



FSP Newslink

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

Issue 3 – May 2005

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

“Registered and Rolling”

Being pleased to learn that the FSP Group is now registered as a charity and being mobile and reasonably fit I decided to Cycle the length of the country end to end from Land's End to John O'Groats to assist in this! This ride is something that I've wanted to do since my early childhood when I learned to ride on a small-wheeled Moulton bicycle. I have bought a modern replacement Moulton bicycle to do this! I have been building up my endurance and hope by early June to be able to manage this daily ride without too much exhaustion. Overleaf is a list of the places and dates of my trip. I also hope this trip will bring funds and publicity for the Group and I hope to be meeting the press during the trip at every opportunity.

Cycling I find to be the only suitable aerobic exercise that I can perform easily as the half toe-straps I use help me keep my feet on the pedals. Without these, I found my feet would slip off the pedals and I would endure much bruising and pain! This event is likely to be the last time I expect to be able to undertake such a long trip as I expect my muscle stiffness will prevent me being able to perform well enough to cover 50+ miles a day. The most frequent question I've had



Richard training for his forthcoming marathon

from sponsors is “What is your support organisation for this trip...?”. The answer is that I haven't really got one. I just have cycle repair & recovery insurance from the Environmental Transport Agency. This I can use for any real disasters but I must rely upon reaching my overnight stops unaided! I will stop during the day, but, on some days, as my mileage is very high, this won't be for very long!

Inside this issue....

Charity Registration! Page 2
Members' Letters Page 5

We hope to have a web site updated during the trip to show my progress and hopefully some photographs as I travel!

Thursday 9th June Fly to Newquay, a lift to Land's End then via Porthcurno to Redruth.

Friday 10th June Travel via Wadebridge & Camelford to Frithelstock.

Saturday 11th June via Wiveliscombe & Bridgewater to Clevedon (longest day this one!)

Sunday 12th June via Pill, Severn Bridge, Chepstow & Monmouth to Hereford.

Monday 13th June via Knighton & Bishops Castle to Shrewsbury

Tuesday 14th June via Market Drayton & Nantwich to Worsley, Manchester

Wednesday 15th June, rest day

Thursday 16th June via Lancaster & Kendal to Shap

Friday 17th June via Carlisle & Lockerbie to Moffat

Saturday 18th June via Larkhill & Glasgow to Bearsden

Sunday 19th June via Rowardennen & Cranlarich to Glencoe

Monday 20th June via Fort William & Laggan to Drumnadrochit

Tuesday 21st June via Dingwall & Bonar Bridge to Altnahara

Wednesday 22nd June via Bettyhill & Strathy to Thurso

Thursday 23rd June John O'Groats & on to Wick, sleeper train via Inverness to Euston

If you would like to sponsor me for this event, the simplest method is to forward donations to our treasurer, Mike Fawcett. Mike can be contacted on 01756 795480. Donations can also be made by visiting www.justgiving.com/fspgroupwcycle

If you have any questions, suggestions or offers of help or advice, I can be contacted on: 01603 821531 or email me at richard.williams@cw.com

Richard Williams

Charity Registration!

We began the journey to become a registered charity some 18 months ago. In those early days close relationships developed with numerous Helpline personnel at Charities Commission after which vast quantities of relevant literature were dutifully presented to our doormats by HM post office. In these days of gobalde goop we would happily congratulate The Charities Commission on the user-friendly style of all the literature we received.

Ultimately a presentation was pieced together responding in detail to all aspects of our operational procedures including accounting, minute keeping, executive committee structure, the newsletter, promotional literature and of course our 2004 Annual report. As with all things the care in making this first impression has most certainly endorsed our suitability for registration. At this very moment all stationery, the flyer and the information brochure are being updated show our number 1109398.

Members of the general public will now see our organisation with a significantly higher degree of accreditation, and consequently may be more inclined to donate funds where and when appropriate.

Our plans for the future include the sourcing of additional revenue by which the group can expand its core task; that is "To Support". Charitable status permits us to actively approach organisations to fund projects we could not have previously considered. Additionally claiming back tax on gifts and annual subscriptions together with legacy provision will become available.

We are currently registering with the Inland Revenue for the benefits of Gift Aid, and for this reason, membership renewal forms, which would normally have been despatched with this newsletter will be distributed with the August edition.

Editor's Column

By Sharon Gradidge

Hello again everybody, spring is in the air, everywhere you look around, and isn't it gorgeous. Belated happy Easter to you all and I hope the Easter bunny was kind to you all. "I don't know" getting over the Christmas indulgence is bad enough, then woe betide it's Mother's Day, then a month later the shops are full of chocolates and Easter eggs. Then guess what, two months after that the T.V. and media are full of holiday promotions, and most of us start thinking gosh I'd better lose some weight. Holiday time is here and many of us are daydreaming sun, sea, sand and relaxation. I anticipate most of you would have started thinking about or already have planned a relaxing summer break. I understand through speaking to several of our members fairly recently that many of you are worried about the difficulties that can and do arise (especially if journeying alone) all I would say is organisation and planning are the key elements for a well deserved worthwhile holiday. There are many organizations in relation to disability issues who would be more than willing to give you guidance that would enable you to take advantages of the benefits of freedom and independence and greater choice if they are given adequate notice before hand. For those of you that are taking a vacation have a superb time and spoil yourselves, you deserve it. You never know you could come back with some useful information that may help other members when planning their holidays for next year (take a glimpse at Petula Baker's letter page 6) or a humorous holiday tale, that could be included in future Newslinks. To draw to a close, I would like to say an immense thank you to those of you, who have, since Christmas, kept in touch, making sure I am still on planet earth so to speak. Your support and kindness have given me the inspiration to keep on track when at times I felt I was leading a two-dimensional life. As always, take care, and I hope to meet many of you at the forthcoming A.G.M.

Sharon x

From the Chairman

Dear all

I so much enjoy the lighter evenings when we put our clocks back the hour and Summer's warmth brightens the day. How very strange that once you settle down to a spot of telly you become cold....and put the heating back on. But then that's our fixation with the weather isn't it.

Well I'm sure you've read the good news on the first two pages, prompting us to delay this issue. I have to thank everyone and especially those who travelled some distance to Jane Bennett's social and the Special General meeting at which the amendment to our constitution was accepted. Having the opportunity to headline Richard Williams cycle trek and our new charitable status shows the group's positive ethos for all to see. At this very moment, approaches are being made with newspapers en route re publicity. Furthermore, we have recently registered with an organization called "justgiving.com", which has given us some very powerful fundraising opportunities. You can appreciate this for yourselves by visiting www.justgiving.com/fspgroupwcycle You will notice that this facility has already achieved great success in raising funds. Please feel free to email a link to this site to anyone you feel may be interested and supportive, whereupon they'll be able to donate online. I was certainly very surprised just how straightforward it is to utilise.

Some of you may be aware John Moore and myself have been sourcing suitable trust making bodies and how best to make application. As with all new things there is a learning curve. If you have any experience in this field we would be most pleased to hear from you. My thanks to Joy and Paul Utting for their information on gift aid etc.

Just a wee word re Conference and AGM. This year apart from one speaker the afternoon session is for us. When returning your booking if there is a particular subject you would like us to discuss let us know. Essentially there will be a selection of alternatives to choose from or simply just enjoy the company. Remember we have reserved accommodation on site so if this of

interest I suggest you get in sooner rather than later. The AGM is also your opportunity to make changes and improvements to the Group. Enclosed with this newsletter is a nomination form so if you feel strongly that we should have new blood on the committee and you have a suitable candidate in mind, then with his or her agreement please use the nomination form and return it to our Secretary. Also, if you have any resolutions to put forward, please make either the Secretary or myself aware of these as soon as possible.

As the group expands its membership and with additional funding we are most certainly needing to increase both the pertinent work skills and volunteers' time at this exciting phase in our development. I remind you of a few words that rather aptly sum this up..... "We need to make a larger footprint in the sand". If you have the time or the skills to contribute to this major move forward don't hesitate to contact me, your coordinator or any other committee member.

Most of you are probably aware that our website has recently been significantly improved, and huge thanks for this must be transmitted to Ian Fawcett (Mike Fawcett's son). Any member can make use of the site and all our newsletters are now accessible. However any members wanting to use the notice boards or view the latest newsletter must be given a username and password. Please contact Ian Bennett if you require a username and password, and once you are up and running you will have the facility to amend these details to something more personal to you.

By the time you read this, Liz & Ronnie Ferguson will have conducted their first (of many, no doubt) socials in Scotland on the 14th May. Well done to the two of them for their commitment to the Group and hopefully we can look forward to reading how well the afternoon went in the August edition. Last but by no means least, extra special best wishes from us all to Richard William's for a safe, fulfilling and successful Cycle Trek throughout June.

Dare I say it? Let's be having you all at Stoke Mandeville on the 25th June.

David Pearce

Useful Information

Disabled Go – www.disabledgo.info/

Freedom and choice for millions of people: Access guide information for disabled people.

Launched to mark the European Year of Disabled People, Disabled Go is an ambitious Internet service which will transform the daily choices available to millions of disabled people, their families and friends. Founded by 29 year old wheelchair user Gregory Burke and supported by Marks & Spencer and leading local authorities, this innovative service is opening up towns and cities across the UK. 8.7 million British People are disabled. Yet where are they? Only a fraction are out and about, working, shopping, relaxing and taking part in the day-to-day life of wider society.

A key reason is the great friction encountered by disabled people when attempting to access the shops, services and leisure facilities that the rest of the community takes for granted. Trying to go out for a meal, visit a dentist, travel by train, and find a solicitor or even pop to the shops all have to be researched before they are possible. There is no easy way to do it. If you phone a venue to enquire the person who answers is unlikely to be able to answer your questions, in fact people often become the subject of searching personal enquiries such as 'What is wrong with you?' or 'What can you do?'

As a result people lose confidence, withdraw and become excluded from family and community life. Society in general is inaccessible – shop and service owners and managers often don't realise that simple changes to the way they deliver their service could open up their business to many more customers. But crucially in a society which is generally inaccessible there is no way to find out what is accessible where you live or in a place you would like to visit. Disabled go is the answer to this problem. By providing free detailed access information Disabled Go can end this exclusion and return choice, independence and confidence to disabled individuals and their families.

Disabled Go access guides provide detailed and accurate data for people with hearing, vision or mobility impairments about access to shops, pubs, restaurants and offices - hundreds of goods and services providers in each town or city featured. People are able to search anonymously and decide for themselves whether a venue is accessible according to their own individual needs. Is a leisure centre accessible to a wheelchair user? Does a restaurant have a menu available in large print or Braille? Will a shop actually welcome an assistance dog? Does a hotel have a hearing loop and flashing fire alarm? Each venue has been visited and assessed.

With one in seven people disabled and the spending power of the disabled community estimated at £45 billion per year, the continued exclusion of disabled people impacts not just upon individuals and their families, but also on communities, society and the economy as a whole. Disabled Go is a tool which disabled people can use to end that exclusion and decide for themselves when, where and how they spend their time and their money. People can enjoy their lives, businesses can reach new customers and towns and cities can open themselves up to millions of disabled people, their families and friends.

Disabled go provides free detailed access information for disabled people across the UK. They believe that society disables people by not making goods and services accessible to all. Their detailed access information will empower you to judge for your self which hotels, cinemas, restaurants, solicitor's offices, pubs, train stations – all kinds of shops and services- are accessible to you. Their aim is to use access information to empower people to break down the barriers to full inclusion within the community.

Developed by disabled people for disabled people Disabled Go empowers you to make direct, anonymous enquiries about particular venues and judge whether they will be accessible to your individual needs. As a result, their guides will enable you to make up your own mind about what you would like to do today; to leave your home with a thorough understanding of the facilities and

levels of access you are likely to encounter and for you to decide whether a venue or service is accessible to you. Never before has local access information been provided in such breadth and depth. Best of all, thanks to our sponsors, this service is free!

Members' letters

Dear Sharon

I have just got round to reading the current copy of the FSP Newsletter and have been somewhat encouraged by Christine Snow's letter, realising that others are going through the same thoughts, feelings and emotions about the condition as I am. I have had the condition for some years and feel it is gradually getting worse. I recently had some physiotherapy and was prescribed Baclofen tablets. I felt the tablets made my legs feel more stiffer and rigid, albeit with slightly less discomfort. I stopped taking the tablets as I did not think they were doing any good. I note from a survey in a previous Newsletter that it would appear others have not got on with these tablets either. It would be interesting to know in what way others were affected. Reading the Newsletter at times, giving details of the problems being experienced by others can make one a little scared as to what the future holds. It would be nice to be able to meet and talk with similar sufferers. I realise there are phone numbers that you can ring, but it is not always easy talking to someone you do not know about your concerns. It is a shame that I live in an area that, as far as I am aware, does not have an active group. I must try to get a long to the next AGM. I did nearly make Peterborough, but had other commitments, which on reflection should have been put to one side. I lead a relatively normal and full life, at present although the condition restricts some of the things I can participate in. A lot of my friends enjoy long walks and ceroc dancing, but these are activities I can not take part in. I can still walk unaided, albeit rather unsteady but am limited to how far I can go. People keep telling me I should try for a Blue disabled badge, but I do not feel I would yet qualify for this as I can still manage to walk over a

mile before I start feeling uncomfortable. I think I try to ignore the condition as much as I can by keeping busy, holding down a full time job with the Local Council, a part time job selling match day programmes for Ipswich Town Football Club, playing in a Samba band and being Chairman of a singles social club. It seems clear, however, that I am not going to be able to continue as I do, lifting boxes at the football is becoming more difficult and I can no longer take part in processions with the Samba band, which form possibly 40% of our performances during the year. I try to remain positive and intend to carry on doing the things I enjoy for as long as possible. Reading Christine's letter has helped to put things into perspective and realise I am-not alone. It is too easy to consider all the negatives and feel dejected and it would be nice to hear from others about their thoughts, feelings and experiences, as I am sure it would help sufferers to understand more about the condition and learn how to cope with it easier. I found the information booklet, issued in December 2004, very useful. Keep up all the good work.

Kind regards

Peter J Gaskin.

Dear Sharon,

I do hope this reaches you in time for the May Newslink, if not maybe you could use it at a later date. With reference to our recent conversation with respect to the difficulties we may encounter when booking a holiday I thought other members maybe interested in how I managed to overcome a lot of problematic issues. Has anybody been cruising? Well I thought I would try a cruise this year, to celebrate my 50th and my 30th wedding anniversary. I have not travelled outside the U.K. much before, other than a couple of times to Cyprus to see my daughter, so was not prepared for the details needed to book a cruise. Eventually, we decided on a Norweign fjords cruise for 7/8 days. I wanted one from Dover/Southampton/Harwich or the like, not Scotland, or having to fly out first. Did we go for a large cruise liner, or would a smaller

one be better. Would they be able to get into port, would I be able to disembark in a wheelchair, or would manage it with help and using my walking stick. I then proceeded to contact many cruise specialists and sent for brochures. It was quite a learning keel, I was even told that one cruise liner had too narrower walkways to take a wheelchair, I found that hard to believe. After talking to lots of people and looking at brochures, I then realised, I had needed to book this holiday, the year before. There are only so many disabled people they are allowed to carry, due to health and safety regulations, and many people book a year or months in advance, so I am probably booking mine in the next month or so, for 2006. I found some good websites, mostly from the Woman's Weekly magazine, which are as follows. www.enableholidays.com, www.accessibletravel.co.uk, www.canbedone.co.uk, www.chalfont.co.uk, and lastly, there was an article about a couple on a Baltic cruise and they went with Saga. They found the crew very helpful and booked again before they finished their cruise. It seems if peoples needs are well catered for, then these cabins go very quickly. Saga Rose has two rooms with wheelchair access and Saga Ruby has seven rooms. So it makes sense to book as early as possible to get the greater choice. I do hope some of you will have found this information useful and informative, best wishes

Petula Baker.

Working together: FES & FSP

The department of Medical Physics at Salisbury hospital was invited to present at your AGM in Gloucestershire, a couple of years ago. A few of your members had been using the Odstock foot drop stimulator and thought that it would be of general interest.

Laptop and projector in hand I arrived at the venue to be warmly greeted by your chairman and set up the equipment. All started reasonably well until the screen went blank. Keys were pressed in panic to no avail. The planned session went out of the window and was replaced with an interactive

forum which seemed to generate a lot of interest.

Since that time I, together with clinical engineer Paul Taylor have developed an interest in FSP and particularly how FES can be of benefit. We are in the process of arranging a day for current Salisbury FES users to collect detailed clinical evidence. Gathering clinical evidence is important, as it is what the purchaser of a service requires to make an informed decision as to whether or not to pay for a person's treatment.

I am also trying to form links with the increasing number of regional therapists who are issuing FES to FSP affected people. Such links and the sharing of information can only lead to an improved service across the nation. Can you help by providing me with details of yourself, and the contact details of the therapist who issued the stimulator. I work Mondays, Tuesdays and Fridays and can be contacted on 01722 429119, or email me using the following address: cmf@salisburyfes.com. Alternatively, please provide Ian Bennett with this information, whereupon he will forward it on to me. All information will be treated in accordance with the data protection act.

Many thanks

Carol McFadden
Research Therapist

Regional News

Region 4 Get Together

"The East Dorset contingent of Region 4 set out for Exeter on a fine(ish) Saturday morning to travel to our regional meeting to be held this time on the fringes of Dartmoor National Park. We had an uneventful journey until we entered the small and (normally) peaceful village of Ashburton where we were amazed to encounter a couple of police riot vehicles and about twenty or so officers all in high visibility jackets.

There were several coaches parked in the village high street. It turned out that some coachloads of football supporters from Brighton were on their way to Plymouth for a match and had stopped off for a couple of

pre-match drinks...The police were there in number just to make sure order was maintained.

Best turn-out ever for our meeting - 22 members and family members turned up and the meeting went on until six pm, and probably would have gone longer, but we needed to clear the room. A lot of people were meeting new friends for the first time, and all were made welcome. There was a high level of conversation throughout the afternoon and everyone seemed pleased at the end.

Seven of us had decided to stay the night, so it was straight to the bar (all that talking makes one thirsty). The meal lasted several hours and we were last to leave the dining room! So there you are, we may be a small group in the far S.W. of England but we are making friends and passing on info to each other, which is making us feel less cut-off from the rest of the group!

David & Carolyn Harris.

Region 10 Get Together

Our second Region 10 meeting took place on Saturday March the 19th. 10 people were present, including Ian Bennett, our FSP Membership Secretary. The venue was the same as last time i.e. The Beechwood Close Hotel, where we once again had a buffet lunch in a room of our own. Although the meeting was in no way intended to be 'formal', we did discuss 2 items which concerned region 10.

1. The possibility of using an alternative venue, one which has a disabled loo.

I have located one, not far from where we meet already, and for the purposes of assessing it, have set a date for Saturday **20th August** in the hope that those who may have been reluctant to visit before, might try this venue out. It is The Dormouse pub on the A19 (north side) of York. It is hoped that the meeting will start at 12:00. I will be more than happy to send a map to those who would like one. There is a snag though (There always is). This venue is a popular mid-day pub and so, we will not be able to have a room to ourselves. A further

suggestion was that perhaps we ought to look at venues in other towns, for say next year. I would be grateful if anyone (in region 10) has any suggestions. York is a tourist town, and therefore, the venues charge 'tourist' prices whilst offering virtually no parking. (This doesn't apply to the venue that we have already used, nor the one I'm suggesting that we 'assess').

2. We discussed transport to the FSP AGM on Saturday 25th June.

We discussed the fact that the A..G.M. was some distance away, and that a round trip could be quite arduous. The use of a mini-bus had been suggested, with the intention of say 3 pick up points.

Otherwise, the conversation ranged from FSP membership, (approximately 224) if I understood Ian correctly, - to horse racing and to the impending 'Royal Ascot' to be held in York this year. Along with that, we discussed where people had been the previous night, etc. And Pattie's dog, 'Amber', was made a fuss of too. In fact, we 'socialised' as much as possible. Some 'falling down' water was imbibed too! Ahem! I have renewed my annual subscription to Disability Alliance. For this payment I receive a copy of 'Disability Rights Handbook.' Some of you may not have heard of it. It is described as 'A guide to benefits and services for all disabled people, their families, carers and advisors'. (All you need to know about benefits and tax credits) It is a reference tool and not something that you would read from cover to cover. The law changes each year, hence this book is reprinted each year to allow for the changes (it is possible to receive updates during the year too). At £11.00, it could be a good investment. If you want to know more, contact:

Disability Alliance
 Universal House
 88-94 Wentworth Street
 London
 E1 7SA
 Tel: 020 7247 8776

So the regional group is established now. If any of you have ideas for events or venues, or have any queries please contact me.

Ray Exley

rayexley@aol.com

Afternoon Tea Regions 1 & 2 Saturday 16th April

Having the SGM as part of the Afternoon Tea was a lovely opportunity to welcome and meet members from other Regions.

Fortunately the Milford Day Centre had the facilities and space for the sixty present to circulate without too many difficulties, with enough room for wheelchairs to manoeuvre.

With the SGM we did not have a guest speaker which gave more time for socialising. The carers were able to have their discussion time, which was enhanced by some new faces.

The SGM was successful and gave the opportunity for members to question and air concerns before the vote. This was also the chance for the Committee to give any updates on current events in the FSP Support Group.

The raffle was a great success again and made a good contribution towards the costs of the afternoon. Thanks to all those that both bought tickets and donated prizes.

We would like to thank all those members who contacted us to say they could not attend the afternoon. We appreciate the response, even negatively, to the invitation.

A big thank you to all those that helped before, during and after the meeting to make it so successful. We look forward to seeing many of you at the AGM on Saturday June 25th and at the next Afternoon Tea on Saturday November 12th.

Mike and Jane Bennett

Region 8 co-ordinator

On behalf of the committee and indeed all our members, a big thank you has to be said to Pattie-Raven Chapman for her commitment in the role as area coordinator for Region 8. Pattie has regrettably had to stand down for personal reasons. We are currently looking for a volunteer to take over this position. Region 8 covers Bedfordshire, Northamptonshire, Leicestershire, Nottinghamshire and Lincolnshire. Anyone interested, please contact David Pearce on: 020 8551 2905.

Forthcoming events

Annual General Meeting

Saturday 25th June. See below and overleaf for details

Regions 1 and 2 Afternoon Tea

Saturday 12th November 3pm – 6pm.
Milford Day Centre. Contact Jane Bennett for details

Region 10 get together

August 20th Midday
The Doormouse Public House - York
Contact Ray Exley on 01904 626799 for further details.

AGM Reminder

If you are currently undecided, please do try to attend our AGM on June 25th at Stoke Mandeville Stadium. It is your opportunity to put any thoughts that you may have forward. It is stated in our constitution that we must have 10% of our members in attendance at AGM for any resolutions to be made. It is very important that as many members as possible attend.

The day's agenda is detailed on the back page of this Newslink. The cost is £12 per person and this includes all refreshments and a buffet lunch.

To confirm attendance, either complete and return the slip that was sent out with the February Newslink, or just drop Mike Fawcett a line. Cheques to be made payable to The FSP Group.

Members who are attending and require directions/map please contact Ian Bennett.

New Members

We welcome the following new members:

Andy Barrett Cullompton Region 4	Ms Elizabeth Anderson Co. Down Region Ire
Mrs Anne Martin Blackpool Region 9	Mr John Andrews Gwynedd Region 6
Mrs Audrey Potbury Honiton Region 4	Mrs Karen Galloway Newton Stewart Region 11
Mrs Audrey Tidmarsh Beckenham Region 1	Mrs Lisa Triggs Hornchurch Region 5
Mrs Carol Davis Chesterfield Region 9	Mr Paul Duffy Liverpool Region 9
Cherie Foster Eastleigh Region 1	Miss Rose M ^c Coll Glasgow Region 11
Mr Eliot Johnson Woking Region 1	Mr Steve Roundhill Lubenham Region 8

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.

Annual General Meeting Saturday 25th June 2005

Venue: The Olympic Lodge
Stoke Mandeville Stadium (on the hospital site)
Guttmann Road
Stoke Mandeville
Bucks HP21 9PP

- 10.15 Coffee & Welcome
- 10.45 AGM (See enclosed sheet for agenda)
- 11.30 There will be a short break.
- 11.40 **THE SALISBURY HOSPITAL**
Paul Taylor: A look at the single and dual channel Functional Electrical Stimulators and their help with a dropped foot condition experienced by some of us. To examine additional areas of benefit and the use of the FES as part of a physiotherapy programme. Short question time.
- 12.30 Lunch
- 2.00 **THE ROYAL FREE HOSPITAL**
Dr Tom Warner: An overview of the clinical and genetic aspects of FSP covering sign posting in the areas of bowel and bladder disturbance. Short question time.
- 3.00 **TIME FOR YOU** Choose to continue those conversations you started over lunch. Find that person you had been trying to talk to all morning or just enjoy the company. Should you wish to, simply listen or participate in an open forum group where topics of interest previously suggested by members can be discussed.
The DVD of Professor Wood's presentation at Peterborough will be available to view.
- 4.00 Coffee
- 4.20 Chairman's closing words
- 4.30 **MEETING ENDS:** We very much hope you will have made some new friends, have a better understanding of FSP and the group's commitment to an exciting and fulfilling future. Have a safe journey home.
-