



HSP Newslink

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

Issue 21 – October 2010

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

Use it or lose it?



Arthur canoeing on Upper Loch Erne, Co Fermanagh, N Ireland

I was born into a family of keen walkers so at every opportunity I was taken for walks in the countryside even completing 18 miles on the Isle of Skye and climbing Snowdon. My condition was not

identified so the emphasis was not to accept my condition. I started cycling at the age of 12. It was natural for me to adopt this form of transport and extend my normal day's ride to about 70 miles. The freedom and normality cycling offered was wonderful. I joined the local YHA group and few fit cyclists could catch up with me in a sprint. I climbed Ben Nevis in my early twenties. The problems I had were identified by my observers rather than myself. I had had an achilles tendon lengthening operation at 13 and toe release more recently to prevent them curling up.

It was not until a few years after my son was born that our condition was identified but I retained my outdoor activities and even though walking has become more difficult have recently taken up canoeing. I would like to open discussion as to whether intense exercise offsets this condition. In the extreme for instance, what would be the effect on an unidentified sufferer who started to take ballet lessons at the age of five? Canoeing, cycling and swimming are pursuits that I have followed, resulting in a level of fitness well above average for my age.

Even then I wonder how much intensive exercise makes a difference to the basic condition over and above the increased health benefits which of course each and every one should obtain by the same means. Individuals have differing effects resulting from this condition. How much is a result of continuous exercise? Dancers train to get greater movement. Is there a responsibility to do likewise? I have problems walking any distance but know that even though I am passed retirement age if I really wanted to, I could cycle from London to Brighton and even suspect that this would improve my mobility. The incentive to cycle, for instance, increases if there is pleasant countryside in which to do so. My motivation comes from being a child encouraged to go on long jaunts whilst having an unidentified condition. If such a condition had been identified earlier it might have been considered 'kinder' not to allow me to attempt such great distances. 'Not so', is what I think. I relish the memory of climbing in wonderful scenery and cycling in remote places and to some extent I still do the later. What I have lost in walking have gained recently with an inflatable canoe on the Thames, Wey and the lochs of Ireland and Scotland. To mention a few. Make the most of it! Life can be enjoyable to the full! What exactly is the effect of exercise on this condition?

You may now be getting the impression that I am only suffering from mild symptoms but I find it virtually impossible to get up from lying down on the floor without aids or assistance and walking presents considerable effort but:

(a) With a Canadian canoe (kneel position) such as an inflatable Gummotex, Scout or Palava can cover 12 or so miles achieving speeds of up to 10Km per hour. On Bank Holiday Monday we overtook a narrow boat on the River Wey for instance!

(b) With a lightweight Brompton Bicycle equipped with their new ultra wide Sturmey Archer gears and a 40 tooth chain wheel at age 70 I have a comfortable range of 15 -20 miles. The low gears enable me to ride up hills as steep as 1 in 7 and the bike acts as a

walking aid when I have to get off. Mounting and dismounting can present minor challenges but one can plan to overcome this. The local police accept my riding on the pavement at times as being covered as 'reasonable adjustment'.

(c) I have a faster bike built from a single 'step in' Giant frame with lightweight equipment. If I trained to get fit (and I feel guilty in not doing so) I would probably have a range of 40 - 50 miles.

Riding in the country lanes presents little difficulty but in towns and cities careful planning is constantly needed to overcome the difficulty in stopping in the road for say a right turn but the car stays in the drive when I go to the shops or the post. My inflatable canoe stays in the boot of the car for excursions on the Thames or Wey or for holidays on the Lochs of Ireland or Scotland or on the Seven on the Welsh borders.

Arthur Wyatt

Secretary's Spot

Time passing again – a good summer in most ways – but it's time to start planning what to do during the winter months.

We had a good AGM with demonstrations of some members' stuff – a worthwhile thing for many people being able to decide or learn about new kit! I'm sure there will be more elsewhere in this issue.

"ClipStiks" (Walking stick clips) are selling well – made about 40 so far and have outstanding requests for more. I'll be trying to find some time to make more later this month.

A cautionary tale...Carolyn's scooter problem..We've had another, larger, scooter for Carolyn to use for about a year now. It is a used one which had only been lightly used before. Having used it for a few months we noticed it was becoming inconsistent – slowing down for no reason – then going OK again. We put up with this for a while and finally decided to send it in for repair. Some £400 and new batteries and throttle control we got it back. Things were OK for three months or so and then the problem recurred. Back to the repairer again – a new brake

cable. Only £60 this time. Once again after a month or two the problem started again.

I decide this time to have a good look myself – we've had at least four different machines now over the years – so it was worth a bit of time I thought. I started by taking the finger control the “Wig-Wag” off the shaft to the electronic throttle control. When I'd got it off I noticed the metal shaft had some scratches around where the fixing grub screws attach the Wig Wag. Everything else looked fine and the throttle worked when tested. I carefully replaced all the parts and took good care to tighten the grub screws properly to avoid any chance of “slipping”. It has now been two months since I did this and the problem has not recurred. Makes me wonder whether my £460 pounds was well spent??

So if you have some mechanical ability it may well be worth having a good look yourself first. Best wishes *Dave Harris*

Chairman's Column

Having been involved with the Group since 2002, I considered it an honour and a privilege to become chairman at this years AGM in June. I'd like to thank Richard Williams for his valuable contribution in this role in the preceding 12 months.

I have seen the Group evolve progressively since I first became involved and this is something that we must continue. Meetings now occur regularly across the UK with Region 3 (M4 corridor) being the latest addition to our list of meeting locations. Thank you to Della Brookman and Ian Kitchen for taking this role on so enthusiastically. On behalf of all of us I'd like to convey huge thanks to Jane Bennett for her dedication and commitment as coordinator for Regions 1 and 2. On November 20th her meeting at Milford will be the 10th anniversary of such events. So many close friendships have developed at these meetings and loads of useful information has been exchanged. I myself have made some great friends as a result of attending the Milford meetings and can't emphasise enough how important these get togethers are. It was the success of Jane's

meetings that inspired me to get a similar regular local meeting organised down in Devon.

HSP awareness has noticeably increased within the medical community and the Group has played a major part in this. We should all be proud that we have recently been able to support medical research teams both financially and by supplying volunteers affected by HSP. We must endeavour to continue this work and explore ways of raising more funds to help with research.

I have got to know some of our European friends and over recent years I've been fortunate enough to attend HSP meetings in Spain and Germany. I'm very proud to say that as a National Support Group, we in the UK are as good as any at supporting and communicating with our members.

However, our European and American colleagues are far better than us at raising funds for research. Let's learn from them and make more efforts to gain funding.

I'd like us to consider approaching some foundation trusts and maybe the National Lottery for larger grants. If anyone has any experience of such activities and would be interested in committing to this, please let me know.

Whilst on the subject of fund raising I'd like to thank members who've raised money for our cause in recent months. Alan Walters, Carole Rowe and Ian Kitchen to name but a few come to mind. Your efforts are much appreciated and I can assure you, all funds raised are put to a very good use, often helping fellow members to purchase life enhancing equipment that they couldn't otherwise afford.

In my role as Newsletter editor, I must apologise for the delay in producing this edition. Since the beginning of May my house has been a building site. All construction work is now complete and we're slowly getting straight which has at last enabled me to dig out my office and catch up on some administrative tasks.

I look forward to seeing many members at forthcoming meetings and may I be one of the first to wish you a very happy Christmas.

Ian Bennett

Useful Information

Poo Problems

It's been the norm for me to open my bowels twice a week, sometimes three if I'm lucky, so I have regularly had a bloated feeling in my tummy, quite swollen as well. It was the AGM meeting in June 2009 at Leamington Spa that I first heard about Peristeen Anal Irrigation, so I investigated further, which led me to meet Sister Muter-a Clinical Nurse Specialist in Urology. It was essential for me to have a full individual assessment first of all to see if it was suitable for me to use this procedure. I was suitable, but then I was given a DVD to watch and some Literature, which was very informative, so I could then make my own decision whether I wanted to go ahead with it. With no hesitation I informed Sister Muter to say yes, so we organised an appointment, I took a friend with me as well.

I can honestly say Sister Muter was fabulous, I felt so relaxed with her, there was no rush, she made us a drink of gorgeous coffee, and actually it was my favourite brand, honestly! So I was smiling. Now then! This is where it gets a little bit more interesting-the actual procedure. I had to have company in the ladies toilet facility, to be taught how to use it. I wasn't in the least bit embarrassed, I actually made a joke of it and told her before the procedure began that I'd brought with me a nice air freshener! Sister Muter was with me initially to observe that I was ok and confident to use it, then I was left with my privacy to finish off the routine. I did rest for about an hour afterwards, my friend and I had a nice cuppa and a bite to eat from the cafe, before I drove back home. It was nice to have her with me, I would suggest to anyone going ahead with this to have a friend or family member with them. I did feel a little dizzy afterwards-shock to the system no doubt, but nothing I was overly concerned with-there was no surprise; I'd been bunged up to put it bluntly!

Equipment I use:

- 1 A Water Bag
- 2 Tubing which is attached to the above

3 Rectal Catheter-for single use only

The Catheters are delivered to you by Charter Healthcare and you also get disposable bags and dry wipes to clean yourself up afterwards.

Sister Muter did ask me to phone her after a couple of weeks to inform her how I was managing. There is a freephone no to access the Customer Care team as well if you need advice.

Now then! I have to say I have not looked back since, it took me a while to get used to using Peristeen but so well worth it, I can't begin to tell you. It's now been a good three months, I feel so much better. I now realise how it feels to be normal, I can irrigate to suit my own body requirements, don't have as much fatigue as I did, my tummy doesn't look as swollen and feel as bloated as it did. I feel I have some sort of normality now, independence, control, what a dramatic difference to my life. I'm actually enjoying my food a lot better as well, I've developed an appetite. It truly is a pleasure to share it with you all.

A special thank you to Sister Muter, I have to add to this, although to say that isn't enough to voice how I feel.

Christine Snow

Control brings confidence

I currently work as a urology nurse specialist within the Sheffield princess royal spinal injuries centre. My role involves not only urology but also helping patients with their bowel management. The group of patients whom I tend to manage are those with a spinal cord injury, spina bifida, and a few with cerebral palsy, and M.S. as they have a neurological impairment with their bladder and bowels

I first had Christine referred to me by a consultant urologist who thought that she may benefit from further assessment and advise on bowel management. Often within the NHS it is the most difficult part of the process actually accessing and knowing how to reach the most appropriate person.

There appears to be very little in the literature with regards to bowel management

and HSP and from my experience I tend to manage few patients with this condition.

However a telephone consultation led to a formal meeting and a thorough assessment, from defecation episodes to dietary habits was discussed. And as you can read from Christine's letter she had a constant bloated feeling and was regularly constipated, not a pleasant way to have to live.

Rectal irrigation is a way of managing faecal incontinence and chronic constipation enabling patients to regain control of when and where they empty their bowel. I have been teaching it for many years before it became available on prescription.

It is important that patients be taught by a qualified health care professional the first time they use it and monitored for the proceeding weeks and months. Realistic expectations are important as everyone is different, the initial outcomes of anal irrigation vary from individual to individual, establishing a personalised regime that fits to an individual's lifestyle and degree of constipation / faecal incontinence is an important part of achieving effective bowel management in the longer term. A lot of patience practice and support from a qualified health professional who is trained in the technique is the key. Not to mention the cups of coffee required to put the patient at ease.

Irrigation of the bowel with anal irrigation empties faeces in a controlled manner. In patients with faecal incontinence the colon and rectum is emptied so effectively that new faeces will not reach the rectum before the next irrigation.

There are special conditions whereby using anal irrigation is contraindicated or precautions are required namely.

Inflammatory bowel disease,

Recent abdominal or anal surgery

Any anorectal condition that may cause pain or bleeding

In patients who are pregnant or breast feeding.

I cannot highlight enough the importance of being taught the system by a suitably qualified health professional.

If you are interested and feel you may benefit from using the system, contact your GP who may be able to put you in touch with the relevant person. I would be happy to answer any telephone queries.

Paula Muter BA Hons RGN

Clinical Nurse Specialist Urology

0114 25715624 voice mail

Holiday Cruises

I can only hope that this subject is of interest to a good number of you, because I have prepared a good few stories in the past.

My principal aim has been to try to make it clear that our typical disabilities need not get in the way of thorough enjoyment. Over the years, my wife (Carol) and I have learned from practice to target various features and to watch for possible limitations.

Oddly enough, we had already made up our minds to do no more "long haul" flights, after experiencing long queues and tight security in some places (e.g. USA)....and then, lo and behold, we found an advert in The Times of a cruise from Singapore to Vietnam, Hong Kong, Shanghai, South Korea, Tianjin and Beijing, at what we thought was a very reasonable price, especially as the flight was on Air Emirates, so we jumped at it. This was to be our first visit to Asia.

When we first received the booking details, we saw that we had to fly via Dubai, both ways....which was nowhere near as attractive as it sounded, because our stop was 7½ hours from midnight onwards, with the airport facilities closed-down until 8.00 ish. (Similarly on the way back, but a little shorter.) All that this did was to reinforce our decision to avoid long-haul flights....in fact, to avoid any pre-cruise flying altogether, so what we now do is to take a cruise which starts from Southampton or Dover, leaving the car "free of charge" in the port's car park.

So, what about this particular cruise?

Marvellous in its itinerary, and in the service and entertainment provided by the crew, but we had been a little disappointed to find that the ship was a little old (of about the QE2 generation). Our cabin was a little tight on space, such that I had to leave my wheelchair outside the cabin-door, but I learned to “live with this”. My biggest overall difficulty was that there seemed to be few “accessible” toilets. This is something that should have been sorted-out better before we left.

The ship was from Costa Cruises, a fairly large Italian fleet, which seems to cover much of this Asian area, and is well known by people from countries nearby (e.g. there were 185 people from Australia and NZ on board). There were at times more people of Chinese descent than Caucasians, which could be expected from this itinerary.

The crew were from China, the Philippines, other Asian territories and Europe, with a heavy splattering of Italians, whose entertainments team were absolutely brilliant.

Next year, we’re back with our favourite Line, which is Celebrity Cruises, on a cruise identical to one which we went on 5 years ago (then on the Constellation), to the Baltic and St Petersburg. The ship this time will be the Eclipse.

This is not a subject which is easy to portray, but if there are any members with any questions, please relay them to me.

John Moore

Members’ Letters

Hi everyone, I’d like to tell you about my day out today, because it has been very therapeutic for me, in fact it was one of my main aims once I got back to tell you while it is still fresh in my mind.

I’ve been to Hardwick Hall in Derbyshire with my friend Zena, it is an Elizabethan House, built by Countess of Shrewsbury, better known as Bess of Hardwick. Oh the furniture in there was beautiful and the Tapestries magnificent.

I got so involved in the history of the place, the Stewards were so helpful and friendly

warning me of the steps I’d have to climb and said that if I couldn’t manage they would be able to take me a shortcut instead. By the way, I wasn’t giving up yet I’d thought. One of the stewards a guy, must have been in his 70’s, he told me I’d been up and down 106 steps - I was aching I have to say, so I wasn’t surprised.

I met another one of the stewards, this time a lady and she stopped me, saying she admired my determination, had so much admiration for me, really touched at my attitude and how I was dealing with my disability. That was so encouraging for me, because I have changed my outlook on how I’m going to enjoy my life and make the best of a bad thing (HSP), obviously it was coming across to that lady and so I was pleased.

Zena, my friend was so pleased and touched, she had noticed a new Christine, mentally and physically.

I am trying to keep my mind positive, I’m conserving energy by taking advantage of various disability aids around. This has enabled me to manage my exercises and stretching more so I have managed a lot better with my walking and my posture has been looking so much better. The mind is very clever, that’s what I have learnt - I’m aiming to control my mind instead of it controlling me, by replacing the negative thoughts it throws at me with positive ones. It’s certainly been working for me, negative thoughts make me miserable, make me tired and make me a lot less fun to be with.

I did give my legs a well needed rest after the House, he he, by sitting in my wheelchair and Zena pushed me around the lovely garden.

Christine Snow Region 10

My husband John was diagnosed with HSP about 12 years ago. We joined the support group and regularly attend the meetings in the South West region and the AGM. We have really enjoyed them and have gained much from meeting fellow members. The feeling of not being isolated and being able to talk about symptoms and things that help,

with fellow sufferers and carers has been tremendous.

John volunteered to act as treasurer and I look after the accounts so we have met people through this also.

In August John who has been suffering new symptoms had more MRI scans and went back to see his consultant. They have now changed his diagnosis and say it is probably MS. It is a very odd feeling. We have been part of an excellent support group for many years and now at some stage we may join another one. We have decided to stay in the HSP support group for the time being because of the great camaraderie.

To all of you who feel there is no one to talk to I would say make every effort you can to attend regional meetings and the AGM. It has helped us enormously knowing there were people out there who were in the same position as us. I say us because as a carer I was affected too. My life also had to change. Thank you HSP group for being there when we needed you.

(Written on the day of the new diagnosis)

Sonya Mason

Dear all,

I've had HSP since birth, but it wasn't until I gave birth to my daughter who is now 19, that I realised I had a problem. She was aged 2 when I was diagnosed with HSP, in that year I felt my whole world had been torn apart, a progressive condition and also I finally split with my abusive husband. I have to say that I didn't want to live, I had to for my daughter and I do have the get up and go kind of nature, nothing beats me.

I love the relationship that me and my daughter have and I've often said if its one thing I did right it's her, she is the heartbeat of my life. Im sounding very sloppy now aren't I!

I've gone through having physiotherapy, seeing Neurologists regularly, constantly hearing that there is nothing I can do, it progresses. The number of times that I've sat and cried I can't begin to tell you, my thoughts so negative. I've watched my

daughter walking, really enjoying watching the freedom she's had with her legs, looking at her shoes.

I've had to be so careful because I have used alcohol as a prop, it has cheered me up, I've not eaten properly, cause of my bloaty tummy (not being able to go to the loo). I was feeding my negative mindset. In between all this I found myself praying to God, on and off, but the strength I've got from that has been fabulous. I've found myself feeling more positive, realising that this negative voice was destroying me.

I had an urge over Christmas 2009 to have a look at some gyms around where I live, so as soon as Christmas was over, that is what I did, I felt a real determination inside me. Before long I was starting a routine with a gym instructor. I was a little worried at first because although he has had training for disabilities, it is not neurological. I took my life into my own hands and trusted this guy, he had a look on our web page and with me informing him of my own personal experience over the last 19 years to how I am now, we began a training routine. I've had a lot of stretching done and afterwards I've felt as if I've been oiled - he he. I've felt tired physically so I've made the effort to rest more, I've had to because these muscles which have been woken up, I've not wanted to over tire them risking damage.

I am a new person now which began in January 2010 and it all began with having a determined mindset, to make the best of what I have physically. The word progressive floats around in my head, but does me no damage now. I am so encouraged by everyone at the gym, a lovely atmosphere. I'm looking healthier, my posture is better, I'm walking better, not as tired, I love the get up and go feeling that I have a lot now and basically I'm free. Im no longer ruled by the negative mindset that I had.

Oh by the way, I don't wish to sound like a religious freak, but I am being totally honest with you guys, praying has helped me. I just felt I wanted to share it with you.

Christine Snow Region 10

H.S.P Support Group Grant.

Just before Christmas 2009 I finally came to the decision to purchase a wheelchair to make my life easier, as I was becoming increasingly isolated, due to legs getting weaker and not being able to walk more than a few yards without difficulty or discomfort. This was also isolating for my husband Roger, even though he never complained.

I contacted my doctor to ask him to arrange an assessment with the Wheelchair service. That was done and February of this year, I went along for the assessment and was measured for a wheelchair. About two months later, we took delivery of a steel manual chair. It was a great release for me and once I had sat in it, I thought "wow, this is soooooo much easier". **I could enjoy days out and look at the scenery about me and spend the day out, rather than just park where I needed to be, get what I needed, then go home.**

The only problem was that I cannot lift a steel or aluminium wheelchair, because I have weak arms as well. So, I decided to apply for a grant from the H.S.P support group, to see if I could get help with purchasing a titanium wheelchair, as these are very very light and very very strong.

I sent off the form and within two months, a cheque was received in the post along with a letter telling me of the award and asking for receipts of purchase for their records. Wow! I thought. That is sooo generous. I went on ebay and searched 'titanium wheelchairs'. I already knew what size to look for, because I had been measured for the N.H.S chair.

I found one the right size. I had £600 to bid with. At the last minute I bid £600 and was soooooo excited to realise that I had actually won the wheelchair for £440. That means I had some money left over to purchase a lightweight scooter at a later date.

Roger and I went to pick up the chair. We are very happy with it. :) Since we purchased it, we took it to the A.G.M in June and showed it to other members. Some even had a go and were amazed at how light it is. We also, took it to Amsterdam with us

in July and I was able to stay in chair until we reached the aircraft at both ends. We had great fun there and **the wheelchair was a real asset, as without it, we wouldn't have been able to enjoy Amsterdam or even thought about going there.**

All in all, it has worked out well with the titanium wheelchair and I thank the H.S.P support group for their substantial help in enabling us to purchase the chair with their very generous grant.

Della Brookman.

Intrathecal Baclofen Pump

Hi All

Those of you on our intranet system may have followed my journey.

This is to let you all know that the procedure as far as I know hasn't been carried out to many with our condition.

It took a bit of a fight with the PCT what with a letter from them to both my consultant and I getting lost and with them not answering my consultants enquires but when both he and I sent in letters of complaint it all got sorted quickly.

The outcome is that I now have the pump fitted within me on the left side of me between belly button and hip. Not at all uncomfortable and the scar both there and up my back are very neat.

The pump measures approx 90mm in diameter and 20mm thick. It has a 20ml reservoir which needs refilling every 3 months or so using a syringe. The pump I have named "Katie" as it sings to my body and I am a fan of Katie Melua who I think sings so sweetly to us all.

She is currently delivering every 24 hours 60 micrograms per ml and is computer controlled and very easy for my Consultant to adjust it. The pump should last between 6 – 8 years before needing to be replaced.

The pump has a capillary tube running from it through my body and up my spine to the point where the nerve breakdown is occurring. It has been clipped to my spine so that it doesn't go wandering-hence the scar on my back.

It was fitted July 8th at Southampton General Hospital by Mr Girish Vagramani. I spent 2 weeks there and then 4 weeks at St Richard's Hospital in Chichester in the DWH Neurological Rehabilitation unit starting to try and retrain the legs!!!! And get the Baclofen dosage right.

It is slow going but the legs feel much easier – Both legs and feet are not twisted; I have come off of the Baclofen, Cocodamol and Gabapentin. I am feeling so much better.

I have been told that it may not work for us all but I urge you to go and find out about the procedure and you can cite me as an active case.

If anyone wants a chat then do give me either a call or email.

Please keep smiling and take some big hugs from me (Mr Smiley) aka as Philly B.

Regional News

Wales Region 6 Meeting

This was the 4th meeting by the Wales region 6 group with a healthy number of 18 people turning up on the day we had full use of the guest lounge for the afternoon which was on the first floor but no worries there is a lift. The views out to sea from here take some beating and we had good sunny weather to top it off.

Ian sent his apologies for not attending but he had to go abroad for an FES conference. I can't remember where he went but it was some place exotic! It's a hard life sometimes but I am sure it was not all fun and games.

We had a new member turn up Mrs Angela Norris with her two sons Rees and Roderick who showed a great deal of interest in talking to other members about HSP and the help that is available.

I gave a short talk on how we are progressing as a group and some of the ways I am trying to get the message out in Wales that there is a support group available to help them.

I wrote to a local free paper as a last minute thought, to mention the meeting and the paper came out three days before the

meeting date. This led to me having a phone call from a local woman some 6 miles away saying she had seen the notice and was suffering with HSP and was on her own with the condition.

Just that one phone call made it all worthwhile.

The day was topped off with 9 people staying for an evening meal first class food as usual and great company

There are now 20 known cases of HSP in Wales and we are keen to find as many as we can, it is not nice being on your own with a condition that you know little about and fear the worst.

I have asked for help on my web site from members to give me details of their local free paper contacts, just think of the potential if we can replicate the effect of the notice I put in my local paper.

I can remember how Sandra and I felt when we were trying to cope alone with no real help or support until we found the group as you all know it gives wonderful support and you make wonderful friends.

Peter Bateman

www.hspwales.co.uk

Forthcoming Events:

Region 4 get together

Saturday October 30th 2pm onwards
The Dartmoor Lodge Hotel, Ashburton
Call Ian Bennett on 01202 849391

Region 6 get together

Saturday April 16th 2pm onwards
Some members will arrive earlier for lunch - All welcome for lunch
The Atlantic Hotel, Porthcawl
Call Peter Bateman on 01656 788502

Region 3 Meeting

June 4th 2011 Venue to be confirmed

Afternoon tea Regions 1 & 2

Saturday November 20th 3 – 6 pm
Milford Day centre
Contact Jane Bennett on: 020 8853 4089

New Members

We welcome the following new members:

Angela Norris
South Wales
Region 6

Jane Victor
Norwich
Region 5

Philip Lago
Cardiff
Region 6

Anthony Wyatt
Somerset
Region 4

John Baverstock
Doncaster
Region 10

Roger Houser
Ashford
Region 1

Carol Rowe
Exmouth
Region 4

John Richardson
Milton Keynes
Region 3

Sarah Clarke
Somerset
Region 4

Chris Paget
Essex
Region 5

Kevin Brand
London
Region 1

Simon Wiseman
North Devon
Region 4

Gail Victor
Sheringham
Region 5

Neal Harrison
Port Talbot
Region 6

Suzannah Nicholls
Stevenage
Region 3

Graham Berry
Hollyhead
Region 6

Patricia Hamilton
Fife
Region 11

Suzi Clegg
Co Down
N. Ireland

Patrick Bowman
Peacehaven
Region 1

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

Useful Contacts

	Email	Telephone No:
Ian Bennett - Chairman 37 Wimborne Road West, Wimborne , Dorset BH21 2DQ	bravoechoonovember@btinternet.com	01202 849391
David Harris – Secretary 18 Lodmoor Avenue, Weymouth, Dorset, DT3 5AF	dave@vadcar.org.uk	01305 772286
John Mason - Treasurer 18 Sandringham Road, Trowbridge, BA14 0JU	john@jrmason.demon.co.uk	01225 761788
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	bravoechoonovember@btinternet.com	01202 849391
David Pearce – Exec Committee Member 8 Brinkworth Road, Clayhall, Ilford, Essex, IG5 0JS	pearcey david@yahoo.co.uk	020 85512905
Jane Bennett - Regions 1 & 2 co-ordinator	luckyjane82@hotmail.com	020 88534089
John Moore	john@moore108.orangehome.co.uk	02392 592784
Peter Bateman – Region 6 Co-ordinator (Wales)	sandra@peterbateman.co.uk	01656 788502
Liz Redmond Neurogenetics Nurse	Redmond.liz@uclh.nhs.uk	020 76762115

HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP

Minutes of Annual General Meeting

Held at Trident Technology and Business Park, Warwick on Saturday 19 June 2010

The Meeting opened at 10.30am

Present: Committee Members; Richard Williams, John Mason, David Harris, Ian Bennett, Stephanie Flower being part of a total of 72 members.

Apologies were received from over 50 members.

Minutes of 2009 AGM. Duly accepted as a true record. Proposed for adoption by Terry Reed and seconded by John Flower. There were no Matters Arising.

Committee Reports:

Chairman (Richard Williams) and Membership Secretary (Ian Bennett). With the use of slides, Richard and Ian covered the following topics:

- Held seven Regional meetings – South Wales now a regular event!
 - Issued five members with grants to purchase equipment
 - Gave grant(s) to research organisations
 - Pushed Gift Aid & claimed £400 back from Treasury
 - Successfully encouraged members to pay by standing order
 - Still not updated Info Book – initiative with MS society.
 - Try for one or two more Regional Meetings
 - Provide more grants to members – Please apply!
 - Support further research with grants. Our publicising Grant availability has resulted in several applications.
 - Continue to use members efforts in research projects
 - .Forum on the European web site not used – email list used “sporadically”
 - Facebook being used more now – there was still a need to Improve / extend our young member networking.
 - We now have 313 members and 45 Honorary Members.
 - Members were asked to keep making contributions to Newslink – it needs regular information to make regular Issues!
 - Della Brookman and Ian Kitchen are arranging a social meeting in Orange Tree pub on Stevenage Road, Hitchin Herts on Saturday 7th August. Members are asked to support the meeting if they can.
-

Treasurers Report (John Mason)

Accounts were distributed to members present, these showing an end-of-year balance of £16,326.59. Thanks were given to Sonya Mason for her work on the accounts, and to Theo White for his work as Auditor. A question was raised by Mike Fawcett regarding the costs shown for 2009 AGM. John did not have a breakdown of those costs to hand but would provide them to the membership. Unanimous approval of the accounts followed their proposal for acceptance by Caroline Begg and secondment by Lorraine Saupe.

Help-line (Stephanie Flower)

Helpline activity had been “business as usual” throughout the year – no particular peaks or troughs. Stephanie had brought her present Canine Partner with her and also Frodo who was now retired. She reminded members that she was happy to discuss the system of Canine Partners with anyone, and also to provide advice for those seeking it.

Election of Officers for the year ahead:

Richard Williams, having served as Chairman for this year had concluded that he was unable to continue in the role and was stepping down for personal reasons.

Position	Nominee	Proposed by	Seconded by
Chairman	Ian Bennett	Pat Reed	Terry Duffy
Treasurer	John Mason	Della Brookman	Terry Duffy
Secretary	David Harris	Pat Reed	Mark Tomlinson
Membership Sec.	Ian Bennett	Terry Duffy	Della Brookman
Helpline	Stephanie Flower	Petula Baker	Caroline Begg
Committee Member	David Pearce	Sadie Bateman	Lorraine Saupe
Committee Member	John Moore	John Flower	Petula Baker

All the above having been duly nominated, proposed and seconded, the meeting formally approved the appointments by a show of hands.

Any Other Business

Two items were brought to members attention by Dave Harris: Phil Burton had been collecting/processing used stamps for the group and had reported that he was now about to get £80 for the group as a result; Dave had made some “ClipStiks” for helping to temporarily attach walking sticks to chairs, tables etc. to prevent them from falling away. Members were requested to make a contribution to the Group if they took one for their own use.

The official AGM was followed by three presentations and some demonstrations:

Physiofunction Ltd: Giving an overview of the application of Physiotherapy to HSP and providing one-to-one consultations during the afternoon

Pat Reed showed a DVD produced by and about Carers in Wrexham

Demonstrations of various members support equipment

An overview of gene structure regarding HSP, by Dr Christos Proukakis of the Royal Free Hospital. This also gave an insight into the results of research which had been found during the last year.

Once again, our thanks go to the excellent presentation of lunch and other refreshments by the Trident Technology team.

The Meeting closed at 5.0pm
