



HSP Newslink

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

Issue 28 – January 2013

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

Two-Time U.S. Paralympian Equestrian Rebecca Hart and Her Journey with HSP



©Lindsay McCall

Article by Lindsay McCall from the United States Para-Equestrian Association with excerpts from Rebecca Hart.

“My parents were both amazing throughout my childhood,” recalled Rebecca Hart. “They never let me think of myself as a disabled kid. It was as simple as ‘Katie (my sister), Jordan (my

brother), get on your coats, Becca get on your braces we are going to go.’ My parents never made it a big deal, it was just one more thing to do in preparation to leave.”

Born with Hereditary Spastic Paraplegia (HSP) in Pittsburgh, Pennsylvania, United States, Rebecca's childhood mimicked most children's. She participated in multiple sports including ballet and gymnastics, went to school, and she was always looking forward to trying something new. Rebecca noted, "As a small child I thought that I would grow out of HSP. Every time I tried a new sport or hobby I thought if I at least put on the uniform, I would dance or tumble like everyone else." As Rebecca continued to mature she found a friend in her father Terry. "My dad has the same disease and it has been great to have an ally. He was always the most positive person growing up and he was able to relate to me like no one else could because he had gone through it too. He knew the challenges of having HSP as a kid and worked to reduce them. He understood the late night muscle cramps and the taunting that can happen at school. He taught me to be the bigger person and not allow the other children's words to affect me. For the most part they didn't, but it could be exhausting to be at school and constantly have your disability pointed out to you and shoved in your face. Luckily my sister went to the same school. She is my best friend, mild-mannered and wickedly smart. She gave me tactics to handle those situations and in return she taught me confidence. My mom and dad taught me the importance of being proud to be an individual; they told me everyone can be "normal" it takes guts to be unique."

Her positive outlook and confident attitude were just two attributes that began to shape Rebecca into a future Paralympic athlete. Rebecca explained, "I was always a bit of a perfectionist. If I started a hobby or sport I didn't just want to be respectable or stand in the back row of the recital. I wanted center-stage and I wanted to be the best."

It was coming back from a family vacation that Rebecca had her first taste of horses that would eventually place her in the center of the world's top athletes. "We lived in the city but I always had pets growing up and I loved animals," smiled Rebecca. "As luck would have it, on that day there was a pony ride sign on the side of the road where children could

ride a pony. I asked my dad to stop and let me try it. I remember getting placed on the pony and being slightly terrified, but completely enthralled at the same time. I always dreamed of moving freely and gracefully. This wonderful animal gave me that gift and that freedom that I never experienced before. I was hooked from that first ride. I unabashedly begged for lessons the entire way home."

It is hard in the equestrian world to find able-bodied teachers and trainers who can trust and help develop an aspiring athlete who may be physically disabled. Rebecca continued, "It took my parents a while to find a barn that would take me on as an "able-bodied" rider. I didn't want to ride in a therapy-only situation. It had to be nerve wracking for them watching their disabled child get on a 1200 lbs. animal. I loved being in the barn and riding, just being around the horses was wonderful. The saying, 'the outside of a horse is good for the inside of a man,' is very true. I found my niche and my passion that I could do, and one that I excelled in."

After years of competing nationally Rebecca heard about the 1996 Paralympic Games in Atlanta, Georgia. These games were the first Paralympic Games to include the Equestrian sport. It was in that moment that Rebecca was set on competing internationally and representing her country in front of the world.

"It took ten long years of blood, sweat and tears, but my parents got me to the 2008 Paralympics in Hong Kong," expressed Rebecca. I would never have made it without them and everyone else who stepped into the adventure with me."

After her debut and just missing the podium with a 4th place finish at the 2008 Paralympics at 24 years of age, Rebecca continued on with her quest as an athlete. With her elite status Rebecca became a mentor, a hero, and a symbol for what anyone with any type of disability can achieve. She became the United States Para-Equestrian Dressage National Champion in 2006, 2008, 2009, 2010, and 2012; She represented the U.S. at the 2010 World Equestrian Games; She flew around the world for the U.S. Equestrian Team and she earned the 2011 Grand Champion at an

International Competition in Australia. In 2012 Rebecca Hart once again excelled on the world stage just missing the podium in the London Paralympics and being only one of four riders representing the United States Paralympic Equestrian Team.

“Being an athlete and representing my country has been immeasurable for me both mentally and physically,” recounted Rebecca. “Riding has kept me mobile. The horses give me ultimate freedom on their back, but they give me borrowed freedom on the ground. They make my daily life easier. I am able to stay stretched out and limber because of the hours I spend on their back. The horses keep muscles that I can't activate myself toned and strong. They also mentally give me confidence and a sense of purpose. They create a rhythm to the day.”



At 28 years of age Rebecca maintains a full-time career with Starbucks Corporation, continues her riding and training on a daily basis, volunteers, and is also a motivational speaker. As the 2013 calendar year begins she is already concentrating on her next goal.

“At the moment I am fully focused on the 2014 World Equestrian Games in Normandy, France and the 2016 Paralympics in Rio De Janeiro,” noted Rebecca. “I retired my horse Lord Ludger after London and I am working on putting a syndicate together to buy my next horse. I am also on several high-performance committees for the United States Equestrian Federation to help grow the sport as a whole. The equestrian sport has done so much for me as a person and I want others to experience what I have.”

The positive outlook and confident attitude that Rebecca Hart's family instilled on her as a young child with HSP continues to support her

each and every day. Rebecca is just one of many individuals with Hereditary Spastic Paraplegia, Familial Spastic Paraplegia, or Strumpell-Lorrain Syndrome who have excelled and defied the odds.

Photographs by Lindsay McCall for the USPEA

Chairman's Column

A belated happy new year to you all. Christmas and New Year celebrations now seem to be some time ago and I'm now looking forward to the Spring. With the help of friends I've spent some time and money making my garden more disabled friendly and the work includes the addition of a pond. I can't wait to have the opportunity to relax in my improved garden with friends, barbecues and beers during warmer months.

Apologies for the delay in this edition. I'd been waiting for a particular article which I believe has made this edition more interesting.

You'll notice that Physiofunction have very kindly agreed to do a regular column for us. They have given us the opportunity to ask the physiotherapist for help or advice and the way we have agreed to work this is to ask them one question each edition. You'll notice that the first question we have asked is regarding back pain and how to improve any such problems. Please let me know of any questions you may have for future editions. Sarah Daniel is the physiotherapist who is answering our questions and some of you will remember Sarah presenting at our AGM. Her expertise is usually available at £95 per hour so we are very fortunate to have this support at no cost. Many thanks to Physiofunction and Sarah for providing us with this very useful service.

Our AGM on June 15th will be with us sooner than we think. I'm currently organising the agenda and will provide full details in the next Newslink which I'll aim to circulate during May. Remember that the AGM is your opportunity to have your say and ask any questions so it is important that members try to attend where possible. If you're interested in standing for a committee position please let us know. I believe that new blood is needed to move any organisation forward, including

the HSP Support Group. I'm not getting any younger and I'm not quite as energetic as I was when I first got involved with the Group so I would gladly consider sharing out some of my tasks.

The Group is now as wealthy as it's ever been which puts us in a good position to make further contributions to research teams. We are however a support group and so a priority is to support our members in any way we can. One way of doing this is to provide grants for mobility equipment. Members are eligible to apply for a grant if they've been with us for more than 12 months so if you're considering purchasing a new mobility aid and would appreciate some financial assistance, please don't hesitate to let us know.

I have now been arranging Devon meetings for just over ten years and they continue to be well attended. I have also been a regular visitor to Jane Bennett's meetings in Milford for in excess of ten years. Jane's meetings are also very popular and one thing that is very apparent to me is just how important these gatherings are for our members. Many good friendships have developed, much advice has been shared and plenty of knowledge has been gained by members who attend these important informal events. Consequently, as a committee, we feel that it is very important to set something up in the North West of England. A few meetings have taken place in the past, Wigan and Ewood Park come to mind, but unfortunately there has been no continuation. For this reason, with the help of John Mason, our treasurer, we have organised the following event:

North West Meeting

Saturday March 16th

Premier Inn, St Helens South, WA9 4TT
2pm – 6pm

Neurocarephysiotherapy will be addressing us on how physiotherapy may be of help and free FES assessments will also be available. Anyone interested in FES needs to be able to walk 10 metres, have no pacemaker and must not suffer from epilepsy. If interested in an FES assessment please let me know in advance.

This will be an informal meeting and much of the time will be spent getting to know one

another and sharing stories, advice and information. Tea and coffee will be available throughout the day. I believe there is a pub next to the hotel which may be useful for lunch before or dinner afterwards. Attendance will be free of charge.

The hotel needs to have an idea of numbers for refreshments and seating plans so if you intend to join us or require further information, please contact me:

bravoechoonovember@btinternet.com

Tel: 01202 849391

Please try hard to join us, these events are so much better if they're well attended.

I look forward to meeting some new faces and catching up with some old friends.

Ian Bennett

Useful Information

Medtronic Pump Recall

Many patients with Hereditary Spastic Paraplegia have profound benefits in the use of the Medtronic Baclofen Pump. However, make an informed decision before choosing this option for treatment. Consult your physician and ask questions on your personal situation. In light of the recent recall from the FDA (U.S. Food and Drug Administration) this article is to help those who already have the pump and those who are considering this option to make an informed decision and ask questions.

From various polls in the HSP community, there is a 50/50 split between recommendations of using the Medtronic pump and not using it to treat spasticity. Those who support the use find a decrease in spastic movement, increased mobility and function for daily living. Those who do not support the use find that the body has a therapeutic threshold. This means that the benefit of the medication is no longer effective as the body has reached a level of tolerance and the dosage can no longer be increased.

An invasive procedure, the pump is surgically placed under the skin of the abdomen. There can be some rejection of the pump and cause irritation in the area it is placed. A catheter is

inserted into the spine and administers the drug from the pump. Baclofen is an authorized drug for the pumps use. The pump is filled with the medication on regular timetables. You will be given a medical card explaining you have the pump and cannot enter electronic scanning devices. They can cause the pump to malfunction and give too much or too little of the medication. You must avoid saunas and hot tubs for the high temperatures can disrupt the function of the pump. If you scuba dive you will not be able to participate in decompression dives as those depths will affect the pump.

When deciding to use this method of therapy, a candidate is given a trial where medications are administered through injection. This will be an indication if the pump will be a worthwhile and effective treatment for the individual candidate. It will not help determine when your body will reach tolerance for the drug.

Recently, the FDA in the United States sent out a warning to Medtronic regarding the Synchronised Infusion Pump. The proper use of authorized drugs in a pump at six and a half years after implant failed at 2.4% . The pump motor would stall and cause drugs to stop being administered to the patient. With the use of unauthorized drugs the pump would fail at an increased 7% rate. This also means that 97-93 percent of the time the pump functioned properly. A motor stall in the pump would cause the delivery of the drug to patients to instantly stop. This may cause serious health issues, including death. If you have any questions you can reach Medtronic at the following address: Medtronic Limited, Building 9, Croxley Green Business Park, Hatters Lane, Watford, Hertfordshire, WD18 8WW

Tel. 01923 212213

Fax 01923 241004

Be sure to visit their website to review the benefits and risks to make an informed decision.

<http://www.medtronic.co.uk/your-health/spinal-cord-injury-disease/device/what-is-it/index.htm>

Plymouth Research Team

A big thank you to everyone for their responses to take part in the second part of our research project looking at the effect of heat on nerve and muscle function. This second part of the project is looking at how we can manage the problems people with HSP find when then walk in the cold. The garments that we are using were selected by people who attended the support group meeting in Ashburton last October a big thank you for everyone's help with this.

We have 17 people booked in to take part so far **but still need 5 more people**. We can pay travel and accommodation to visit Plymouth University to take part. If you would like more information please contact me: amanda.denton@plymouth.ac.uk or 01752 587995

Thank you.....*Amanda Denton*

HSP Group Funds

One of the interesting parts of managing a small charity like the HSP group is working out how best to use the funds which are donated. Detailed below are some of the recent donations we've received.

David Britton was given a cheque for £65 from his former work colleagues for helping to run reunion meetings and he has given it to us
Linda Ryan has sent us a donation of £100
Sophie Pritchard raised money running the London Marathon, total now £942.46
Maurice Charge donated a box at Sandown races enabling us to collect money totalling £889.

Marlene McMahon has sent us £200 after making and selling cushions.

Megan Powell is involved in a three peaks challenge to date has raised £428.66

David Harris has contributed £173.00 from selling his stick clips

Donation received from Maurice Charge's Masonic Lodge for £500

Donation received from Barclays for £716 to match Sophie Pritchards fund raising

Leanne Piccarillos mother asked for donations instead of wedding presents raising £615

Peter Bateman has contributed £180 through Justgiving for key rings. In 2011 he raised £725.74. Total 905.74

£476.57 has been received from Gift Aid
Not all donations are listed here, but many thanks to everyone who has raised funds for our charity whether they're included above or not.

Sometimes donations are given with a specific proviso. One that has recurred for us is "to be used for research". This means that we may only use that gift for supporting research into HSP.

Currently the group is in the best position financially that it has been since it was set up over 20 years ago. We now give grants to members every year for a range of purposes and we also give grants occasionally in support of various research activities. Even so the amounts donated lead to an increasing amount held in the bank.

During the dozen or so years that I have been involved, I have seen the "reserves" held by the group increase from a few hundred pounds to several thousand pounds.

Part of this, no doubt, is due to the change to charity status which took place in 2005. This allowed an increase in the range and variety of fund-raising activities which could be undertaken, together with the use of charity donation web sites (e.g. Just Giving) which make collecting monies easier.

So much for the good news. What I want to turn to now is the other side of the coin - how to use the money as intended. Whilst occasional grants have been made from time-to-time in support of particular research projects within the UK, it is becoming clear that HSP research is world-wide and there is an international "network" of researchers operating in a wide range of countries.

The size of our organisation and the funding we receive (around £5-£15 thousand per annum) restricts us to considering research which can be funded by that sort of budget.

This is not a simple as it seems because there is a mismatch in size between that amount and the cost of research projects (which tend to start around £200,000). So we are not in a position to commission a project of our own

or indeed to have a significant financial influence on one.

What we endeavour to do is search out opportunities for helping existing projects or their related activities so that we are using the funds in the way that donors and members expect. **To that end we are requesting all our readers and members to let us know if they are aware of existing or proposed projects or activities where this level of funding might make a tangible difference to HSP research.**

We will then be in a position to decide how we can best use the funds entrusted to us. Please let any committee member know if you are aware of ways our funds might be used. We do not need to have detailed descriptions of projects - a single A4 page is plenty with a covering letter.

David Harris

Members' Letters

Cruising with HSP

A cruise is a pretty good holiday. Nice surroundings, entertainment, excellent food and generally good company. And you get to see somewhere different every day. On price it compares well with any other holiday. We enjoy driving around Europe and it usually costs about £220 a day for two when you add in a decent hotel, food and petrol. A cruise is a similar price or better.

We have been on a couple of cruises with Thomsons, and enjoyed them, but their ships are comparatively old and not built with disabled passengers in mind.

We heard from a friend that P&O offer a visit to their cruise liners when they are in dock at Southampton. For £25 a head you get a tour of the ship and lunch. So we took a couple of friends, one a wheelchair user, along to see what the ship was like.

When we got to Southampton dock the sheer size of the ship was breathtaking. It had 14 decks and seemed to be impossibly long. It was the Ventura (built in Italy in 2008, 956ft long and 116,000 tons). We registered and were taken onto the ship in groups of 10 with a P&O minder.

We had a comprehensive tour of the ship. As there was one of us in a wheelchair and one in a buggy we were particularly interested in the cabins for disabled passengers. They were spacious and had a bathroom fitted as a wet room.

There were nice touches – a sliding glass door to a balcony. As the door was opened bits of metal moved to make a ramp over the door frame so getting out was easy in a wheelchair.

The ship as a whole has been designed with us in mind. There were plenty of disabled loos and space allocated in the theatres for wheelchair users. And I can take my buggy and have my bit of independence around the ship and hopefully on shore.

After touring the ship we were treated to lunch in one of the formal restaurants and a very good lunch it was too.

So, our day was slickly organised and really very useful for us as we now know that we could cope with cruising on that type of ship.

I did ask P&O afterwards about the dining rooms where I didn't think a buggy was suitable. The solution – I can take a buggy AND a wheelchair so I am equipped for every eventuality.

We have since booked a cruise in the Ventura's sister ship the Azura to go to the Norwegian fjords in the summer so I will be able to tell you about the experience in a later newsletter.

PS When we booked the cruise we got the £25 tour money back.

John Mason Region 4

Italy

I had been fretting to go back to Italy for some time. I have been learning Italian for 6 years and Sonya studied Italian before me and we are not using the language sitting at home. So I planned a short visit of 6 days to Tuscany at the beginning of October, 3 days in a B&B in Lucca and 3 days in a small hotel in Pisa.

We i.e. Sonya, were rather apprehensive as we had never taken the electric buggy on an aeroplane before. When we booked the flight we also booked assistance. Our concerns were unfounded, Bristol Airport and EasyJet took it

all in their stride and there were no problems at either end.

Through the B&B I had arranged to be met at the airport and we were driven to Lucca which is about 20 miles away.

Lucca is a fine Renaissance town surrounded by a wall that has remained intact as the city expanded and modernized. Our B&B was located maybe 500 yards from one of the gates of the town so seemed to be pretty convenient when we booked it.

We explored several routes to town because the Italian pavements in that part of town were variable, from awful to shocking. There were 3 types of pavement:

- tiles that seem to have been dislocated by earthquake;
- gravel that the buggy just sank into;
- archaeological excavation.

So a lot of the time I took to the road which was OK even late at night as the Luccan drivers are well used to cyclists. I never felt in danger.

Old towns don't have dropped kerbs so you have to go on the road a lot of the time anyway. In the newer parts of towns there MAY be dropped kerbs. We saw a zebra crossing once with a dropped kerb on one side of the road but no way to get up on the other.

Lucca is a lovely city. I have since told many friends that we have just been there and we appear to have been the last people on the planet to go.

We saw just about everything there was to see. We walked round the intact city wall, there is a road on top of the wall and it is like a 4Km long thin park. Museums and churches had ramps for access. We ate well and again the restaurants were buggy friendly.

The owner of our B&B took us to our next hotel in Pisa in a tremendous downpour. "The Luccans don't know how to drive in rain" he said as we shot across 3 lanes of traffic through traffic lights that weren't working. I tried chatting to him in my best Italian. When he turned the radio on I took that as a signal to shut up and stop torturing his language.

We “did” Pisa in 2 days. It is a commercial centre but has a wonderful cathedral close and of course the leaning bell tower. So on our third day we decided to take the train to a fashionable seaside resort, Viareggio.

To cut a long story short: you book a disabled place on a train, two members of the railway staff take you to the right place on the right platform at the right time with a Heath-Robinson contraption. When the train arrives you drive the buggy on to the contraption and the railway staff winch you up in the air so that you can then drive the buggy onto the train. Heath-Robinson it is but it works! At the other end there are another two people waiting to help you off in the same way. The staff of Trenitalia were just brilliant and the stations were quite easy for us to use, there were lifts to each platform and ramps into the stations.

Don't ask about Viareggio. It was out of season, the beautiful people had gone home and it was basically CLOSED. We never saw the sea either, the beaches are all private and are fenced off.

John Mason Region 4

Electrical Stimulation and a day off

On 7th November I drove to Northampton to the Physiofunction Open Day as advertised in September's HSP newsletter. The venue was the Holiday Express hotel. I wanted to find out the latest Physiofunction had to offer.....I find that new gadgets are available every couple of years. I'd heard of an implanted electrical stimulation walking aid called ACTIGAID and was keen to find out more. I also needed some motivation to start exercising again – I had a robust physio schedule this time last year which stopped this year coz of lack of funds and other 'life happenings' needing attention.

I had 2 appointments which I'd arranged when booking weeks before. The morning one involved trying the Bioness system once again – for those that have not been introduced to this form of FES, it is a wire-free version of electrical stimulation of the nerves of the lower legs intending to raise each foot for

floor clearance during walking therefore making it easier and less tiring. As has been the same over the years, before reaching a level of intensity which would allow floor clearance, my leg muscles would spasm – the nerves interpreting the electrical stimulation as pain.

The afternoon appointment was a review of the daily stretching exercises needed by most of us to improve mobility – nothing new but a much needed prompting – other 'things' are taking my time at the moment (but that may be an excuse, I realise!).

The suggestion was that I make an appointment to see Charlotte – the physiotherapist that I used to see at the Physiofunction York branch. I should get an 'intelli-stim' box from her which allows stimulation of the nerves at rest (for example, whilst watching TV!) for practise and hopefully making nerves more accustomed to the sensation of electrical stimulation and to try the Bioness system again in 1-2 months – hopefully, a higher intensity could be used.

Over lunch, I managed to talk to John Graham – the 'big boss' and founder of Physiofunction – to ask him about Actigait. This may be a consideration for the future – there is, at present, only one person in the UK who has the implant and suffered a stroke years ago. The implant has greatly improved mobility for this person in the affected leg. The cost greatly prevented me from further enquiring.....I think John understood. The NHS version is called STIMUSTEP, which sadly, is not quite as effective and John has found the referral process frustrating.

I have always found the Physiofunction staff to be very kind and patient. I was certainly looked after well and plied with endless cups of coffee. I first saw Charlotte in 2006 when we discussed the possibility of Sarah Daniels (one of the head physiotherapists) talking at an HSP AGM - I found the subsequent talks very useful, as did other members I have spoken to.....

A good day and time away from the daily routine!

Laura Branigan --- Region 10

Dear all

This is my account of the ups and downs of living with HSP and how it has affected my life at age 30/31. Looking back, I feel I started to get symptoms of HSP whilst I was in my last year of university, at roughly age 22. I noticed that I found it quite difficult simply walking. I found that I became really tired quite quickly.

In my school years I loved sport, and sprint running was the one thing that I knew that I was good at. At the age of 15 I would win the school sports day, and I remember winning the inter-schools 100m and 200m race. It was quite a shock that during my last year of University, at about age 22, I began to experience slight weakness in my lower limbs.

However, I didn't do anything. I remember feeling a bit awkward walking, and knew that something wasn't right. During my last year of university, and because of my eagerness and motivation to progress in my life, I wanted to find something else to do afterwards. I went for and got a job in Southampton as a Health Care Support Worker, working with people with learning disabilities. I did enjoy this work, but began to notice the weakness in my legs even more. I did see my GP at this time, who referred me to a neurologist in Southampton. I began to take Baclofen, ranging from 10mg – 90mg a day. I still had a working life, so its impact on my life (not that I remember too well) was not too bad.

After about 6 months of working as a HCSW, I decided that I wanted more, and applied to start my mental health nurse training at Southampton University. As I was completing my post graduate degree in nursing, I was quite concerned about my legs, but again did nothing further. I did tell Occupational Health whilst at university, but of course they were happy for me to carry on attempting to sort the issue out with my GP.

I qualified as a Mental Health Nurse in February 2007. I was fortunate to gain employment straight away as a full time Mental Health Nurse for an acute ward. I worked here with no problems, but because it was only a temporary position I did leave here after about 6 months. However, before I left, I gained employment as a Mental Health

Nurse for a new adolescent forensic unit, also in Southampton.

Working in this environment was quite a strain seeing as 'control and restraint' is needed to be used frequently. I communicated with senior members of staff about how it was affecting me and my concerns, and saw Occupational Health (OH). OH helped me to move job to a Community Mental Health Nurse with older people. I really did enjoy this work, although by mid 2010, I felt I was becoming extremely tired, and was finding it so hard coping with work stress as well as stress from the HSP itself.

A lot of stress was in my life after this, and looking back I'm not sure how I got through, but I did and I need to keep reminding myself this. There were a lot of staff shortages within the Community Mental Health Team where I worked from August 2010, when 2 care coordinators from the team I worked found alternative employment within the Trust, and because of my general deterioration in HSP, I did go off sick from work for a week. I then went on a planned A/L for one week. When I returned to work, and walked back into the office where I worked, my Manager called me into her office. She told me that that because of recent falls I had had during work time, she was concerned for my safety. She asked me to stay off work as sick, and to see Occupational Health. This request had come from my Manager, so believed this was the best thing to do.

From this time I began to be represented by the Royal College of Nursing (RCN). I had many meetings with the RCN, and various meetings with the Trust's representatives. At this time, a RCN Solicitor started to put together an employment tribunal case for me, with the strong belief that I had been treated unfairly whilst working for the trust. The RCN encouraged me to apply for ill health retirement.

At this time I lost a great deal. I lost my job, my relationship at the time broke up so I therefore lost my home. I had to move back to my Mum's house in a different area, so I therefore lost contact with the close friends I had built over the years that I had lived in Southampton. However, whilst I was at my

Mum's home, I found out that I would receive ill health retirement, and received a lump sum.

I had the Employment Tribunal in February 2012. I found out a short while ago that the Judges at my Tribunal mainly agreed with me, and I was awarded a small amount of money as compensation from the Trust. In June 2012 I moved in, and started a mortgage, with my boyfriend, in another area.

However, it's been about 8 months since we moved into our new house, and I have to say that I feel completely lost. It's really hard for me to finish this. I don't know people in this area. I don't work. I have no structure to the day. I have joined the local gym, but I have no motivation to go. But overall, I must say that I'm in a really low state of mind at the moment.

I feel I need to end on a positive note, but I just don't know what to say. I am extremely low in mood at the moment. I am taking anti-depressant medication, but I don't really feel that it's helping. I can see why though, seeing as I have no structure to my day. I have too much knowledge having been a mental health nurse!

I know you're probably thinking that I should just get out there on my mobility scooter, or wheelchair, but to be honest I'm so self-conscious. I also received an email yesterday to say that my application for the flying scholarship will be considered in February, so fingers crossed for that! Hopefully I can write another section in the newsletter when I've picked up in mood. I am determined to, and I know I'll get there!

Leanne Piccirillo

Hi All,

I am a member of a disabled diving group :- DiveAbility.org Dive Ability is a member led scuba diving charity committed to enabling people who have disabilities or disadvantages to discover the adventurous world of scuba diving.

Achievement is realised through regular, educational pool sessions and diving holidays, with specialist support and equipment being provided so that positive scuba diving experiences are accessible to all.

In November a group of 16 went to Sharm El Sheik in Egypt for a week's holiday. We stayed at the Camel Dive Centre. 13 able bodied and 3 of us on chairs. From meeting up at Gatwick I had an **AWSOME** time – I'm rating this holiday in my top ten of my life's experiences. I have been diving for 13 years which coincided with the onset of my looking after HSP. I am now on my chair 24:7.

The attention from the hotel and the boat crew was amazing. As was the care by our group.



Phil being assisted aboard

Each day we wheeled to the dock where I was lifted onto our boat confidently by the crew. Then we sailed between 30-90 minutes out into the Red Sea, kitting up as we went along. An extra piece of kit for me was a builders harness which the crew would use for lifting me from off of my chair to the deck's edge where I would sit and then roll into the water when instructed and then at the end of the dive I would come to the deck's edge and the crew took my harness to pull me on the deck and then onto my chair.

After a briefing by the crew instructors we split into 3 groups. I feel I was so lucky as I had an instructor to myself and he was mine for the week and he looked after me so very well. After the morning dive the crew cooked us a lunch before the afternoon's dive. The variety and colours of the fish and coral was astounding and with a water temperature of 27°C at 10 metres (33ft) down it was very comfortable.

Each evening we gathered to sample the culinary delights of the hotel and the

surrounding restaurants and I can say that none of us had an upset tummy.

I find diving is magical – you really are in control of what you do in the water and the guidance from my instructor was great, he pointed out so much to me which added to my learning and fun.

Our last dive was at night which I've never done before. With the other 2 groups at lower depths than me it was like watching a star wars scene as we all had torches, so that was 16 + our 3 guides. I can only dive to 10 metres as I have 'Katie' my Intrathecal Baclofen Pump fitted.

This was my first diving holiday and I am already saving for my next one later this year.

DiveAbility hold monthly training sessions on the 2nd Saturday of the month at a private school's swimming pool in Alton, Hampshire.

Either go online to www.diveability.org or call Andy Wood on 07721 890 058.

Phil Burton Region 1

Regional News

Regions 1 and 2

Meeting at Milford 18th Nov 2012

Wow!! What a pleasure to see David Pearce

David, who had been our Chairman until recent years, but who had cancelled his membership of the Committee due to health problems, turned-up at this Meeting, looking very well and enjoying everybody's company. His apparent recovery is a great pleasure to see.

On behalf of the Group, Lorraine Saupé, presented a gift to David, in the form of a glass tankard: this had been purchased by our committee and duly engraved. This was in appreciation of the years of great service David has put in on our behalf over years gone by. Unfortunately Ian Bennett had hoped to do the presentation but had been unable to attend due to ill health.

Jane and Michael organised the meeting to their usual high standard. Our expected demonstration was performed by Jenny Commerford who is a yoga teacher: she demonstrated several exercises and techniques of relaxation, which was very interesting and hopefully rewarding. Jenny's display was performed while she was poised on a table, either standing or sitting on a chair thereon, or laying on a cushioned mat, so that all could see her actions, essentially of her feet. Visitors included Roger and Della Brookman, who have been coming for quite some time now. Della told me that they attend several meetings all over the country, such as the West Country, Wales, their local Hitchin, of course, and indeed the AGM: what tremendous support and interest!



Members enjoying an afternoon in Milford

New attendees on the day were Margaret and Tom Caluori and Gary Cliffe, and we also had the great surprise of a threesome from Sheffield, Linda Ryan, her daughter Michelle and son Sean. Well done for making the long journey.

Phil Burton devotedly ran the raffle (which made £84 this time, out of gifts brought along by members) and he still receives postage stamps from attending members: his sale of this builds up into a fairly substantial ongoing income.

John Moore

Region 3

Della Brookman, the coordinator for this area has a new mobile telephone number. Della can now be contacted on 07710637941

Forthcoming Events:

North West Meeting (Region 9)

Saturday March 16th 2pm – 6pm
St. Helens South Premier Inn
Eurolink, Lea Green, WA9 4TT
See page 4 for further details
Call Ian Bennett on 01202 849391

Afternoon tea Regions 1 & 2

Saturday April 20th 3pm – 6pm
Milford Day Centre
A representative from the local Citizens Advice Bureau will be speaking about benefits.
Call Jane Bennett on: 020 8853 4089

Region 4 get together

Saturday April 13th 2pm onwards
The Dartmoor Lodge Hotel, Ashburton
Call Ian Bennett on 01202 849391

HSP Support Group AGM

Saturday June 15th
Trident Technology and Business Centre
Leamington Spa
Full details in next Newslink

The Mobility Roadshow

Telford International Centre TF3 4JH
27th, 28th & 29th June
www.mobilityroadshow.co.uk

New Members

We welcome the following new members

Frank Haynes
Brighton
Region 1

Gloria Winson
London
Region 1

Sarah McCulloch
Glasgow
Region 11

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

Ask the Physio

Physiofunction have kindly agreed for us to have an 'Ask the Physio' column in our Newsletter. The first question we asked was how we can help back problems which are common in HSP.

Back Pain in HSP.

Back pain is often an unwelcome consequence of HSP and can be very debilitating and make day to day activities increasingly difficult or painful.

So why is back pain so prevalent?

Our spines are designed to bend, twist and turn. This is achieved by lots of little joints in the spine being moved in a particular direction, by a number of different muscles. The movement requires the right muscles to do the right job, at the right time. If we accept that the resting position of a joint and it's movement is dependent on the muscles acting on it, it becomes clear that changes in muscle function can have significant effect. Over and under activity in different muscle groups or the presence of spasticity frequently results in changes to joint position and movement. It is common that individuals with HSP adapt the way they move or rest to achieve or maintain function. If sustained over a period of time, these altered movement patterns can result in pain as joints and muscles are not moving as they are intended to.

Depending on the severity of the back pain you are experiencing, treating back pain can be managed by self-directed exercise or may need to be assessed and treated by a physiotherapist. If you are experiencing pain that is disrupting your sleep, limiting what you are able to do (i.e. pain when sitting or walking) I would suggest you need to seek professional advice.

Self Management - Stretching and Core Strengthening

Stretching

Any form of inactivity or movement dysfunction is usually associated with some progressive stiffness. Therefore, it is necessary to gently stretch the lower back. Individuals with long term pain may find it takes weeks or months of stretching to mobilise the spine and soft tissues, but will find that the increase in motion provides meaningful and sustained relief of their back pain.

Strengthening Exercises

Core strengthening

Core stability training is essential for back pain. The body's core muscles are the foundation for all other movement. The core muscles of the spine act like a natural corset around the back that provides stability and support during movement.

These core muscles lie deep within the torso. They generally attach to the spine and pelvis. When these muscles contract, the spine becomes stabilized creating a solid base of support. We are then able to generate powerful movements of the limbs.

Training the muscles of the core also corrects postural imbalances that can lead to pain. The biggest benefit of core training is to develop functional strength - that is, strength that is essential to both daily living and regular activities.

The main concepts of core strengthening programs involve using many muscles in a coordinated movement. Rather than isolating a specific joint as in most weight lifting, stability exercises focus on working the deep muscles of the entire torso at once.

Dynamic stabilization exercises

These exercises involve the use of a variety of exercises and can include the use of gym balls. The point of dynamic stabilization exercises are to strengthen the secondary muscles of the spine and to help support the spine through various ranges of motion.

Low-impact aerobic conditioning

Conditioning through low-impact aerobic exercise is very important for both pain management and maintenance of the lower back. Aerobically fit patients tend to have fewer episodes of low back pain, and tend to experience less pain when an episode occurs. Well-conditioned patients are also more likely to maintain their regular routine, whereas patients with long term low back pain who do not work on aerobic conditioning are likely to gradually lose their ability to perform everyday activities.

Examples of low impact aerobic exercise that many people with back pain can tolerate include:

- Water therapy/ Swimming (also called pool therapy or hydrotherapy). For people with a great deal of pain, water therapy provides a gentle form of conditioning as the water alleviates gravity and provides buoyancy as well as mild resistance. Swimming is also a great all round aerobic exercise.
 - Walking. Many people think that walking as part of their daily routine (e.g. at work or while shopping) is enough. However, this stop-and-start type of walking is not adequate for aerobic conditioning. Instead, continuous walking at a sustained pace for a minimum of twenty to thirty minutes is required to provide aerobic conditioning. In HSP you may need input from a Physiotherapist to look at your walking pattern and help re-train it to achieve these benefits.
 - Stationary biking. Riding a stationary bicycle provides aerobic conditioning with minimal impact on the spine. This is also a good exercise option for people who have limited mobility.
-

Examples of exercise you can do at home:

I would advise that performing any new exercises can result in pain exacerbation. If in doubt seek input from a physiotherapist.

Sarah Daniel

Consultant Neurological Physiotherapist

PhysioFunction

Cat Stretch



Starting Position: Kneeling on the floor with your head and forearms resting on the ball, your back in a neutral position and hips and knees at 90 degrees.

Movement: Gently arch your back up like an angry cat. Hold this position for 5 seconds and slowly lower your chest and stomach to gently curve your back. Hold for 5 seconds and repeat.

Repetitions: 2 x 10 Repetitions (20)

Progression: Gradually increase the movement as your back becomes more mobile.

Caution: Do not force the movement so there is discomfort and stay within your pain limits.

Ball Hug



Starting Position: Kneeling on the floor with the ball in front of you.

Movement: Gently reach forwards over the ball with your stomach supported on the ball. Hold this position for 15 seconds.

Repetitions: 5 x 15 second holds.

Progression: If comfortable with the first part of the stretch progress to pushing through the toes and raising the knees off the floor, increasing the stretch. Hold as above.

Caution: Do not force the stretch so there is discomfort and stay within your pain limits