track. The centre has residential accommodation priced at £42 for a double room. We have reserved 10 rooms for 24th and 25th June for anyone who wishes to stay.

These rooms are en suite, with full wheelchair access. Continental breakfast can be provided at an extra £3.50. This accommodation can be reserved on a first come first served basis. Please let Emma Warren on 01296 484848 know, if this is of interest. There is however an abundance of alternative accommodation in the town. I'll have complete details nearer the date. Parking facilities are excellent as you might expect.

Since this is the once a year occasion when we meet en masse as it were; we are going to experiment with just two speakers enabling us all to share a greater part of the day together. If of course there is a particular issue you would like us to address (anonymously, if you wish) please let me know in advance.

Don't forget Richard William's cycle trek this Summer (see Richard's comments on page 6). Once we have more details I'll be speaking to those coordinators en route to see just how we can help and of course maximise the publicity. Some really good news. Our application for charitable status was submitted on 4th February and all we can do now is wait for further instructions.

A reminder; if you are seeking to purchase mobility aids etc and would like some financial assistance, Ian Bennett or Nigel Bulbeck will be pleased to send you a simple

application form to complete. On a similar vein we are happy to fund socials, ultimately though it seems with a small contribution and a raffle they can be self funding. My thanks to Stephanie and her team for the proposed get together in sunny Essex.

Last but not least, congratulations to those of you who have successfully sought review to your DLA entitlement. Over time we all compensate as our condition changes. Might it just be the time for you to take a look at page 13 of the information brochure?

As always don't hesitate to contact me at any time. Lets have a really big turn out on the 25th.

Bye for now

David Pearce

“Hello, FSP helpline!”



Hi Everyone, I am Stephanie Flower (alias Marg.Proops!) and I have run the helpline since 1990.

I am a qualified counsellor and currently work voluntarily for my local Citizens Advice Bureau, part time. I also have FSP as do my 3 children, so when you phone me for a chat, I really do know what you are talking about. It is lovely to talk with so many of you and if I don't know the answer to your query I always do my best to help with the correct information, or point you in the right direction. I do not do problems only solutions. As many of you will agree it really helps to talk things through.

I wish you all a Happy New Year and hope you all had a lovely Christmas, I will be arranging a Social Meeting in the near future for all you Essex Guys + Girls and anyone else that may want to attend, please email me or give me a call if you are interested.

Regards to all,

Stephanie

(Not forgetting John & Frodo of course).

It's your Group

The Group has made great advances over the last 12 months. We are now working towards gaining recognition as a registered charity. The membership now exceeds 200. The web-site is currently under review to bring it more up to date and the newsletter is also undergoing a makeover. We would hasten to add that this in no way diminishes the great work that was carried out by our members on these two items in the past.

Whilst this is all great news, the Committee feels that it is very easy for them to get carried away in the excitement of all the change and forget about our most important commodity, YOU, the members. We (The Committee) would like you to contact us and give us your thoughts on the Group. Are there things you would like us to do that we are not at this moment in time? Do you have any view on the future of the Group and its direction? Do you have any ideas that you feel we should be putting into practice? This in no way suggests that the Committee do not have ideas of their own, but this is your Group and we do not want to rush ahead leaving the members trailing in our wake.

We look forward to receiving your responses; written, e-mail, telephone; whatever you feel comfortable with.

Nigel Bulbeck, Secretary

Useful Information

Council Tax Reduction for Disabled People

You may be able to have your Council Tax reduced if a disabled person is living in the property; to get a reduction the property must confirm to the following guidelines. If you, or any member of your household, is disabled and your home contains:

- A second bathroom or kitchen required for meeting the needs of the disabled person
- A room set aside to provide facilities for the disabled person
- Sufficient room for the disabled person to use his or her wheelchair indoors

Then you may qualify for a reduction in your Council Tax bill. The amount of Council Tax payable will be reduced to the band below your property's band assessed by the listing officer of the Valuation Office Agency.

You can receive this reduction even if your property is in Band A.

A regular review of all reductions is carried out. If your circumstances change *you must* [contact us](#) immediately.

Further Information/Contact your local council or visit

www.gov.uk/housing/domesticcouncil

If you want more information about reductions for people with disabilities, then please [contact us](#)

[Council Tax Benefit](#) is available to help people meet their Council Tax liability. It can be awarded to people who have low income.

Help With Adobe PDF Files

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(www.adobe.co.uk/products/acrobat/readstep2.html).

For help on converting PDF files into HTML or ASCII text for improved accessibility, visit [Adobe® Online Conversion Tools](http://www.adobe.com/products/acrobat/access_online_tools.html) (www.adobe.com/products/acrobat/access_online_tools.html).

A number of our members now receive their quarterly newsletter by email, as an attachment in PDF format. If there are any further members who would be happy to receive the newsletter in this manner, please contact either Sharon Gradidge or Ian Bennett.

DIRECT-ENQUIRIES

On the home page at www.direct-enquiries.com/default.aspx you will find specific access and facilities and you can prioritise your search results by clicking on the various icons available. Available to you is an A to Z search, whether it's your local butcher, dentist, newsagent, or hardware store – in fact any business that sells to the public you will find an entry in Direct Enquiries. The more businesses and service providers that register on the directory the more choice disabled people, as well as their families, friends and carers will have.

If you have a favourite business or service provider, why not make sure that they register with Direct Enquiries. It only costs £35 per year per location and for every business that registers, up to £10 is donated to charity.

At Direct Enquiries, their goal is to provide the best possible service to disabled people and companies that cater for their specific needs and requirements. They welcome feedback because this will help them to identify what they are doing well and also highlight areas for improvement.

To leave feedback for Direct Enquiries online, please use the [feedback page](#).

If you would prefer to write to them, send your comments or questions to:

Direct Enquiries Ltd
Amber House
Market Street
Bracknell
Berkshire
RG12 1JB

Alternatively, if you would like to e-mail them, please select the appropriate address below. This will ensure that your query is sent to the correct department where it will be addressed quickly and efficiently.

To request more information please email us at this address info@direct-enquiries.com.

To make comments or to send feedback please email us at this address customerservices@direct-enquiries.com.

To talk to one of their team, please call 01344 360101. If lines are busy please leave your name and number and they will call you back.

Land's End to John O'Groats!

Here is an update in my plan for the cycle ride covering the country End to End. I will arrive in Cornwall on 9th June leaving Land's End on the 10th and I hope to be back on 24th June. This is the idea but my route is still evolving and I have yet to book any accommodation. This will be in Youth Hostels or in Bed and Breakfast depending upon availability and location.

Since the autumn I have been training at a gym to increase my fitness and I hope to be able to cover at least 50 miles every day. The distance is longer than the 800 road miles I had guessed and I expect it to be 1000 miles. Later this month I go to Scotland to pick up a 2nd hand Moulton APB bicycle which I have chosen to use for this trip. No doubt David Pearce will be talking to the coordinators on the routes through which I travel and any support from members would be gratefully received."

Richard Williams

Members' letters

Hello Readers.

I'm Deborah Best, one of the newer members of the FSP Support Group residing in Armley, Leeds, West Yorkshire Region 10

As a child I used to trip and fall quite a lot, but didn't think anything about this. I was not very good at P.E and games at school, I put this down to not liking it.

It wasn't until I saw one of the Registrars at the hospital, he asked me a simple question "What were you like at sport at school?"

I said, I didn't like it, He said why, **because you didn't like it, or because you couldn't do it.**

This seemed to give me a clearer picture of things.

I was first diagnosed with FSP 6 years ago after going through all the routine tests.

When I was told that I had FSP, like a lot more of you I suppose, said "what's that". I had all this explained to me and I then thought is there anybody else out there.

I sat down and tried to put things into perspective, and carried on the way I had done, until just recently when I visited my GP and he gave me the name of a lady at D.I.A.L. (Disability Information Advice Line), who pointed me in the right direction. We met and she filled out all the forms for me to be able to get D.L.A., details on the FSP Support Group, information on the Blue Badge scheme and various other concessions available to people with a disability. I can now tell you I have been awarded D.L.A., received the Blue Badge and a Concessionary Bus Pass for half fare bus and rail travel in West Yorkshire.

The greatest thing of all though was when I rang Stephanie Flower and explained my situation to her, she passed on my details to Ian Bennett who then contacted me and sent me all the necessary paperwork needed to

become a member of the FSP Support Group.

From there I attended my first Meeting, the AGM in Peterborough.

I wondered how I was going to get there, until Ian Bennett came to the rescue. He telephoned another member of the Group for me and we took it from there.

Through a couple of telephone calls, it was here that I met Christine Snow, someone else in exactly the same position as me and it was lovely not to feel lonely any more.

All this being new to the pair of us, we, as you can guess, had plenty to talk about, and not enough time to do so. We now have regular telephone conversations with each other. If one of us is feeling a bit down, we have each other to talk to and share our feelings.

Since Peterborough, Region 10 have had their own Regional Meeting, arranged by their Co-ordinator, Ray Exley at The Beechwood Close Hotel in York. The meeting went really well and was attended by:-

Ray Exley, Anne Sykes, Christine Snow, her Partner, Richard, Mark Tomlinson, the Group's Chairman and Treasurer, David Pearce and Mike Fawcett respectively, and last but no means least myself ("**Trouble**" as **Ray now calls me**).

I would like on behalf of myself and all the other members, to thank Ray for all the work he did in arranging such a successful first meeting, and hope that there will be many more to follow.

And finally, what more can I say than I am so lucky to have met such a great bunch of people.

"WE CAN BE THERE FOR EACH OTHER"

Adventures

We all need adventures from time to time. A target to aim for, a challenge to achieve, a boost to our self-esteem. My attitude is to do what I can and accept what I can't. I had got my flat more or less how I wanted it and had come to terms with being disabled. Now it was time for adventure.

In my case, it is travel. Not everyone's idea of a challenge, I know. So I took the bit by the teeth and planned my trip. And so I determined to go somewhere where I had NEVER been before, somewhere I probably would never go again. Where? South Africa, Cape Town, to be precise. Everything was a first, I had never been to the Southern Hemisphere, never been on a 747, had never flown and I had never been disabled before. I had quite forgotten how big Heathrow is.

Planning and preparation are the name of the game. I started planning (and saving) about a year before hand. A Tour Operator [not travel agent] did all the travel arrangements; I found a guesthouse and asked the Tour Operator to make all necessary payments on my behalf. The Tour Operator made certain that the Airlines knew that I would need assistance and everything was as 'clockwork'. I travelled alone, and found that assistance was first class. I had a marvellous time in Cape Town. I met nothing but courtesy and politeness from all South Africans, and was lucky enough to choose a guesthouse where the owners made me feel 'one of the family'.

Two things I learned from that experience:

- 1 never go in May if you expect summer weather (it's their autumn)
- 2 never hire a wheelchair out there, take your own, it's safer.

That was in May 2002, I've been back! I again went last year. This time, I went in February, just after the peak of their summer, and I took my own wheelchair

MUCH SAFER. The Tour Operator arranged the travel. I arranged everything else. There are some good people out there. Everyone was polite and willing to help me with whatever difficulty I had. (They all speak English, and they drive on the correct side of the road, hehehe) My guide, Brian was excellent and is now a fully qualified wheelchair attendant. Brian had spent a lot of time learning BSL for the deaf. He thought it amusing that one of his first clients could hear OK but couldn't walk. He soon got used to not hitting my feet against everything in our path, once we agreed that it would 'cost' him a beer each time he did so.

I had no idea what to expect as a disabled person, I'm so glad I did it despite my disability. I have been back since, I learned a lot about me, and how to relate to others, it was well worth the effort. All I can say is; **DO IT NOW.** Do it while you still can! Plan ahead, but DO IT. Those 2 journeys cost me a lot of money ... but nothing else would have replaced the experiences that I've had.

Ray Exley Region 10 co-ordinator.

Hawaii

Public transport companies are doing more to accommodate disabled travellers, but in many ways there is still a long way to go.

Whilst on holiday on Waikiki, Oahu, we were astonished by the commitment and consideration given to the disabled. There were many Kneeling Buses that lowered to kerb level. These buses had a hydraulic platform enabling scooters and wheelchairs to alight, but occasionally the platform and the kerb did not meet, so the bus was lowered.

Nothing seemed too much trouble. On one occasion a disabled traveller had moved onto the platform with her motorised scooter. She was at the wrong angle and could not reverse into the bus correctly. With that, the bus driver got out and helped. I'm not sure I have seen that level of consideration on London buses yet!

All toilets were for the disabled and kept to a very high standard. No priority was given to non-disabled people.

For those travellers with limited mobility, who don't travel with their wheelchairs and scooters, it is possible to hire a suitable 'vehicle' for the duration of your stay.

Understandably Waikiki is the main tourist centre for the Hawaiian Islands and does cater very well for the disabled. The other islands, which are not as popular with tourists, are not as well provisioned, but still offer disabled options when possible.

Mike and Jane Bennett

Regional News

Region 10 meeting Saturday 30th October 2004

Group 10 held it's first meeting on Saturday 10th October. Seven of us attended, along with David Pearce (the FSP Chairman). I had managed to book a buffet and room of our own at a local hotel. If I'd left the date any later, it would have clashed with 'Christmas parties'. The buffet was already laid out on a table before us, so we didn't need to carry a thing.

Once I had introduced fellow members to each other (some members had not attended a meeting before), David took over by posing a question and answer session. Various questions were raised in which some interesting results came out of this. It was clear that different people 'cope' with similar problems in different ways the reason for this I suspect, was designed to 'break the ice' and encourage people to have their say.

The purpose of the meeting was for those who had managed to attend to get to know each other. Possibly the best replies came after the question 'how do you cope with your disability'? Whereupon, most people had something to contribute, and more importantly, to realise that they were not

alone. This objective was achieved, so much so that members exchanged telephone no's and friendships made. Towards the end of the meeting, it had become obvious that there was a 'need' for these meetings and so, I have 'booked' a further two dates for 2005 (19th March and 15th October) just to test the water again. This time, I am hoping for more members to arrive! It was well worth the effort, if only to get to 'know' each other better.

Take Care everyone

Ray Exley region 10 co-ordinator.

Afternoon Tea Regions 1 & 2

We are always delighted to meet members who venture out to attend our Afternoon Teas, but especially the one held in November. Those attending the November meetings realise that their return journey will be in the dark and could be affected by unpleasant conditions. The weather and road conditions are of special mention as Regions 1 and 2 members have to travel from Kent, Surrey, Sussex Hampshire, London and Essex without our adopted members who join us from Dorset and 'deeper' Essex.

The afternoon Teas are very social events. There are always various opportunities to discuss the many aspects of FSP and catch up with other members. Open Forum, when topics can be discussed by all. Small groups comes when those Carers and family members who want to spend time together, go to another room enabling sufferers to have time to talk. The last part of the afternoon is given to Afternoon Tea, allowing for more friendly discussions.

This year we invited speakers. In April a Neuro-physiotherapist from 'Heads Up' joined us to talk about FES and this November we had a brief talk about benefits from Waverley Council.

We are fortunate in that between thirty and forty people join us each time.

The meetings evolve as areas of interest change and our membership changes. There is no agenda, only to ensure Carers have time together, with time for an Open Forum and the last hour available to take refreshments.

Mike and Jane Bennett

Region 7 co-ordinator

We are currently looking for a volunteer for the position of area co-ordinator for region 7, which covers Herefordshire, Shropshire, Staffordshire, Birmingham, Warwickshire, & Worcestershire. Anyone interested, please contact David Pearce on: 020 8551 2905.

For Sale

Pattie-Raven Chapman has a **red electric scooter** for sale. This scooter is in excellent condition, it has a basket at the front and is only one year old. Pattie is asking for £200. Pattie lives in Doncaster and can be contacted on 01427 728759.

Renault Scenic Dynamique 2 ltr petrol, Automatic in platinum.

Registered 31/3/2004

Extras on it include:

Multi cd player, metallic paint, cruise control, climate control, hands free card for locking & ignition, folding electric door mirrors & wired for mobile phone.

It has a Midi Hoist fitted.

9000 miles.

£14260.00

I am changing the car because I need something bigger so I am going for an Espace grande as I have been very pleased with my Scenic - it drives really nicely.

I am looking to sell during March.

For further details please contact Phil Burton on: 01903 503776

New Members

We welcome the following new members:

Helen Bowdler Ipswich Region 5	Mr Adrian Styles Testerton Norfolk Region 5
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Mrs Alison Brazier Pitsea, Essex Region 5	Mr Andrew White West Bromwich Region 7
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Debbie Mayhew Rochford Essex Region 5	Debbie Miller London Region 2
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Deborah Monnington Newton Abbot Region 4	Mr Derek Hodson Risca Wales Region 6
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Mr Martin Lawrence Cobham Surrey Region 1	Mrs Margaret Barr Hessle Region 10
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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.

Forthcoming events

Region 10 get together

March 19th Beechwood Hotel - York
Contact Ray Exley on 01904 626799 for further details.

Regions 1 and 2 Afternoon Tea

Saturday 16th April 3pm – 6pm. Milford Day Centre. Contact Jane Bennett for details.

Region 4 get together

Saturday 2nd April 3pm – 6pm. The Dartmoor Lodge Hotel, Ashburton, Devon. Contact Ian Bennett for details.

FSP Support Group AGM

Saturday 25th June. Sports Stadium on The Stoke Mandeville Hospital site

The Mobility Roadshow – Donington Park near Derby 7th, 8th & 9th July

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
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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.chapman@tesco.net	01427 728759
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