



# HSP Newslink

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

**Issue 31 – January 2014**

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

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## Too Good to be Forgotten!

**Eric Spalding 09/01/1941 – 09/11/2013**



Eric and his daughter Kim celebrating his 70<sup>th</sup> birthday with a flight experience

Eric grew up in the Horseshoe pub, Thornton Heath with his large family - one of seven. Moved to Wallington, where he met and married Maureen Moss (lived in same road). They had two daughters, Kim and Dawn to whom he was very close.

HSP progressively affected his mobility and cognitive function (the condition only came on in his forties). He had a difficult time in later years, constantly in and out of hospital,

but enjoyed a relatively normal life before that e.g. a keen DIY enthusiast.

He was sociable and loved big get-togethers with family and friends. He particularly enjoyed day trips to the seaside, pub lunches, family BBQs and weekend breaks away with his disabled swimming club. A keen Crystal Palace supporter, he relished every opportunity to watch a big game on Sky sports and occasionally went to see a live game with his friend Frank Hayden.

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A respected and intelligent man, he worked hard as an accountant, even when he retired he still continued to help people do their accounts. Strong work ethic, a perfectionist, a sense of pride and achievement ran through whatever he turned his mind to e.g. For the last few years he has belonged to a disabled swimming club and won cups for his achievements and also attended a gym, where he tried to keep as active as he could.

Others describe him as a gentleman, honest, kind, caring man. He did lots of voluntary work – including fundraising and treasurer for the groups he belonged to (e.g. disabled swimming club and shopmobility scheme).

He loved chatting to others and banter. Made new friends very easily, was sincere and had a genuine interest in people. Appreciative of other people's efforts, he'd go out of his way to write lengthy thank-you notes or phone calls thanking people for good service. ...Dad liked to vocalise his happiness, he used to stand up and publicly congratulate people for all their achievements and encourage them further. He did the same with family too.

### **What he meant to us**

We're proud to have had such a caring dad, he always had time for us and supported us in whatever we chose to do. There's never been a moment where he hasn't encouraged us through our careers and studies and he was so proud of our achievements. He was the most sincere, honest man you could ever meet, who always saw the good in people. We admire him for his strength and the way he's coped with his condition. He was always so positive and in awe of the medical profession, never giving up hope that he could get better, so he would have been chuffed to know that he was in the hands of the top consultants and even baffled them right till the end!

*Kim George & Dawn Nolan*

### **Further thoughts**

Was a sad day when I heard that Eric had passed away.

Feel privileged to have known him in a sentimental way.

Eric was a considerate caring man, a pure gentleman and loved a giggle.

A proud family man and a people's person happy to be open in discussions

Nothing was too much trouble, always there to help others

I will remember him always for his warm embrace and his cheery smile

Eric was a great guy and will miss him loads

*Lorraine Saupe*

### **My Memories**

Eric was a regular at HSP meetings. I don't believe he ever missed an AGM and I remember him vocally encouraging and appreciating the work that the HSP Group does.

He was always after information regarding any specialist therapies or equipment that myself or others were using and I often later discovered he was trying similar himself. When we've had medical experts addressing us at events, Eric was regularly after further information and was often the first to have a hand in the air during question time. He was a fighter who never gave in to HSP and always maintained a smile.

I enjoyed a natter with Eric every time our paths crossed and particularly loved his cheeky sense of humour.

A very special day for me was having the privilege to take him flying on his 70<sup>th</sup> birthday. This was secretly arranged by his family and Eric knew nothing about it until he saw the aeroplane. I know he thoroughly enjoyed the experience and this can be seen by the expression on his face in the photo on the front cover.

Eric was one of the best!

*Ian Bennett*

## Chairman's Column

I know I'm a bit overdue but let me begin by wishing you a Happy New Year. What a wet start to the year we've had and particularly so down here in Dorset, but so far we've been unaffected by flooding. Let's hope it dries up quickly and this is a sign that we're going to have a lovely spring and summer.

Christmas and New Year festivities seem a while ago now but it all went very well and miraculously I managed to avoid any severe hangovers. I suffer a bit with IBS and this is often aggravated by the feasts over the Christmas period and this year was no different. I've had trouble with bloatedness and discomfort since my early twenties and although this was long before my diagnosis I'm sure it's a symptom of HSP. Since I've been involved in the Group I've met many other members who are affected in a similar way. A few weeks ago a friend of mine told me about a special diet that targets the problems of IBS. This diet is called the FODMAP diet and I've since been experimenting with it with very some very encouraging results. If it turns out to be as good as I'm hoping I'll include an article on it within the next issue of the Newslink, but I would recommend anyone who has IBS problems to at least Google it and do some research.

Shirley and Cara (my wife and daughter) had been attending a local gym in November to use a vibration plate. They were very impressed with the resulting weight loss so I bought them one for Christmas. Since Christmas day they have both used it every day and when I read that one of its benefits is improving circulation, I decided to use it myself. I stand on it for ten minutes per day while it oscillates at varying frequencies and I don't think I'm imagining that my feet haven't been getting quite as cold as usual. The one we have is called a Confidence Vibration Plate and I bought it on line for £149-99.

Thank you to those of you who have contributed to this Newslink. I was

particularly interested in Barbara's letter discussing her raised beds and love of gardening because I share the same interests. The next Newslink has to be circulated in May as it gives members a months notice and details of our AGM. That means I'll be compiling it in three months time so please put pen to paper and forward me some material.

I'd like to thank Adam Lawrence for agreeing to write a regular research column for the Newslink the first of which is included in this issue. Some of you will have been following Adam's interesting blog so you may be familiar with his name. Adam keeps a close eye on what is going on within the HSP world and he wrote excellent summaries of the AGM presentations for the previous issue.

Plenty of people have been fund raising and we've also had some good support from organisations, particularly the Masons. Peter Bateman's efforts stand out and warrant special recognition and thanks. We recently received a cheque for £1000 from Peter and this wasn't his first contribution to group funds. Many members will know Peter who is the co-ordinator for Wales and he raises funds by having collection boxes in various locations including local hotels, golf courses and the Porthcawl Pavilion. Next to the collection box is either a selection of key rings or pens and people are invited to take one for a small contribution. Many thanks Peter, I'll buy you a Jail Ale in Ashburton.

I have recently acquired a new scooter which I'm delighted with. It is a class 3 scooter meaning I can use it on roads (it is taxed and registered with DVLA). It has a long range and I've found myself going into town on it whenever the weather has been suitable and it'll certainly be my mode of transport for trips to the local pub when the evenings are warmer.

I look forward to meeting up with members at forthcoming events and I'm always on the end of the phone if required.

*Ian Bennett*

## Whole Genome Sequencing: An opportunity and update on our progress in HSP

**Henry Houlden and Arianna Tucci**

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The National Hospital for Neurology and  
Neurosurgery, Box 12, Queen Square,  
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In the Neurogenetics clinic, at The National Hospital for Neurology in London we are able to genetically define and give patients their gene, in around 55% of those with HSP. This improves patient care significantly and often opens up the discovery of treatable disease pathways. Our aim, with the help of new technology like whole genome sequencing, is to increase this figure to over 90%.

Recently, the NHS announced a government project called Genomics England (<http://www.genomicsengland.co.uk/>), which is aimed at carrying out whole genome sequencing (all of the genes and intersecting regions that we have in our DNA) in rare diseases in the UK. From the National Hospital for Neurology, I put forward HSP as one of the rare diseases that we wished to sequence. This is a very important opportunity for HSP patients who do not know their gene, to obtain an exact diagnosis and for our team to obtain a very comprehensive test that the hospital could not usually afford to do. I am grateful to the HSP society for publicizing this and the many patients that have already enrolled, completed questionnaires and had their blood taken. So far we have enrolled and taken blood for genome sequencing on 22 patients and their families.

### How to be enrolled in the whole genome sequencing?

We require the HSP patient and their family to be enrolled in the sequencing, where

their HSP gene is unknown. This can be in small families such as;

1. Affected patient with HSP and their parents (three members, a trio). Parents can be affected or unaffected.
2. Affected patient with HSP and two unaffected members as in brother, sister or parent (three members).
3. Affected patient with HSP and one or two other affected family member such as parent, brother, sister, child, cousin or distant relative.

Any person in the UK with an NHS number and GP can be enrolled. We then require the three members to read the information sheet and if they agree sign the consent form, have a small amount of fresh blood taken and post this back to us at the hospital. This can be done by visiting our hospital in London or through your GP as we have very easy to follow blood packs that we post out, containing bottles, packing, information sheets, consent form and GP letter. The blood is taken at your GP or local hospital and then posted back to us by standard Royal mail post.

The blood from each family group is sent to Cambridge for DNA extraction and sequencing there. The whole genome data is expected back in 2014 but I think this is optimistic and I expect it back mid 2015. From these results we hope to identify your HSP gene, this will be easier in some families than others. Which will define the exact type of HSP and also be informative for families and may lead to the identification of new HSP pathways, biomarkers and treatments.

In addition to the whole genome sequencing we have approval to enroll HSP patients, with their consent, into an HSP registry. Some patients have already taken part in this and it will be of great benefit to HSP as it will allow us to define patient groups and numbers of willing and

interested patients in potential drug trials when a good therapy is offered.

If you and your family are interested in the whole genome sequencing and HSP registry please email or write to us at the address above and we can arrange for you to come to London or have a blood pack sent to you for your GP to take blood.

Thank you for your potential interest in this project and I look forward to seeing some of you in clinic in 2014.

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## Research Column

I met with Ian Bennett towards the end of 2013 as we both happened to be near the same pub at the same time. Following on from my articles of the AGM last year Ian asked if I would write a regular column for Newslink, with more of a medical focus. I am honoured to be asked, and it is a pleasure to write to you all.

- It is my aim to cover a few issues in each column, considering one or more of:
- Identifying new HSP research/findings
- Exploring HSP symptoms/treatments
- Finding out how HSP progresses
- Trying to find out why things are done
- Understanding medical terminology

Initially my focus will naturally be on things relevant to my own situation, but I would be pleased to hear from any readers who would like me to try and answer questions they may have (remembering, of course, I'm not a doctor, just someone else with HSP). Please e-mail/write to me, my details are in the table on the final page.

### Information Sources

I aim to be open and honest when I look into something, and (to start with) I'll only be using things I can find out on the internet. There are a number of websites which I visit regularly, including other HSP

groups, on-line HSP communities and medical websites.

### Bladder Problems

Bladder problems get mentioned quite frequently for people with HSP, yet there appears to be little research/information available about this.

Firstly I tried to find out what is "normal": The bladder normally holds 400-600ml ( $\frac{3}{4}$  to 1 pint) although the urge to urinate is usually felt at about 150 ml ( $\frac{1}{4}$  pint). Most people go to the toilet four to eight times a day. Most people can sleep for 6 to 8 hours without having to urinate.

Bladder problems normally seem to increase with age. Middle aged and older men often wake to urinate once in the early morning hours.

Up to a third of the female population over the age of 60 years is estimated to be incontinent. One sixth of men over the age of 60 experience urinary incontinence, with the proportion increasing with age.

In July 2012 a research paper was published in the journal Spinal Chord (Volume 50, Issue 7) which reported bladder problems in people with HSP.

29 patients with HSP were analysed, and there were no other complications detected, meaning that all bladder issues are likely to be as a result of HSP. The headline is that more than four out of five of HSP patients have some kind of urinary symptoms, the most common of which is "urgency" - a sudden need to wee. The five main issues are:

- Urinary urgency - is a sudden, compelling urge to urinate.
- Urinary frequency - the need to urinate more often than usual
- Urinary incontinence - any involuntary leakage of urine
- Urinary hesitancy - a delay between trying to urinate and the flow actually beginning
- Detrusor sphincter dysynergia - once started, the flow of urine is interrupted

This table shows the approximate proportion of patients with these issues:

Symptom	Proportion
Urinary urgency	3/4
Urinary frequency	2/3
Flow of urine interrupted	2/3
Urinary incontinence	1/2
Urinary hesitancy	1/2

Other issues reported include the bladder contracting suddenly whilst filling, affecting about half of the patients, and there being some urine left in the bladder after finishing, affecting about two fifths.

There were five patients with HSP who had no bladder issues at all.

**Title:** Bladder dysfunction in hereditary spastic paraplegia: a clinical and urodynamic evaluation

**Authors:** M Fourtassi, S Jacquin-Courtois, M C Scheiber-Nogueira, A Hajjioui, J Luaute, K Charvier, D Maucort-Boulch and G Rode

**Abstract:**

<http://www.nature.com/sc/journal/v50/n7/abs/sc2011193a.html>

*Adam Lawrence*

## Useful Information

### Wheelchair basketball - Fun for Everyone!

Wheelchair basketball is arguably one of the sports that has transferred most successfully from the able bodied game, allowing players with and without disabilities to compete on an equal footing. It's fast moving, free flowing and competitive nature attracts large audiences to major games and it was a sell out success at the London Paralympics when our son Tim was lucky enough to watch the action first hand.

Tim is 21 years old and he joined our local club in Bury St Edmunds, The Bury Bombers, when he was 10 years old, seven years before HSP announced itself. He played as one of several able bodied players alongside friends with varied disabilities for years until, shortly before he tested positive for the SPG11 mutation, he was reclassified disabled.

The club was started in 1997 by the parents of three boys of the same age who all used wheelchairs. One of the three later transferred to other wheelchair sports and was selected for the Beijing Paralympics. The other two remain leading members of the Club although one has played professional wheelchair basketball for a team in Germany.

At one time, though, club numbers dropped so low there was a danger that the club would fold so one of the founding parents recruited more able bodied players from the school at which she taught. These players happened to be old friends of Tim's so, in early 2003, he joined too.

Since then, the club has continued to grow with members travelling from Essex, Cambridgeshire and Norfolk as well as various parts of Suffolk. The club now has a 1<sup>st</sup> and a 2<sup>nd</sup> team, and when possible, has contributed to a junior team representing the East of England. The 1<sup>st</sup> and 2<sup>nd</sup> teams play in leagues against other teams from across the country and there is also a league for junior club teams. In addition the East of England Junior team plays against teams from all over the country in a weekend tournament held at Stoke Mandeville once a year. The club also has a strong Development section including a group for those with learning disabilities. The numbers involved mean that the different sections train at different times but on the same evening. The team even has its own volunteer physiotherapist.

The Bombers are very proud that one of their former team mates played for the women's GB team at London 2012. Sadly, her move to university after the Games

meant that she had to change clubs so we only see her now if the two clubs play against each other.



The club's head coach frequently visits schools in the region with some of the sports wheelchairs and gives pupils and teachers the chance to have a go at the game. After a demonstration by the Bombers the children learn the skills of manoeuvring the wheelchairs and handling the ball and finish with a game. These are popular events and club members have regularly visited the school on the American airbase at RAF Lakenheath coming home with bulging goodie bags!

The fundraising, too, has been great fun for those helping out although it is a huge amount of work for the main organisers. The club invites people to make up teams, maybe a group of work colleagues, the regulars from a pub or the local rugby or cricket team. The teams have a training session, a match against one of the other teams and finally a match against the Bombers. These sporting people pay for the privilege and then buy raffle tickets and burgers and cakes and so on. However, the same teams keep coming back so they must enjoy it – the visitors haven't yet beaten the Bombers but one day.....?!

Tim has loved wheelchair basketball because it is so inclusive and sociable. The wheelchairs are great levellers – when Tim used to play at Stoke Mandeville everyone, able bodied and those with disabilities alike, lived in their chairs for the weekend. I think it is an unwritten rule at Tim's club

that people don't talk about their disability so everyone can just focus on enjoying themselves.

Anyone can play wheelchair basketball – you don't have to be a wheelchair user and you don't even have to have a disability except to play at a very high level. The club has had a mix of players with disabilities and those without from the very early days and, at the present time, there are father and son pairs and a set of twins, one able bodied and one with a disability, who play together. It is a great activity, either to get involved in as an individual or as a family. There is scope for those who are seriously competitive and also for those who just want to have fun. Men and women, girls and boys, ranging in age from five to fifty five years old all play with the Bombers. The wider families can also take part even if they don't wish to play. Some attend training sessions and matches taking responsibility for care of the sports wheelchairs or acting as team managers or qualified coaches; others help out with fundraising events.

Wheelchair basketball was developed from the running game in 1945 by US veterans of World War Two and was introduced to this country in 1955 when the first international competition was played at Stoke Mandeville. Today the game is played at sixty five clubs throughout Britain. They all come under British Wheelchair Basketball which has a Club Finder section on its website at [www.gbwb.org.uk](http://www.gbwb.org.uk).

If you would like, you can see pictures of Tim and his team mates at [www.burybombers.org.uk](http://www.burybombers.org.uk).

If anyone would like to find out more about wheelchair basketball do give us a ring or drop us an email. If we don't know the answer we know a man or woman who does!

***Hilary Croydon Region 5***

tohiti@btinternet.com

## HSP Group Funds

The HSP Support Group is now in a position to support research projects with a maximum grant of £10 000. Applications for such support are welcome. Please apply in writing.

Funds are also available for members to apply for financial assistance with the purchase of mobility aids or equipment that may improve quality of life or simply make life easier. If interested, please request a grant application form from a committee member.

## Members' Letters

This tickled me so I thought I'd share it with you. John Mason and I went to Norwich late last year to host a small get together for local members. Shortly after we returned John sent me a copy of an email he'd sent to his daughter. Here is that email:

**Hi Bec,**

I am back from Norwich. Drove up with Ian on Saturday morning, had an inaugural meeting of the HSP Support Group there, had a curry on Saturday night and drove back (awful weather) on Sunday. Norwich is a nice town but it is a long drive.

I must say the curry was excellent (the Oasis restaurant) and the staff were very friendly and helpful.

We drove back to the hotel from the curry house and wandered into the hotel. There was me on my scooter and Ian hobbling along on his crutches. I guess it was not much after 9:30 in the evening. In the lobby there was a chap and 3 tall girls who were dressed up for clubbing. Legs up to ..... the top of their legs. We didn't grow girls like that when I was a lad. We also only went out with one girl at a time not 3. So there was an exchange of banter

between us all. Saturday night in Norwich is club night apparently.

Anyway, Ian persuaded me to go to the bar and I had a (small) glass of red wine. That was enough, Ian can drink real ale for England but the bar didn't serve a decent beer so he was stymied. We agreed on an early night and to meet the next morning at 9am for breakfast, the first one up should knock on the other's door.

Well, I was pretty tired, and dropped off to sleep quickly.

I was dreaming. I was at home. There was the sound of The Twins coming in downstairs (our 2 grand-daughters aged 4 who stay with us on Mondays). They seemed a bit noisier than usual. And more of them too. Slowly slowly I came round to realise that I was not at home but in a hotel in Norwich and that there was a group of girls in the corridor. They sounded like Japanese schoolgirls, I couldn't understand a word of what they were saying or what they were so excited about or where they were going for their day out. There were certainly plenty of doors banging. And then there was a knock. Three knocks to be precise, quite soft. It was Ian's knock. Just like last night when we met up to go for the curry. I looked at my watch. I could see the luminous hands of the watch in the darkness. It was twenty past nine!!

Aaaarrggghhhh! I got out of bed, frankly feeling as bad as I usually do the morning after drinking with Ian. I washed, no time for a shower, shaved, brushed, patted and dressed in record time. Frankly I am not a morning person but Ian is always on-time and I did not want to keep him waiting.

I finally got out of the room in about 20 minutes and went over to his. I didn't bother with the soft knock, I banged on his door with the handle of my stick.

No reply .. so I banged again. Still no reply. I guessed he must have got fed up of waiting and had gone to the restaurant to start breakfast without me.



I pointed the scooter in the direction of the restaurant and set off.

Hang on a minute, isn't that an outside window? How come it is dark out there? I looked at my watch in the light of the corridor. It was ten past four. Suddenly the bits of the jigsaw started to form a different picture: When I had looked at the hands of my watch it wasn't twenty past nine, it must have been a quarter to four. The girls weren't Japanese, they were just pissed. They weren't going out, they were coming in.

I went back to my room very VERY quietly before a member of staff appeared and asked why I was cruising the corridors of the hotel in the middle of the night.

I haven't told Ian.

Poppps

### Dear all,

I love gardening, always have! As a child during the war years I helped my father putting in vegetable seeds and watching them grow. As I grew older I took over quite a lot of the garden as my lovely dad was ill.



After getting married, my husband, who was in a wheelchair and I had a home in Streatham SW London. There I grew all our own vegetables. Favourites were salad items and tomatoes. Roses and dahlias were loved too. Eventually I had two wonderful daughters. When they were young they weren't interested in gardening. Different story when they grew up and got

married with homes of their own. Phone calls asking for horticultural advice.

I'm on my own now living in Norwich with one of my daughters. I have a lovely 13 year old grandson who helps with sweeping and cutting back. I have HSP now and unable to get down and pull out these nasty weeds. So I have a walled raised bed garden, it's wonderful. I can sit on the top of the wall and hoe and weed to my hearts content. It's a lot of money to lay out for it but it's worth it.

Barbara Jones Region 5

### Dear all,

Managing HSP requires an odd mixture of two contrasting qualities- obstinacy and realism. Obstinacy, because it's all too tempting to use the disease as an excuse for taking the easier path- driving or being driven rather than walking for instance- and it's necessary to fight hard to maintain for as long as possible the maximum use of such faculties as the disease leaves you. Realism, because it's important to be clear sighted about the condition and when new forms of support become necessary to be ready to accept them and indeed embrace them.

I personally have been good on obstinacy but poor on realism. As my walking capacity declined I found my cycling less affected by HSP, and became an enthusiastic touring cyclist. In the last decade I did long-distance rides in 16 European countries. Cycle touring became a big part of my life. My self-belief was strongly buttressed by what I could do on the bike, even though I was always slow compared with my friends. I could tell myself that many fitter people could not do what I was doing and I was further bolstered and inspired by meeting on my trips many others who were cycling to combat crippling conditions- Parkinsons, Muscular Dystrophy, heart disease (I had that too), various forms of cancer.

But because cycling was so important to me

I ignored beyond common sense the evidence, clearer every year, that I was getting slower, that my stamina was declining, that my participation was becoming a burden, or at least a problem, for those cycling with me. At that point my wife Anne stepped in. She has been wonderfully supportive throughout, which included learning to ride a bike at 57 to go on cycling holidays with me; but she now supplied the realism which I ought to have shown myself. She told me that she would only agree to my going on my latest project, cycling from Pisa in Northern Italy to Catania in Sicily, if I either (a) promised to get in the support vehicle as often as necessary or (b) got an electric assisted bike to make up for the power I was losing. I would still be pedalling, but my power output would be supplemented by about 30%. Anne was supported by our neighbour and friend Andrew, a larger than life character who had cycled many thousands of miles with me and who is by profession an electrical engineer. Andrew said he would help me select a bike and would service it on the Italian ride, on which he would himself be cycling.

I wriggled, argued and procrastinated but Anne and Andrew are an irresistible if unlikely combination and there was only going to be one outcome. I did stipulate that if I was getting electric assistance it would have to be a conversion of my much-loved touring bike on which I was comfortable for long distances, not a new e-bike with which I was unfamiliar. So one day in July Andrew and I drove from our village in Hertfordshire to an aircraft hanger at Shoreham airport, in Sussex, where a two-man firm gave my bike a new motorised front wheel and put a huge lithium ion battery on the back. On my trial ride I shot off at 15mph exulting in the speed but wondering what was going to happen when this new machine encountered Italian realities.

What did happen? Reader, I made it. The electric bike did 864 miles from Pisa to

Catania in 14 days on Italian roads (in southern Italy often a disgrace); it survived some actual off-road riding where the roads were too dangerous even by Italian standards; it survived lethal Italian drivers in towns like Naples and Messina where the only traffic law is the law of the jungle; it survived two bad crashes- first one in a huge pothole south of Rome, the second when I was knocked over by a crazy Italian scooterist; it thrived through temperatures which often topped 40 degrees centigrade; it came through thunderstorms and torrential rain. It climbed on the trip a total footage substantially greater than going up Mount Everest. The electrics took all this and came up smiling. Unfortunately, the plastic mounting by which the batteries were attached to the bike was a great deal less robust. The casing, cracked, came apart in pieces, and ripped off the backstep on the bike to which it was attached. The resourceful Andrew dealt with a new problem every evening, attaching the battery and the casing to the bike with an ever more implausible, but remarkably effective, combination of sticky tape and luggage straps (see picture!)

So I did it- and I am still a functioning touring cyclist. But you can see what you need. You need obstinacy, which I can supply for myself. You need common sense and realism, supplied by my wife Anne. But along with this you need good friends. Andrew was an absolute star, and others on the ride, David M, Sue M, David R, Phil, Rob, Barry, Chris and Pamela all helped hugely with their companionship and encouragement. And they did this while themselves cycling huge distances without the electric help I had, and with most of them suffering injury or bike malfunction on the way. I feel very fortunate in my friends. And yes, despite all the trauma, I love Italy and I absolutely loved the ride!

*Michael Horsman Region 3*

# Regional News

## Regions 1 & 2

### An Unusual Sunday Afternoon

This last November Debra Barnes demonstrated Zumba Gold to members in Milford. There is a tendency for Zumba to be thought of for the very fit and active, not necessarily traits many of us now have. Zumba Gold is different. Zumba Gold is specially designed for disabled people, people with injuries and complete beginners. Zumba Gold is adapted so that disabled people can interact with able bodied people to have fun and exercise. In Zumba Gold you only go to your limitations. Debra used a good selection of music to demonstrate a variety of movements, especially for the upper body, that can be tried whilst sitting in a chair. Margaret Caluori recalls the afternoon.

#### Best wishes Jane

Despite having been to the Milford meeting before I still felt a bit apprehensive. Mostly, I think, because I remembered from last time that as well as feeling a bit nervous I had to face my demons about having hsp. But this time, as well as before, I went into a room full of happy, sociable people and was able to greet people I knew from last time. Everyone was willing to talk to people they had not met before; so unlike the so called 'real world'!

The afternoon started with a Zumba session and I was really surprised by how enthusiastically people threw themselves into it whatever their limitations. Unfortunately I was unable to join in much because one of my arms is quite painful at the moment but it didn't matter, the atmosphere was full of fun and enjoyment and it felt very 'normal'.

I have to admit that I've been slacking off a bit lately as far as exercise is concerned but lots of people told me how important it is both physically and psychologically. I think

I already knew this but sometimes it helps to be reminded!

After a lovely tea I went home with the message 'exercise, exercise, exercise' firmly in my mind. I have been exercising fairly regularly since then and at the moment I'm trying to find a pilates session in my area because I think that I'm the sort of person who needs encouragement (and sometimes a big stick) even about doing something which is good for me.

*Margaret Caluori Region 1*

## Forthcoming Events:

### Region 4 get together

Saturday March 22<sup>nd</sup> 2pm onwards  
The Dartmoor Lodge Hotel, Ashburton  
Call Ian Bennett on: 01202 849 391

### Region 5 Meeting

Saturday March 29<sup>th</sup> 2-6pm  
The Restaurant  
Premier Inn Norwich Airport  
Call John Mason on: 01225 761 788

### Region 9 Meeting

Saturday March 29<sup>th</sup> 2-6pm  
Meeting Room  
St Helens South Premier Inn  
Eurolink, Lea Green, St Helens, WA9 4TT  
Call John Mason on: 01225 761 788

### HSP Support Group AGM

Saturday June 21<sup>st</sup>  
Trident Technology and Business Centre  
Leamington Spa

### Afternoon tea Regions 1 & 2

Saturday April 5<sup>th</sup> 3pm – 6pm  
The Clockhouse Milford  
Call Jane Bennett on: 020 8853 4089

### Region 3 Meeting

August 16<sup>th</sup> 2014 1.30pm – 4.30pm  
The Orange Tree Public House  
100 Stevenage Rd, Hitchin, SG4 9DR  
Contact Della Brookman: 07710 637 941  
or Ian Kitchen: 07540 476 735

# New Members

We welcome the following new members

Matt Harmer  
Brentford  
Region 5

Philip McGuinness  
Glenaniff  
Ireland

Robert Ellis  
Milton Keynes  
Region 3

Sheron Miles  
Amersham  
Region 3

Stephen Burrows  
Northampton  
Region 8

If you are interested in contacting the new members listed, please contact the relevant area co-ordinator, or the membership secretary, who can then supply the necessary contact details

## Useful Contacts

	<a href="#">Email</a>	Telephone No:
Ian Bennett - Chairman 37 Wimborne Road West, Wimborne , Dorset BH21 2DQ	<a href="mailto:bravoechonovember@btinternet.com">bravoechonovember@btinternet.com</a>	01202 849 391
David Harris – Secretary 18 Lodmoor Avenue, Weymouth, Dorset, DT3 5AF	<a href="mailto:dave@vadcar.org.uk">dave@vadcar.org.uk</a>	01305 772 286
John Mason - Treasurer 18 Sandringham Road, Trowbridge, BA14 0JU	<a href="mailto:john@jrmason.demon.co.uk">john@jrmason.demon.co.uk</a>	01225 761 788
Stephanie Flower - Help-Line 37 Alexandra Road, Great Wakering, Southend, SS3 0HN	<a href="mailto:FSPgroup@aol.com">FSPgroup@aol.com</a>	01702 218 184
Ian Bennett – Memb Sec/Reg 4 co-ordinator 37 Wimborne Road West, Wimborne , Dorset BH21 2DQ	<a href="mailto:bravoechonovember@btinternet.com">bravoechonovember@btinternet.com</a>	01202 849 391
Simon Hubbard – Research co-ordinator	<a href="mailto:si@sjhubbard.com">si@sjhubbard.com</a>	01908 508 866
Jane Bennett - Regions 1 & 2 co-ordinator	<a href="mailto:luckyjane82@hotmail.com">luckyjane82@hotmail.com</a>	020 8853 4089
Della Brookman – Joint Region 3 co-ordinator	<a href="mailto:Della_brookman@msn.com">Della_brookman@msn.com</a>	07710 637 941
Ian Kitchen – Joint Region 3 co-ordinator	<a href="mailto:Ianpk2008@hotmail.co.uk">Ianpk2008@hotmail.co.uk</a>	07540 476 735
John Moore – Exec Committee Member 66 Drift Road, Clanfield, Waterlooville, Hants, PO8 0NX	<a href="mailto:john@moore108.orangehome.co.uk">john@moore108.orangehome.co.uk</a>	02392 592784
Peter Bateman – Region 6 Co-ordinator (Wales)	<a href="mailto:sandra@peterbateman.co.uk">sandra@peterbateman.co.uk</a>	01656 788502
Adam Lawrence 18 Mayflower Court, Staple Hill, Bristol, BS16 5FD	<a href="mailto:adam@idios.co.uk">adam@idios.co.uk</a>	07834 505 161
Liz Redmond Neurogenetics Nurse	<a href="mailto:Redmond.liz@uclh.nhs.uk">Redmond.liz@uclh.nhs.uk</a>	02034 484 487