



HSP Newslink

The Newsletter of the Hereditary Spastic Paraplegia Support Group
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HSP & FSP – Hereditary Spastic Paraplegia,
Familial Spastic Paraplegia & Strumpell-Lorrain Syndrome

Arthur's Paralympics Target



Arthur competing recently at The British Para-Swimming International Meet in Glasgow

Arthur Morley is a 16 year-old Fareham Nomads swimmer, who has Hereditary Spastic Paraplegia. He has recently been voted Portsmouth Junior Disability Sportsperson of the Year. He has been selected to be part of the Hampshire Talented Athlete Scheme for 2015-16 and also for the Amateur Swimming Association Development Programme for swimmers with podium potential. The Swanmore College student was inspired to take up swimming competitively after

watching the London 2012 Paralympics. He now has his sights set on competing in a future Paralympic Games.

At a recent appointment Arthur's physio remarked on how remarkably well his body is working considering his impairment. Psychologically, swimming has certainly helped him with the undoubted challenges of being a teenage boy with a disability plus it has given him a great outlet for his competitive streak.

Arthur's most recent competition was the British Para-Swimming International Meet in Glasgow where he competed amongst swimmers from 15 other nations. His competition schedule will be quieter over the summer whilst he takes his GCSE's but he will continue to train hard-up to eight times a week.

The following is an excerpt from a recent newspaper article: Coach Stewart Crowe has been delighted with Morley's performance in recent championships. He believes Arthur's progress has been remarkable after he only joined Fareham Nomads last January. He feels the talented teenager can go on and achieve plenty of success in the sport. He said: 'Arthur performed fantastically at the disability championships and should be proud, having beaten some strong swimmers. Over the past 12 months he has shown much improvement and is gradually edging towards his goal of Paralympic squad selection. Arthur doesn't make excuses if he can't do something. Every now and again I have to tell him if he's not performing but he keeps pushing himself further and never expects special treatment. I don't think Arthur really comprehends how far he has come. Sometimes he thinks he should have done better'.



'He once left a competition disappointed that he set only four personal bests in five races. This is a great achievement for any swimmer, so he needs to put in perspective how much he has achieved. Over the past year, Arthur has gained recognition for his

increasingly impressive performances in the pool. He is also currently ranked first in his age range for S8 breaststroke and second for S9 butterfly and freestyle, marking a meteoric rise for the teenager'.

Looking ahead, Crowe is certain the Fareham youngster can continue to improve. Beyond that, his target will be to swim in the competition that first ignited his passion. Crowe added: 'He is an intelligent lad who does well in school and is really well accepted within his peer group. He's been racing competitively for only two years, so the progress he's made has been fantastic. If he continues as he is going, he stands a good chance of making the Paralympics. It's up to him and how hard he wants to work.'

Tamsin Rowlinson & The Portsmouth News

Chairman's Column

This is definitely the longest HSP Newslink I have ever compiled and this is all down to the input I've received from members.

Thank you very much for all your contributions, please keep up this great input which makes my job much easier and the newsletter a far more interesting read. Thanks also to Adam Lawrence for his very interesting column discussing the results of his latest HSP survey.

You'll have received notice of the AGM with this newsletter together with a form for confirming attendance and a nomination form to elect members to the committee. Please have a serious think about this. It is my intention to stand as chairman for one more year. There's an agenda for this years AGM included later in this issue.

Although the AGM is our main meeting, I'm delighted to say that our regional meetings are thriving. We now have meetings in St Helens, Colchester, Norwich, Hitchin, Milford, Porthcawl, Birmingham and Ashburton. You will also notice that another meeting in Scotland has been organised on May 30th. All these meeting

are very important and the hard work of all those involved in putting them together is invaluable.

I'm planning to be at a meeting in Madrid on June 1st and 2nd where almost every HSP organisation in the world is getting together, including the Americans and Australians. Hopefully I can give you some interesting feedback on this in the next issue.

People continue to participate in some amazing fundraising events for us. Several people have done, or are about to do running events including the London Marathon and we have been pleased to be able to provide HSP running vests. I recently went down to Bideford to support a member's niece who was running in a half marathon for us. Peter Bateman continues to do an unbelievable job selling pens on counters all around the Porthcawl area of South Wales. At the recent Ashburton meeting I witnessed him surprise our treasurer by handing over a serious amount of cash. Sally Meikle-Janney has also

recently been involved in a great fundraising scheme at the gym where she works. You'll read about this later in this Newslink. I know of three pubs that are raising money for us including Terry Duffy's local, The Royal Standard in Woodburn Common and The Amberwood on the Dorset /Hampshire border. I have only named a few but to all individuals and organisations who have been involved in fundraising for HSP, I can't thank you enough. It is my wish that one day the HSP Group will be in the position to make a significant grant to a research project.

Annual subscriptions are due on May 1st. A special thanks to all those who have renewed by Standing Order. If you wish to set up an SO please email or write to John Mason to get a form. To date 72% of our members pay by Standing Order.

I look forward to seeing many of you at our AGM on June 20th.

Ian Bennett

Adams Research

Readers may remember back in autumn I launched my second survey which some of you subsequently completed. I have now completed my analysis and published the results. The text below is the same as reported on my blog, where there is a link to a full version of the results for anyone who likes looking at results in greater detail: <http://hspjourney.blogspot.co.uk/2015/02/2014-survey-results.html>.

Many thanks are due to the 97 people who gave their time and completed the survey, predominantly from the USA and the UK – this wouldn't have been possible without you.

In similar news people may be interested in a new study which shows that Dalfampridine/Ampyra has benefits for HSP. There are more details on this on my blog! As always I welcome any feedback and suggestions.

Mobility Analysis

All 97 respondents gave answers to this question. Around half of respondents use walking sticks/poles/crutches/canes and around two fifths of respondents use a wheelchair or mobility scooter. FES is the aid used by the least number of people, with a take-up of around 5%.

The results also allow the distribution of respondents within a scale of mobility which I devised last year. This is an "HSP mobility score" which allows me to cross-reference mobility against the other questions in the questionnaire. The definition of the HSP mobility score is:

- 0 No mobility effects
- 1 Can walk without aids but some effects
- 2 Orthotics/AFO/FES and/or Sticks/Poles/Crutches/Canes some of the time
- 3 Sticks/Poles/Crutches/Canes and Frame/Chair some of the time
- 4 Sticks/Poles/Crutches/Canes most of the time
- 5 Sticks/Poles/Crutches/Canes all of the time
- 6 Rollator/Walking frame most of the time
- 7 Rollator/Walking frame all of the time
- 8 Wheelchair/Mobility scooter most of the time
- 9 Wheelchair/Mobility scooter all of the time

Overview of mobility aids used

Mobility Aids Used - Overview:	Respondents	Percentage	Mobility Score
Those without aids	19	20%	0-1
Those who use mobility aids some of the time	24	25%	2-3
Those who use sticks most/all of the time	24	25%	4-5
Those who use frames most/all of the time	13	13%	6-7
Those who use chairs most/all of the time	17	18%	8-9

Medication

I wanted to explore which reasons people take which medicines for and how effective they perceive those to be. In total 91 respondents answered this question. There were 68 people who indicated that they took at least one medication and 23 respondents who indicated that they did not take any medication at all.

Around three quarters of people are prescribed at least one form of medication for their HSP. Of the 23 who responded that they did not take any medication 10 indicated that they have not ever been on medication for HSP. The other 13 had previously been prescribed at least one medication, but no longer take any either because of side effects, because the medication was not effective or a combination of both. Naturally, readers should consult with their doctor if they wish to change their medications.

The majority of respondents included which symptoms they took their medication for, as shown for symptom experienced by at least 10 respondents;

Symptoms that people take medication for

Symptom	Number of medications taken
Spasticity	49
Pain	29
Bladder	22
Spasm	19
Depression	12
Nerve Pain	10

Spasticity and Spasms

Almost half of the medication being taken is used to treat spasticity and spasms, the key features of HSP. The biggest proportion of this group of medications comprises people taking Baclofen. The list of medications where at least 5 respondents are taking is shown in the following table, with descriptions of the medications taken from the UK NHS and drugs.com websites.

Spasticity and Spasm Medication

Medication	Description	People taking medication
Baclofen	Baclofen reduces muscle tone and unwanted muscle contractions. This helps to reduce painful muscle spasm.	43
Botulinum toxin A / Botox / OnabotulinumtoxinA	Botulinum Toxin Type A is used to treat muscle spasms. It works by stopping muscle contraction in the muscle that it is injected into. This prevents muscle spasm. It also blocks pain signals, which indirectly block the development of a migraine.	7
Diazepam	Diazepam is a medicine which helps to control feelings of anxiety. It makes people feel less agitated and less tense. It also acts as a sedative and an anticonvulsant. It can help to relieve muscle spasm.	7
Tizanidine / Zanaflex	Tizanidine reduces muscle tone. This helps to reduce painful muscle spasm. The effect of Tizanidine usually lasts for a few hours.	6

Baclofen

43 Respondents indicate that they take Baclofen for HSP symptoms. The symptoms, as described, fall into two areas, spasticity, with 31 respondents and spasms, with 7 respondents. 6 of the respondents indicate that they take their Baclofen through an intrathecal pump whilst the other 37 take tablets.

In addition there are 26 other respondents who indicated that they have tried Baclofen in the past, but no longer take it, including 1 who used use an intrathecal pump.

The 38 respondents who currently take Baclofen for spasticity and spasms cover the full range of mobilities. Daily doses range between 10mg and 180mg for oral tablets. Generally, the dose of Baclofen is higher with increased spasticity/loss of mobility, but there are exceptions to this trend both ways. 15 Respondents indicate that their dose has increased over the years, with 5 respondents indicating no change.

31 of the 38 respondents who currently take Baclofen gave details of their side effects. 10 respondents had no side effects, 11 respondents found Baclofen made them sleepy or drowsy. The other 10 respondents indicated a range of side effects including bowel/bladder issues, dizziness, dry mouth, stomach ulcers, blood pressure issues and short term memory loss.

Of the 26 respondents who indicated that they no longer take Baclofen, 19 indicated why they had stopped taking it. 9 respondents indicated that they did not perceive any benefits from the medicine, 3 indicated it made them too drowsy/sleepy with the other 7 generally noting side effects outweighing benefits.

Most respondents indicated that the benefits of Baclofen have not changed over the years whereas other respondents were not sure if there had been a change. One respondent noted a “huge” difference moving from tablets to an intrathecal pump.

Respondents showed that, on the whole, people currently perceive benefits from the medicine, it is important to them and they follow the prescribed dose. There are some

respondents who take the medicine but who do not perceive any benefits. The majority of respondents who currently take Baclofen would recommend it.

Baclofen is one of the recognised treatments for HSP. The first paper to mention the use of Baclofen to treat HSP seems to date from 1989, in the Journal of the Medical Association of Thailand (PubMed ID: 2738487). Papers continue to be published on this into 2015, with just over 20 papers altogether.

Botulinum Toxin Type A

7 respondents indicate that they take Botulinum Toxin Type A for treatment of HSP symptoms, predominantly spasticity but also spasms. This is commonly known as Botox, although there are several different types of treatment. For ease I will refer to this treatment as Botox in the remainder of this section. One respondent indicated that they have previously taken Botox but no longer take it because it ceased to be effective.

All respondents who take Botox use mobility aids to some degree with mobility scores ranging between 3 and 9. Typically Botox is injected every three months and the effects are noted as lasting for between a few weeks and a few months. Side effects are generally not experienced, although one respondent noted weakness for around a week after injection. Apart from one respondent, Botox is perceived as having benefits and would be recommended to others.

Botox is one of the recognised treatments for HSP. The first paper to mention the use of Botox to treat HSP seems to date from 2003, in the journal *Developmental Medicine & Child Neurology* (PubMed ID: 14667075). Papers continue to be published on this into 2015, with 4 papers altogether.

Diazepam

7 respondents indicate that they take Diazepam for treatment of HSP symptoms, predominantly spasticity but also spasms. No respondents indicated that they have previously taken Diazepam but no longer take it.

All respondents who take Diazepam use mobility aids to some degree with mobility scores ranging between 3 and 8. Typically one dose is taken daily, often at night, although some take more frequently and less frequently than this. The principal side effect noted is sleepiness, by 4 respondents. Diazepam is generally perceived as having benefits and would be recommended to others.

Diazepam is mentioned in one HSP paper from 1989, in the Japanese journal *No to Shinkei - Brain and Nerve* (PubMed ID: 2803825).

Tizanidine / Zanaflex

6 respondents indicate that they take Tizanidine for treatment of HSP symptoms, for both spasticity and spasms. 10 respondents indicated that they have previously taken Tizanidine but no longer take it, either due to side effects or to no perceived benefits.

Most of the respondents who take Tizanidine are able to walk, with 4 having a mobility score 3 or less, with one respondent scoring 5 and one scoring 8. The principal side effect noted is tiredness or fatigue, by 5 respondents. Those who currently take Tizanidine generally perceive it to have benefits. There are some reservations recommending it to others.

Tizanidine is reported as having benefits for spastic paresis in 1982, in the Journal of the Neurological Sciences (PubMed ID: 7035623).

Other Treatments (Fewer than 5 respondents)

Of the other treatments for spasms and spasticity taken by respondents, only Levodopa is described as a treatment for HSP in the Movement Disorders Journal in 2006 (PubMed ID: 16463348). It is interesting to note, however, that Nabiximols/Sativex is reported to also control pain and has benefits on bladder issues, that Dalfampridine/Ampyra is reported to reduce fatigue and that Levodopa is reported to improve the control of muscles. One respondent indicated that they had a spinal cord stimulator implanted which was the biggest benefit they had of all.

Pain

Many people are taking a range of painkillers, some are over-the-counter medicines like paracetamol right through to strong opioid medication like morphine. At least 5 respondents are taking antidepressant or anticonvulsant medication as shown in the following table;

Pain Medication

Medication	Description	People taking medication
Amitriptyline / Elavil	Amitriptyline is a tricyclic antidepressant. It is also a medication that is used in management of long term (chronic) pain, especially nerve pain. It can also be used for improving sleep. It is prescribed in low doses for managing pain and is not addictive. Amitriptyline is also used for the treatment of bedwetting in children	6
Gabapentin / Neurontin	Gabapentin is an anti-epileptic medication, also called an anticonvulsant. It affects chemicals and nerves in the body that are involved in the cause of seizures and some types of pain. It is also used to treat restless legs syndrome (RLS).	6

Amitriptyline / Elavil

6 respondents indicate that they take Amitriptyline for treatment of HSP symptoms including nerve pain, pain and restless legs. 1 respondent indicated that they have previously taken Amitriptyline but no longer take it, due to trying a different medication at the moment.

The respondents who take Amitriptyline include most of the full range of mobility, having a mobility score between 2 and 9. In terms of side effects, 4 respondents note no side effects with 2 noting tiredness. Based on the 6 respondents currently taking Amitriptyline, it is perceived as having benefits and would be recommended to others. None of the respondents indicated that they take Amitriptyline for bladder issues, but this medicine can be prescribed to treat bedwetting in children by helping the bladder wall to relax.

Amitriptyline is not reported in any HSP papers.

Gabapentin / Neurontin

6 respondents indicate that they take Gabapentin for treatment of HSP symptoms, predominantly nerve pain and also pain. 7 respondents indicated that they have previously taken Gabapentin but no longer take it, 2 indicating because of side effects and 2 because of lack of perceived benefit.

The respondents who take Gabapentin use mobility aids to some degree with mobility scores ranging between 3 and 8. In terms of side effects, all respondents note side effects including tiredness/drowsiness (5 respondents), dry mouth (1 respondent) and unpleasant dreams/thoughts (1 respondent). Based on the 6 respondents currently taking Gabapentin, it is generally perceived as having benefits and would generally be recommended to others.

Gabapentin is reported in one HSP paper from 2007, in the European Journal of Neurology (PubMed ID: 17539946) although this indicates no difference in tests between Gabapentin and a placebo.

Supplements and Diet

Respondents were asked to give details of supplements that they take. 58 respondents answered this question. Six of these indicated that they did not take any supplements and 52 indicated that they took at least one. Generally people take up to 3 supplements with a small number taking more than this.

Eight respondents are certain that they get benefits from taking magnesium to reduce spasms/cramps and to relax muscles, including bladder muscles. There is one paper which reports using magnesium glycerophosphate to reduce spasticity in paraplegia caused by MS (PubMed ID: 11136367). There were two respondents who were certain that taking cranberry tablets was beneficial in maintaining a healthy bladder.

There was also a general question about dietary changes. 39 respondents have not made dietary changes and 32 people had made changes. There were 7 respondents who made changes due to bowel issues, with some adding more or cutting down on fibre and/or fruit/vegetables. One respondent avoids caffeine and alcohol due to bladder issues. Low/No gluten and carbohydrate diets are mentioned as giving benefits to several respondents, with one noting improved mobility on a gluten free diet and another noting reduced inflammation with a low carb diet. One respondent limits alcohol to assist with balance, and another notes caffeine and sugar make their symptoms worse. Seven respondents have just made general health improvements in their diet, including two partly as a result of weight gain from reduced mobility.

It is worth noting that the Spastic Paraplegia Foundation website indicates that “There are no known studies indicating that vitamins or food supplements are an effective treatment for HSP.” (<https://sp-foundation.org/understanding-hsp-pls/treatments-and-therapies/>). Any readers wishing to make changes to their diet or to change any supplements being taken may wish to consult their doctor.

Exercise and Relaxation

The final section of the questionnaire looked at respondents exercise and relaxation routines. Overall 90 respondents answered this question. The following table shows the distribution of answers given.

	Stretches	Yoga etc.	Weights	Power plate etc.	Cardiovascular	Walk/Run/Cycle	Swimming	Massage	Aromatherapy	Acupuncture	Physiotherapy	Chiropractic
I do this several times a day	8	0	0	1	1	1	0	0	0	0	1	0
I do this daily	38	8	8	2	1	15	2	1	0	0	5	0
I do this weekly	9	5	13	4	13	17	14	9	3	2	13	1
I do this monthly	4	2	0	1	0	1	0	10	1	2	10	1
I do this occasionally	17	3	13	2	8	20	23	13	3	4	10	5
I don't do this	11	55	42	61	50	24	35	42	59	63	34	62
Total Answers	79	73	76	70	72	77	74	75	66	71	72	69

This shows that stretches are the most common form of exercise being undertaken with over 85% of respondents doing this. Other activities which are commonly undertaken include weights, cardiovascular machines, walking/running/cycling, swimming and physiotherapy.

Of the 90 respondents only one did not undertake any of the activities or indicate other activities. Respondents who undertake activities weekly or more frequently are grouped together as undertaking that activity “regularly”. Overall 71 respondents undertake at least one activity regularly.

To look at this in more detail Yoga/Tai-Chi/Pilates, Weights, Power plate/circulation booster, walking/running/cycling, swimming and physiotherapy are grouped together as “exercise”. Overall 81 respondents undertake at least one exercise activity, and 66 of these undertake at least one of those activities regularly (weekly or more often). Grouping the other activities together shows that these activities are undertaken regularly, but the general take-up of the other activities is lower than the exercise activities.

This information shows that for people who do not use mobility aids at all (mobility score 0 or 1) over 80% undertake at least one activity regularly. Activities are likely to include walking/running/cycling. Many respondents also do stretches and take part in swimming. Other activities undertaken include physiotherapy, massage, yoga/tai-chi/pilates, weights and cardiovascular.

Almost 80% of people who use mobility aids some of the time (mobility score 2 or 3) take part in at least one activity regularly. Activities are likely to include stretches and walking/running/cycling. Many respondents also take part in weights, swimming and physiotherapy. Other activities undertaken include cardiovascular, massage and yoga/tai-chi/pilates.

Three quarters of people who use sticks most or all of the time (mobility score 4 or 5) take part in at least one activity regularly. Activities are likely to include stretches. Many respondents also take part in physiotherapy and walking/running/cycling. Other activities undertaken include massage, swimming and weights.

Two thirds of people who use walking frames most or all of the time (mobility score 6 or 7) take part in at least one activity regularly. Activities are likely to include stretches. Many respondents also take part in walking/running/cycling. Other activities undertaken include physiotherapy and weights.

Almost 90% of people who use wheelchairs most or all of the time (mobility score 8 or 9) take part in at least one activity regularly. Many respondents take part in stretches. Other activities undertaken include swimming, physiotherapy, massage, weights, power plate/circulation booster and aromatherapy.

HSP Group Funds

Funds are 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. Completion of one year's membership is a requirement for applicants. If interested, please request a grant application form from a committee member.

Useful Information

Countryside Mobility

Later in this newsletter you'll read a letter from Mike Cain describing his visit to Mount St Michael in Cornwall where he used an all terrain tramper mobility scooter. I've used trampers myself and they're excellent for getting out and about in environments we couldn't usually consider due to inaccessible terrain. For this reason I thought I'd highlight an organisation called Countryside Mobility.

Countryside Mobility South West is a not for profit mobility equipment hire scheme working to improve access to the countryside for people with limited mobility living in or visiting the region.

Explore the South West with freedom and ease. Access areas that may have been difficult or impossible in the past and experience everything that being outdoors in the region can offer.

Countryside Mobility provides safe, enjoyable and easy access to the South West's countryside and visitor attractions for anyone who has difficulty walking, through an off road mobility scooter hire scheme.

Their all terrain mobility scooter hire is available at a wide range of wheelchair accessible outdoor visitor attractions and their wheelchair accessible Wheelyboats provide access for all to inland lakes and waterways.

For more information visit:
<http://www.countrysidemobility.org/>

Members' Letters

Travelling with HSP

Different people have different needs and aids. I have neither aids nor car and rely on public transport and places being what they say they are. I do a lot of planning in detail, but I enjoy planning and using Google street view to look where I am going and what it looks like so I don't have a lot of walking about looking for the way in.

Unless I have been before, planning starts several weeks before either because a friend has offered to drive or cheap rail tickets become available. (if you are planning a rail trip, the cheapest advance tickets go on sale about 12 weeks before a journey). A Disabled Railcard is useful, not least because it allows TWO people to travel at about two thirds the cost. Having a rail ticket is often useful to get cheap admission to attractions – sometimes it is worth buying a rail ticket (any ticket) as holding a valid ticket gets the discount even if you haven't travelled by train.

I book by telephone using RAIL ASSISTANCE which all train companies are obliged to provide at no cost to passengers. It helps to know about seats and access (for example I know where I want to sit so I can cope with toilets and refreshments) On Virgin pendolino trains it is C1/2 in standard class as they are next to the buffet and have a table and loads of grab rails; in first class I choose H36 because it is near a toilet and had something to hold whilst walking. Refreshments are brought to seat, include spirits and wine as well as food and are free.

Booking via rail assistance is a bit of an insurance. When a lift wasn't working in Wales, the train stopped at some rural location where a luxury taxi awaited to take me and friends to another station to connect back to Manchester (they were very impressed), and in Scotland when bad

weather stopped trains, a taxi took me the 1 hour journey from the Highlands to Perth to take a train to Edinburgh and home. It's useful because buggies drive around main stations and wheelchairs are brought up at others.

So far I have been to London, Norwich, Cornwall, Aberystwith, Thurso and Orkney as major journeys and others as well. In Orkney it was useful to be prepared as the ship could not open the foot passenger walkway, which I had judged I could cope with. Their alternative was to ask foot passengers to go ashore through the car deck. Am I glad I asked for a wheelchair. It was a long way and UP a steep and bumpy ramp to the quayside.

So with a lot of planning and using Google street view, and speaking with people on the ground I confidently journey to interesting places and generally travel alone.

A visit to Mount St Michael in Cornwall

I had always wanted to visit this off shore tidal island near Penzance, so when a friend offered to drive me I took the opportunity.

Whilst the tide is out, a causeway from the mainland is open, but when the tide is in, boats travel but some landings are not accessible except to the fittest.

I set about working out what I could and could not do. The first obstacle was getting from the mainland to the island. The second was getting around the island.

The island has a website which I read and whilst the National Trust manages the place, it is also part of a private estate. I looked at the causeway which seemed the only way across that I could manage, but thought that the number of people might be a problem. I hadn't thought of the number of vehicles that utilise this to service the island.

After a bit of work, I got to speak with the estate and after several discussions, they offered to take me to and from the island by 4 wheel drive and use a Trampler around the island. A Trampler is an electric scooter that is particularly stable and rugged.

They arranged a parking place right by the place that the 4WD would come to pick me up. It was a 4WD because there is still some water and rough places, and we went across the beach.

On the island I was given an introduction to the Trampler. It was so easy, and remember I had never driven anything before. Within 5 minutes I was off across the cobbles and into the garden and up the hill.

Getting to the top was beyond me. My friend looked and even fit people were having difficulty with the medieval boulders and steps. So I had a coffee whilst she went up.

All in all it was a wonderful sunny day, but I now need to work out how I'll get to the top!!

I suppose it took a month of planning

We went to other properties in Cornwall, and all had walking aids available and some had electric scooters and again it is worth phoning ahead to get precise details and parking places near the aids.

The South West seems most organised than other regions, and I want to spread the availability of aids available to those who arrive. On Lindisfarne, another tidal island off the North East Coast, it is easy to get there by bus or car, but once there it is not possible to get around.

There are country parks, lakeside paths, woodland glades and coastal promenades and paths. All are inaccessible to those without their personal walking aids, yet all have disabled parking spaces and toilets and are paid for by us all. It's these places that people like me should be able to use.

How to do this is a challenge especially as councils are limiting services. (I found that my local council had a Trampler, but I found out about it because they were about to decommission it. Nobody had ever used it. Nobody knew it was there, and when asked, it was in disrepair and had never been maintained.)

Both the above from Mike Cain

Scalding

My wife Joan scalded herself with a mug of Horlicks she was carrying in her lap in her wheelchair last Friday. Although I was there in seconds, with three pans of cold water, wet cloths and frozen veg bags, her inner thighs got badly burned.

She's getting excellent care from Broomfields adult burns unit and daily dressing changes at home.

In Joan's case, we failed to realise that the hot liquid had pooled round her thighs in the wheelchair cushion. We also missed the blistering there when checking with 111, though we saw it after ten minutes and called them back. They got the ambulance out to get her to A&E - an essential move as it progressed to horrific injury to both inner thighs.

Joan had her mug in a saucer on her lap! Never again!

It's worth looking at devices/aids to use to carry hot meals and drinks safely in a wheelchair.

Also worth providing advice on what to do if you do suffer a scald. Obviously, lots of cold water, hot clothes off, cold cloths and frozen veg packs - but from our experience, the most important thing is not to think it's not that bad.

If there is any sign of blistering, you WILL need urgent treatment at A&E and probably a specialist burns unit and face some months of treatment. The danger is in not realising this soon enough. The damage continues to spread.

If possible, put cling film over the affected area to keep it clean.

The nature of the liquid is important too. The tremendous damage Joan received was from Horlicks made with three quarters hot water and one quarter cold, plus a teaspoon of sugar. The sugar causes heat to be retained for longer.

At A&E, you will be asked so many times by multiple people what happened. If possible, I recommend making notes

including your details, allergies etc so you can show these to each enquirer.

Note that lack of pain is not a good sign as it indicates deeper damage.

We think 111 should have advised instantly calling an ambulance when blistering was notified. The delay waiting for a call back from a Clinician should not have occurred, given the location of the blistering scald.

Joe Cooke

Our Story

At the age of 2 we noticed Amber walked flat-footed and toes slightly turned in. We were referred to NHS physio and they gave us some exercises and said she would grow out of it.

Around the age 7 she was still the same and often complained of pains in her legs and knees. I always tried to get her to walk "heel, toe". We returned to the GP who sent us to back to physio and podiatry. They decided she had growing pains and gave her insoles for her shoes.

A few years later she was still struggling and had outgrown her insoles so we were given replacements and they said she had Severs disease.

Then when she was 13 the bigger issues came in. Amber couldn't walk properly and couldn't put her heels down. We went back to the GP who referred us to Orthopaedics and podiatry who said "it's out of my area, it looks Neurological".

Many many months of waiting, back and forth to various hospitals. MRI scans, nerve conduction tests, blood tests, x-rays, Botox injections and I'm sure there are more, we were told its probably HSP. Amber has had genetic exome testing but all has come back showing nothing.

Progressively this condition has got worse. She had a baclofen pump fitted in September 2014, which has helped.

However her mobility is very limited. She first started using crutches, then a wheelchair, of which we bought her a

“trendy” chair costing over £2000.00. NHS provide such boring or as Amber would say “old person grey” equipment. Also she has a walking frame.

As a parent I can't sit around and do nothing.

Last year Amber decided to take up new hobbies to give her a focus away from her school studies and her condition. We contacted Disability Snow Sports UK and she now has mono ski lessons. This is where she sits down in a specially designed ski.

Amber is passionate about this sport and her instructor is so impressed with how well she has taken to this sport he wants to develop her to join the Disabled Ski Team, entering races and progressing towards the Paralympics.

But all this costs money.

First of all we have just held a fund raising event combining Fitness Classes and a Cake Sale. (I am a fitness instructor at our local gym). We set up a Just Giving Page for online donations for anybody who wanted to donate. This raised £467.32. We also raised £611.25 selling cakes and having donation buckets in the gym where I work.



Amber and Sally's cake stall at the gym

This money we have donated directly to HSP Support group.

Our next mission is to raise money to buy Amber her own mono ski in order to progress. We need approximately £4000.00.

I am now organising a 5km run, which Amber has called WALK, WHEEL, and WOBBLE wearing silly socks. This is taking place in our local park in Huddersfield on Saturday 4th July. There will be an entrance fee and all participants will also get sponsors. We are holding this in conjunction with the Park Run that is a free community event.

If anybody is local and would like to join in or donate, then please contact me on sally@coffeecommunity.co.uk

To keep positive Amber has created a fantastic video explaining HSP in easy terms.

<http://hspawareness.wix.com/spasticparaplegia> She has shared this with the HSP support group and many other places and had brilliant feedback. She is amazing.

Sally Meikle-Janney

“Time flies when having fun”

As we are already into the first quarter of 2015, I have been thinking of what I achieved in 2014.

As I write this I realise that anything can be possible with the right frame of mind and the help of great friends and family

The year started in France with family, we celebrated New Year 3 times.

South Africa, France and then UK.

It was great spending the time in France, getting to see the lovely scenery and was able to go on most walks using my scooter. I flew there and back and had no problems with scooter.

January disappeared very quickly and then started getting excited for Thailand. It was great being able to pack just summer clothes, bag only weighed 13kgs.

I used my wheelchair and crutches as I knew Thailand would not be disable friendly.

Arriving in Bangkok by myself and finding a taxi was not too hard. The taxi driver was very friendly and taught me a few words that would come in handy, once we got to the hotel I was shocked at how hot it was.

The hotel staff were very helpful and helped me to my room. I then went on wheelchair around the market that was just outside the hotel. Got some lunch, everything was so cheap.

I then went for a swim to cool down and then to bed.

Got the same taxi driver the next morning, back to the airport, to meet my friends.

The two weeks were amazing, spending as much time outside as we could and enjoying the sights. I struggled a few times in getting around on the wheelchair, but friends were very helpful.

The two best moments for me was the boat ride, snorkelling was incredible. Getting in and out of the boat while it was moving was an experience.

The best of all was the ride on the elephant, I felt so balanced once I was on her.



Back for 2 weeks and then off to Dublin for St Patricks Day, that was good fun, gave Guinness a go, but not for me.

We had fun going around the Guinness factory, Dublin and visiting the coast by

train, Scooter was a life saviour after using wheelchair.

Went to South Africa in May to visit my mum and family, It was great spending the time with them all, we went down to Knysna by car, it was interesting having to drive a manual again after so long, got the hang of it after awhile .

When it came time to look for a new car, I did start looking about 6/7 months ahead. I loved my Honda Jazz that I had, had the last three times. I needed to look for something a bit bigger and think about getting a hoist for my scooter.

I am happy with my choice and the hoist is great, I use the scooter even more.

Once summer arrived it was time to enjoy the weather and spending time outside.

I tried a few new things and had so much fun.

Thorpe Park was great and went on most of the scary rides, I couldn't stop. It is something worth doing as most of the rides are easy to get on and off and there are people to help.

I did a few events with Sportability, will definitely try to do more this year.

I did Quad biking and archery, Archery is not that easy but worth a try.

Went waterskiing which was amazing, once the boat gets moving you feel quite balanced. As the boat goes round corners your two buddies come back in towards you and hold you up. Now that the weather is warming up, I need to get back there. The last Sportability event I did was going on quad bikes, other speedy motor things and then into a Land Rover, we went through the forest and water, was so exciting, thank goodness the guy was there to control the speed as steering was rather tiring.

Visiting RIAT once a year is always great, getting to see the aircraft as well as seeing old and new friends. Great seeing the new scholars get their certificates and bringing back such good memories.

Went to Krakow in Poland in August, for friend's wedding, The old town is stunning such beautiful architecture, was so easy getting around as it was all flat.

Spent a week away in York. Drove up with a friend and went to see a great friend and the sights. Was great to catch up and she drove us through the Moors which were gorgeous. We visited Harlow Carr, such beautiful gardens and then lunch and tea at Betty's Tea Room.

It was fun helping my friend up hills by pushing her wheelchair with scooter.

I still hesitate on where I can go on holidays because of my disability. After visiting Thailand my mind was opened. Once you start seeing all these lovely places you get the travelling bug.

This year is to be a quieter one, well I am trying

Caroline Begg

My trip to Venice.

Having read on the HSP page of Facebook readers misgivings concerning going to Venice, I thought I would provide details of my holiday there and how easy it was.

I should start by explaining that I am totally unable to walk more than a couple of steps and need to use my mobility scooter on any journey away from home. So our journey was based on this lack of mobility. We chose the overnight ferry to France and then used the toll roads because they are dual carriageway and much quieter. We stopped one night on route in Eastern France which provides an easy run into Italy via Switzerland, and with so many tourist attractions in the area, chose to stay on Lake Garda which is about a 2 hour journey into Venice.

We stayed in Simione a lovely resort on the southern end of the lake which provides easy access to other tourist spots such as Verona, plus lovely boat trips around the lake.

Driving into Venice across the combined road and rail bridge was easy, as was

parking the car which was free using my disability parking permit. It was then just a short hop on my scooter to the Vaporetto Water Bus terminal. There can be a slight problem when boarding because a greater number of passengers means the boat will sit lower in the water, so a greater step down when boarding, but no real problem. The secret here is to pick up a tourist guide that shows the many water bus routes, so that you can pick your route and avoid bridges, but this is all part of the fun of Venice and despite my limitations was able to take in the whole experience, something that you could do too. We even managed to get to some islands in Venice Lagoon. It really is a must do.

Peter Axten

Visit to Mexico

I never expected to travel to Latin America but our son, abroad for a year, was due to arrive in Mexico in January and getting there offered the only chance for me and my wife Anne to see him for many months.

So we went to Mexico in January for a fortnight spent partly visiting the ruins of the Mesoamerican Mayan civilisation (amazing and fascinating) and partly lazing in a beach resort in the sun (fantastic after leaving England in a grim cold January). And we saw our son and his girlfriend, which was wonderful.

So we loved Mexico, but this article isn't a travelogue, it's a discussion of the difficulties of long distance travel and travelling around when you have HSP, at least as those difficulties impinged on me; and a discussion of the strategies we developed to deal with them.

I should start off by saying I am fortunate, as HSP sufferers go, in having some mobility if I use a stick, though very slow and ungainly. The best form of mobility assistance for me is an orthotic splint on my right leg which makes my walking faster and less ungainly, but which if used over a certain length of time gives me blisters and substantial pain. I counter this by putting

bandages and other padding on the vulnerable parts of my right foot and ankle. That's the background. A trip to Mexico posed big new challenges.

1. Getting through the airport, where considerable walking is difficult to avoid.
2. Coping with an 11 hour flight from London to Cancun in the Yucatan, Mexico.
3. Coping with a 1,000 mile trip in a cramped mini-coach with eight other people to see the Mayan sights.
4. Getting round the archaeological sites which are very big (substantial cities some of them) on rough ground with a lot of scrambling about.

How did we cope with all this? I have a list of points that I've compiled looking back on the experience.

Point A: You have to want to do it. I did want to do it, to see my son and, if I was going there, to see as much of the country as I could.

Point B: You need consistent support. My wonderful wife provided unstinting support, psychological as well as physical, the whole time.

Point C: You should get the maximum assistance you can all the time and never hesitate to ask. We asked for, and got, wheelchairs to transfer me to the boarding gates at Heathrow and Cancun, and to the exit gate (even to the awaiting coach) on arrival. I asked for bulkhead seats on the plane and they were provided by Virgin Atlantic on the day for no extra cost. (We were lucky the plane was not full.)

Point D: You have to recognise that when others are helping you have an obligation to do everything you personally can to maximise your mobility, not just rely on others. On the 11 hour flight I forced myself to walk round the plane every couple of hours to try and prevent my legs freezing up entirely. And treat your aids with commonsense and realism. I used the orthotic boot when I walked but took it off every time I was in a vehicle to prevent the pain and blisters building up.

Point E: You must be ready to be firm when it's necessary and accommodating when you can. At the beach resort (a huge place) our initial room was a significant distance from the facilities and on the first floor. My wife took it in hand and organised for a more convenient room on the ground floor. That was something the hotel could undoubtedly do, something to be firm about. On the mini-coach touring the sites my fellow tourists were a lovely bunch who let me have the seat with the most legroom. I was grateful, but made a point of saying each day that I was willing to move to another seat if someone else wanted a shot at the legroom. This was quite sincere, I would have moved, because I could have lived with a period in another seat and it's vital people don't feel you are using your disability as a weapon to get preferential treatment in cramped circumstances. In fact everyone insisted I stayed where I was, but making it clear you understand other people have rights too is vitally important.

Point F: Recognise there are some things you can't do. At the enormous site of Calakmul, the guide suggested I get back to the entrance in a strange kind of bicycle wheelbarrow powered by a grizzled old Mexican. I agreed because I could see I was holding up the rest of the party. At another site, Uxmal, I was told firmly that some of the climbing was too much for me. So compared with the others I didn't see everything, but you know that what have seen is a lifetime memory (it really was amazing) and you accept what you can get.

I am sure that my fellow members of the HSP support group have their own strategies and rules for dealing with the circumstances in which they find themselves. Everyone faces challenges which are individual and different. But applying intelligence, determination, commonsense, realism and a respect for the rights of others is, I suspect, something we all have to learn as part of the coping process.

Michael Horsman

West Highlands with HSP

I recently journeyed by train to Fort William and Mallaig and then took a ferry around the Small Isles

The weather was fine and sunny. The sea was calm and deep blue. The mountains were snowcapped and glorious pastel colours from afar whilst the scenery close by was spectacular.

I organised rail assistance from Manchester Airport Rail station, Wigan, Glasgow Central, Glasgow Queen Street and Fort William. It all worked extremely well both at the stations and on train. On reflection I would choose to route via Edinburgh Haymarket as it is a case of crossing platform, rather than crossing Glasgow. The tickets do allow this. It is also useful to book tickets on the assistance line for all people travelling. Then the seats are reserved together and the assistance line can book priority seats – that are roomier than others.

On the day we went to Mallaig and round the islands it was a glorious day and I had booked wheelchair assistance with CalMac – the ferry company.

I had looked on Google to see how far it was from the train to the boat, or rather the ferry terminal. I had organised that they would wheelchair me onto the boat and they left the wheelchair for when I returned. Am I glad I had! The access to the boat was down a long ramp formed by a concrete road onto which the boat had lowered another ramp which all vehicles and people used. There is no way I would have felt safe being wheeled by someone not used to the slope and certainly on return to Mallaig, a strong person was needed. In fact, the steward handed me over to a burly man to wheel me the 100 yards or so up to the top of the ramp and then to the terminal.

On the boat I was happy to move about and spent most of the 4 hours out on

deck in the sunshine. It was helped by the calm sea.

The coach to Inverness was a CityLink (normal long distance coach in Scotland) equipped with an access lift, comfortable seats and warm air conditioning. The journey was through the Great Glen along the length of Loch Ness and Loch Lochy taking in most scenic vistas along the water edge to the mountains.

One problem I found was that the Highlands do have a lot of slopes! Don't know why that is surprising. They had pedestrianised town centre areas but then it is often 'shared space' which planners seem to favour so that people and cars share the same what appears to be pedestrian paving which rapidly deteriorates from installation standards.

I did find taxi drivers were helpful as I used them for the 30 second drive from the station to my hotel

I had asked for a room with a walk in shower and that is what I got; no grip handles or roomy toilet.

Would I do it again – yes but I would route via Haymarket

Mike Cain

Regional News

Region 5 Norwich

On 14th March members of Region 5 met at the Oaks Restaurant, Premier Inn, near Norwich airport. We were lucky to have a neurology consultant from the Norfolk and Norwich Hospital come to answer questions put to him. He said that he enjoyed being with us and would like to come again to one of our meetings. At the end of our gathering all agreed that it had been a most pleasurable afternoon. We are going to meet again at the same venue on September 12th.

Barbara Jones

Region 7 - Midlands

We held our first meeting in this part of the region on Saturday 18th April, at the Kenrick Centre in Harborne, Birmingham - a very pleasant, modern building and meeting room, with light refreshments made available throughout the afternoon.

We had a lovely informal get-together, meeting new people, and catching up with old friends - a huge thanks to everyone who came along.



We had invited a sales rep from Monarch to tell us all about the Mobie Scooter that was highlighted in our September Newslink. We spent a good time trying it out, together with other mobility aids he brought along with him. It was all very low key, and was a great introduction to a 'sensitive' issue, but was all very informative, and we had a bit of fun too.

We have booked our next meeting also at the Kenrick, on October 17th 2015, from 2.30pm until 5.30pm and we'd love to see you.

Please feel free to contact Penny by email: pennycohen57@hotmail.com or mobile phone- 07818288738, to either let us know if you'd be interested in attending, or to find out more. We will also be at the AGM in Leamington Spa in June, and will ask Ian Bennett to point us out for any of you to come and say 'Hi'.

Penny Cohen & June Masding

Colchester Branch Meeting

Our first meeting in a village hall went ahead on 8th March at Feering Community Centre in Essex. Fourteen of us got together and chatted over tea, coffee and an impressive selection of cakes brought by members. Thank you to everyone for the cakes and for the help in setting up and clearing away. Sadly, a few members were unable to come because of ill health.

Rachel Elding from TGA Mobility demonstrated a selection of products including the Breeze mobility scooter, the Minimo, their smallest scooter, some wheeled aids and a battery pack which can be attached to a manual wheelchair to make life easier. She also brought some examples of the Safe Sip which is a universal cover for cups and glasses designed to reduce the risk of spillage. She stayed all afternoon, answering members' questions. There was even the chance to try the scooters in the car park.

I think we all felt that Feering Community Centre worked well for us as a venue. It made it much easier for us to move around and talk to different people.

Thank you to the HSP Group Committee for supporting us by funding this first meeting in a village hall. We plan to meet again on Sunday, 11th October 2015 from 2.30 - 4.30 pm.

Hilary Croydon

Forthcoming Events

Region 5 Meeting

Saturday September 12th 2-6pm
The Oaks Restaurant
Premier Inn, Norwich Airport
Call Barbara Jones on: 01603 423 267

Region 9 Meeting

Saturday October 10th 2-6pm
Meeting Room
St Helens South Premier Inn
Eurolink, Lea Green, St Helens, WA9 4TT
Call Irena Pritchard on 01524 261 076

Region 4 get together

Saturday October 3rd 2pm onwards
The Dartmoor Lodge Hotel, Ashburton
Call Ian Bennett on: 01202 849 391

Afternoon tea Regions 1 & 2

Sunday November 15th 3pm – 6pm
The Clockhouse Milford
Call Jane Bennett on: 020 8853 4089

HSP Support Group AGM

Saturday June 20th
Trident Technology and Business Centre
Leamington Spa, CV34 6SW

Region 3 Meeting

August 15th 2015 1.30pm – 4.00pm
The Orange Tree Public House
100 Stevenage Rd, Hitchin, SG4 9DR
Contact Della Brookman: 07710 637 941

Colchester Meeting

Sunday October 11th 2.30pm – 4.30pm
Feering Community Centre
CO5 9QB
Contact Hilary Croydon: 01284 728 242

Scotland Meeting

May 30th 2015 1pm
The Riverside Inn, DD2 1UH
(Next to Dundee Airport)
Contact Liz Ferguson: 01413 168 648
Email: fergusonlizandronnie@gmail.com

Region 7 Meeting Birmingham

Saturday October 17th 2.30pm – 5.30pm
Kenrick Centre in Harborne
Contact Penny Cohen: 07818288738
Email: pennycohen57@hotmail.com

The Mobility Roadshow

25th – 27th June 2015
Donington Park, Derby, DE74 2RP

New Members

We welcome the following new members:

Christine Pollock
Sutton
Region 1

Karen Woodroff
Swindon
Region 4

Mark Newton
Malton
Region 10

Tess Trafford
Hayling Island
Region 1

Janine Conniff
Coventry
Region 7

Marilyn Beastall
Nottingham
Region 8

Steven Dixon
Bristol
Region 4

Andrew Walker
Crawley
Region 1

Douglas Beckwith
Northamptonshire
Region 8

Janet Forbes
Peterborough
Region 5

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

HSP Support Group 2015 AGM Details

Saturday 20th June

The Trident Technology and Business Park
Poseidon Way
Warwick
CV34 6SW

- 10.00 Coffee & Welcome
10.45 AGM
11.30 Break
11.45 Prof Henry Houlden – The National Hospital of Neurology and Neurosurgery The differences and management of pure and complex HSP Research and network update
1.00 Lunch
2.30 Cahir O’Kane – Reader in Genetics – University of Cambridge
3.30 Coffee and mingle with friends, old and new
4.30 Close

Useful Contacts

	Email	Telephone No:
Ian Bennett - Chairman 37 Wimborne Road West, Wimborne , Dorset BH21 2DQ	bravoechonovember@btinternet.com	01202 849 391
David Harris – Secretary 18 Lodmoor Avenue, Weymouth, Dorset, DT3 5AF	dave@vadcar.org.uk	01305 772 286
John Mason - Treasurer 18 Sandringham Road, Trowbridge, BA14 0JU	john@jrmason.demon.co.uk	01225 761 788
Stephanie Flower - Help-Line 37 Alexandra Road, Great Wakering, Southend, SS3 0HN	FSPgroup@aol.com	01702 218 184
Ian Bennett – Memb Sec/Reg 4 co-ordinator 37 Wimborne Road West, Wimborne , Dorset BH21 2DQ	bravoechonovember@btinternet.com	01202 849 391
Simon Hubbard – Research co-ordinator	si@sjhubbard.com	01908 508 866
Jane Bennett - Regions 1 & 2 co-ordinator	luckyjane82@hotmail.com	020 8853 4089
Della Brookman –Region 3 co-ordinator	Della_brookman@msn.com	07710 637 941
John Moore – Exec Committee Member 66 Drift Road, Clanfield, Waterlooville, Hants, PO8 0NX	johnmoore.9@btinternet.com	02392 592784
Peter Bateman – Region 6 Co-ordinator (Wales)	sandra@peterbateman.co.uk	01656 788502
Adam Lawrence 18 Mayflower Court, Staple Hill, Bristol, BS16 5FD	adam@idios.co.uk	07834 505 161
Liz Redmond Neurogenetics Nurse	Redmond.liz@uclh.nhs.uk	02034 484 487