



HSP Newslink

The Newsletter of the Hereditary Spastic Paraplegia Support Group

Issue 40 – February 2017

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

Michelle's 1,000 Mile Marathon for HSP



Michelle, Neil and Finnegan enjoying some winter sun

I've taken on a challenge – to walk 1000 miles in 365 days!

Last year both my husband (Neil) and son (Finnegan) were diagnosed with Hereditary Spastic Paraplegia (SPG4). While other members of my husband's family have it, it still came as a shock to us; given Neil had always been active, enjoying cycling regularly and playing rugby twice a week throughout his teens and early 20's. No one had really

understood HSP, how it affected them and how it was passed on through generations. So it was never explained to Neil that he had the potential of being a carrier of the gene, and even develop the condition at some point. Neil had his genetic test done first and it took longer than expected for the results to come back, his bloods were taken in December 2015, and he eventually received the results in June 2016. Although we had accepted they would come back to confirm HSP we still had to wait before we would be able to send off for Finnegan's DNA to be tested. The results for him came back much quicker and unfortunately confirmed what we already suspected; he too has HSP.

By this time we'd had some time to look into HSP and get a better understanding of the effects. Both Neil and Finnegan had great support through physio, occupational therapy etc and the support from Neil's employer and Finnegan's nursery has been amazing. Neil has changed from a very active role where he was on his feet all day to an office based job which has meant a lot of training and learning a new role but means it gives him the option to work from home when needed.



Michelle modelling the HSP charity polo shirt

As a wife and mother who would do anything I could to help them, I started to feel helpless. There's nothing that I can do to make them better. At the beginning of January, I started to see stories related to the walk 1000 miles challenge. I've always struggled with my weight and fitness, even more so in recent years. The emotion of finding out about Neil and Finnegan having HSP made me eat – a lot! I made a decision there and then that if the mobility of Neil and Finnegan could potentially deteriorate, I needed to be there for them, fitter and stronger than I am now.

So I decided to take part in the challenge, to get my fitness back, for me and for them. While out on my first walk Neil and I were talking and I suddenly had the idea that I could do this and raise money for, and raise the awareness of HSP.

So now, I'm out walking nearly every day to count up the miles and to make sure more and more people are aware of HSP.

Michelle Brookes

Chairman's Column

I often seem to begin this column by apologising for the delay on issuing the newsletter. True to form, the same applies but on this occasion I have two feeble excuses. I have been unwell for a couple of weeks and I've also been holding on while waiting for a couple of promised articles.

I know many of you use the Facebook group, Hereditary Spastic Paraplegia's Unite. It's great to see that this group is so well used and amazingly it now has over 1200 members. Recently there's been a surge in membership in HSP'rs from the USA. It's as if the word has got around that it's a very well used group providing great value to the HSP community.

On the subject of membership, our support group has now got very close to 400 members, which is a figure we've never reached before. I'm confident we'll have in excess of 400 in the coming 12 months. You'll notice listed later in this issue that we have a further ten new members.

I'm already very busy planning the second Potato Pants festival which will take place on June 3rd. We've listened to feedback received following last year's event and a few changes are being made. If the weather behaves itself, I'm very confident that we'll have a better turnout than last year and I'm hoping that it can become a very good annual fundraising event.

Fundraising has been so good this year that I've written a separate article to thank individuals who've been involved in many events. However, following Michelle's great article on the front, covering her challenge to walk 1000 miles, there's one thing that I need to add. Michelle didn't mention that she has a fundraising page on virginmoneygiving. To support Michelle, please visit:

<http://uk.virginmoneygiving.com/MBrookes>

I'd like to briefly mention Personal Independence Payment (PIP). Many of our members have now been through the process, including myself. I also have friends with other disabilities who have been through the process. I'd just like to inform members who may be worrying, that in my experience

there have been no horror stories and many have been surprised what an efficient process it was and got the result they'd hoped for. In my case it all went smoothly, my assessor was lovely and I got exactly what I expected. I know it's hard but please try to ignore the many horror stories we all come across on line which are often written by people who haven't yet applied for PIP. I still advise that you get help to fill in the form from somebody like Citizens Advice or DIAL, but the paperwork is certainly less complicated than the DLA claim forms. They have definitely tightened up the mobility requirement a little but the only people I know who, with PIP, lost the upper level mobility allowance (two ladies with M.S.) both won their cases on appeal. Possibly controversially, but I for one agree that the system needed tightening up a little.

Over the years, I've come across many members, particularly so in recent months, who suffer badly with constipation and often hemorrhoids. The men involved are often particularly reluctant to talk about it, but I know first-hand that it's a very unpleasant problem to have. I'd just like to remind members of two aids that may make a big difference. The first is the squatty potty which is a simple plastic platform that ergonomically curves tidily around a toilet and provides a platform to raise the feet, placing you in a much more natural position to empty the bowel. These are available from many suppliers including Amazon for around £25.00 and many members have found them very helpful. At the other end of the monetary scale is a colonic irrigation system (one manufacturer is called Peristeen) enabling a set quantity of water to be pumped up the back passage, causing the bowel to naturally empty itself. The members I know who use this or similar equipment have all found it life changing, so it's well worth highlighting. Please contact me for further information.

I continue to do a little in the garden whenever I can although I've now taken on a gardener who comes once a fortnight to help me keep on top of things. I think I've mentioned before the challenge that I set myself every year which is to have something in flower every day of the year. Although I

was successful with this last year, unfortunately, this year I failed. I had a good three weeks with nothing in bloom. Further research is obviously required and maybe a couple of appropriate horticultural purchases, and I'll have another go next season. On the bright side, while I'm sat here typing this, I can see snowdrops in flower in my front lawn. Spring is definitely on the way!

I'm still lucky enough to be enjoying regular aviation activities but after my medical expires this Spring, I'm considering the possibility that I will no longer continue to maintain the validity of my license. This is partly for medical reasons and partly for financial reasons. I will however continue to regularly enjoy flying; it just means that I'll have to be with one of many friends who are license holders. Some of you will be aware that my youngest daughter Cara recently flew solo, which not only made me a very proud dad, but also gives me the exciting possibility of flying with her one day with her as the boss.

Horse riding on Friday mornings continues to be one of the highlights of my week. It's not just my 30 minutes on board big Jim that's so enjoyable, but all the volunteers and fellow disabled riders are lovely people. Many of the other riders have multiple sclerosis and it amazes me how much we have in common. Surprisingly, it's been a good foundation to some very good friendships. Riding for the Disabled (RDA) is an amazing charity and I'd recommend it to anyone.

I look forward to seeing many of you in the coming months, including on April 1st at the next get-together in Ashburton and on July 1st at our AGM in Birmingham. You'll notice in the next article that we have changed our AGM venue, so please make a good mental note of this and don't show up at Leamington Spa. Although at short notice, I stood in for an extra year as chairman at last year's AGM, this year I will definitely be standing down. If you are interested in standing as chairman or for any other committee position, please let us know. There are many new members on board now who could bring new skills and ideas to the table.

Ian Bennett

New Venue for 2017 HSP AGM

For the last few years we have held our AGM in Leaminton Spa which has proven to be an excellent facility. We've always had very positive feedback which is why we've used this location for so long. Unfortunately, on making early arrangements for this year's event, we discovered that the cost of the Leaminton Spa facility has almost doubled so we decided to move on.

The 2017 AGM will be on July 1st at the **Tally Ho Conference & Banqueting Centre**, Pershore Road, Birmingham, B5 7RN. It looks as though we've found a brilliant venue with a large car park and it's a ground floor facility.

The cost will remain at £7-50 per member and will include lunch and refreshments. Agenda details will be included in the next Newslink.

I'd like to thank Penny Cohen and June Masding for all their hard work and time spent in finding a suitable replacement venue for us.

Fundraising Thanks!

Since the start of our last financial year which began on May 1st, we have benefitted from some amazing fundraising from several members and other individuals.

I'm not going to highlight how much people raised or how they raised it but on behalf of everybody involved with the HSP Support Group, I'd like to thank the following individuals and organisations:

Peter Bateman	Stuart Montrose
Simon Hubbard	Terry Duffy
Graham Moody	Jade Bennett
Stephanie Flower	Heather McRobb
Sally Meikle Janney	Sir Ian Denholm
The Old Thatch	Ukele Band
Michelle Brookes	
	Hoare Lee (dress down day)
	Wyevale Garden Centre
	Allianz Global Assistance

I'm aware that there are some exciting plans for fundraising in the coming months and I'm hoping that the music festival becomes a bigger event, raising more than last year.

Many of you are aware that we recently made our largest ever financial commitment to

research, in agreeing to provide £10,000 a year for three years to Exeter University to help with important work they are doing. A large percentage of this financial commitment comes from fundraising activities, so please continue to keep up the good work.

If you're considering doing a running event (tricky for many I know!) or know of anybody considering such an event, we now supply charity running shirts. If you still have a copy of the last newsletter, you'll see these being modelled by my friend Graham Moody and my daughter Jade.

If anybody needs any help or advice with fundraising plans, please don't hesitate to contact me or any other committee member. We can supply sponsor sheets which clearly show our logo and charity number. We are also registered with JustGiving and VirginMoneyGiving.

MAKING THE EXCEPTIONAL HAPPEN

The University of Exeter Campaign

I was delighted to recently receive the following letter which may help clarify our recent financial commitment to support research at Exeter University:

Dear Mr Bennett

Re: HSP Support Group PhD studentship

My name is Olivia Rickman, the newly appointed researcher on the Hereditary Spastic Paraplegia Support Group PhD Studentship. I am writing to introduce myself, and sincerely thank you for your very generous donation and support for our study and this PhD studentship.

Originally, I am from Blandford Forum in Dorset, although I have lived in various places around the world. Prior to starting at the University of Exeter, I was a student at the University of Reading where I graduated with a first class bachelor's degree in biochemistry. I thoroughly enjoyed the course and during

this time I developed a particular interest in the scientific fields of genetics and neurobiology. This scholarship is a wonderful opportunity, enabling me to embark on a career in scientific research; a desire that I have had for a number of years.

This particular PhD study stood out to me because it provides a fantastic opportunity to follow my interests in neurogenetics. In this project I will investigate particular biochemical processes that we believe are important and underlie motor neurone degeneration. We hope that this research will make an important contribution to medical and scientific understanding of the biological basis of hereditary spastic paraplegia, which we hope may ultimately be translated to aid clinical management and lead to treatment development. I have a personal interest in this area as a few years ago my grandmother sadly passed away after a very rapid decline with motor neurone disease.

I am tremendously excited and look forward to persuing this project, and am hopeful to see how it will unfold. Once again, I thank you for your extremely generous donation, and support of this study.

I hope that we are able to meet in the near future at forthcoming meetings of the HSP Support Group.

With very best wishes

Olivia Rickman

Adam's Column



Right at the end of January the HSP support group was invited to attend the Physical Activity in Rare Conditions Collaboration (PARCC) Meeting in Cardiff. I attended with Ian Bennett. The group organising the meeting are just starting a piece of research looking at how to promote/support physical activity in people with rare conditions.

The research is being run by a group of researchers with an interest in rehabilitation for people with rare neurological conditions from three universities in the UK - Dr. Gita Ramdharry from Kingston/St George's University, Prof. Monica Busse from Cardiff University and Prof. Jon Marsden from Plymouth University.

HSP was one of five conditions invited to the meeting, along with Muscular Dystrophy (represented by Muscular Dystrophy UK), Ataxia (represented by Ataxia UK), Huntingtons Disease (represented by the Huntingtons Disease Association) and Progressive Supranuclear Palsy (represented by the Progressive Supranuclear Palsy Association).

No Branch Meeting Near You?

Now, I'm with Della when she says that two HSP'rs getting together is a meeting – and is mission accomplished.

Branch meetings of the HSP Group don't have to be large affairs in a village hall, with speakers – though they can be, if that's what works for the members who meet.

Informal gatherings of a few people in a pub are just as valuable, just as informative, just as supportive and just as much fun.

Have you ever wished there was a branch meeting near enough for you to get to? If you have, the chances are there are other people in your area wishing the same thing.

If there is nothing within striking distance of where you live, why not ask someone on the committee whereabouts members live near you so you can plan where to meet. Then invite people to a pub which is convenient for you and for others.

Put the details in the Newslink and post it on the Unite Facebook page, as well.

I found it was really helpful to have an idea of how many to expect, especially the first time, so it's worth asking people to let you know if they plan to come.

Some people won't reply at all. Transport can be a real problem for some and, for others, well, get togethers aren't for everyone, which is fine. But other people will be so pleased you made the first move.

They have conducted initial research with Huntingtons Disease which has shown the importance of structured support and information to allow people to find ways of keeping physically active that they enjoy and helps them to manage their condition. You can read about this here:

<https://www.neurology-central.com/2016/05/12/11072/>,

This research shows that "a short-term exercise intervention is safe, feasible, and leads to significant improvements in fitness and motor function in people with HD"

The group of researchers has experience working with neurological conditions, physiotherapy and exercise, and they are looking to expand this concept to cover more rare conditions so that there is a sufficiently large program of work to bring people together, to have more study power and to give stronger, more conclusive results.

The initial starting point of the discussion was on the challenges around using physical activity as a treatment. The first step is to define what is meant by "physical activity" - this means different things to different people, and whilst it might mean specific exercises/activities to some, it might be more like just getting out of the house more often to others.

There has been a history of poor advice given, people have differing physical challenges, there are varying issues with access to facilities and costs, the support from professionals and/or carers varies, along with issues on motivation, choice and the time taken. Essentially the group is trying to get a good handle on these issues to develop a solution/intervention to support people.

Part of the day was spent with each charity describing the main features of each of the conditions, and taken together there are many strong similarities - principally that they all have a long term gradual deterioration in mobility, there are often mood changes with the conditions and day-to-day variation can be bigger than the long term changes. There were also some subtle differences, for example those with PSP and HD often are better in the afternoon, whereas some with HSP are better in the morning.

An interesting aspect was talking about how to get physical activity into the daily routine. For some the benefit might be greater if they get the activity in their routine before it is needed, so that it can be practised before it becomes difficult. Activities will need to adapt to peoples changing conditions - for example activity for someone who can still walk may be different from someone who spends most of their time in a wheelchair. There are also a range of personal factors which need to be considered - some people are happy to go to the gym, whereas others are more self-conscious and would dislike going. Some people prefer to undertake activity in a group, whereas others prefer to do it alone.

Another topic is how the activity would be measured. The group are keen that the activity can be measured easily, and this might be by indirect methods - how often people leave their home or how their quality of life changes rather than how the specific activity might be assessed in the clinic.

The group are keen to develop a tool that is individualised, accessible when needed, meaningful, and focuses on what is trying to be achieved rather than the specifics of what could be done. Overall, I thought it was a really useful day, and I'm looking forward to the next stage.

My fourth survey

This report covers the results of my fourth on-line survey for people with HSP, which covers fatigue, bladder and bowel effects and sources of HSP information. The report is a brief version of the results, and interested readers can view a more detailed version on my blog

<http://hspjourney.blogspot.co.uk> on or after the 28th February.

There were 169 respondents who completed this survey which I launched in September 2016, predominantly from the USA and the UK. About a quarter of the respondents had also completed at least one of my previous surveys.

Mobility Analysis

From the answers to mobility questions it is possible to see which mobility aids are used the most regularly. 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 mobility aid used by the least number of people, with a take-up of around 5%. Broadly these results are similar to those from previous years.

I have devised an “HSP mobility score” which then 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. Walks without aids but has 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

The overall results show;

Overview of mobility aids used

Mobility Aids Used - Overview:	Respondents	Percentage	Mobility Score
Those without aids	30	18%	0-1
Those who use mobility aids some of the time	42	25%	2-3
Those who use sticks most/all of the time	55	32%	4-5
Those who use frames most/all of the time	13	8%	6-7
Those who use chairs most/all of the time	29	17%	8-9

Fatigue

Fatigue is noted as a symptom of HSP. My 2013 survey showed that 62% of people experienced fatigue as a significant symptom and 30% experienced fatigue as a minor symptom. I wanted to find out more about fatigue.

I could only find one paper on fatigue in HSP, a study from 2015-2016 which examined non-motor symptoms in people with SPG4 in Brazil – *Non-motor symptoms in patients with hereditary spastic paraplegia caused by SPG4 mutations*, by Katiane Servelhere and others.

(<https://www.ncbi.nlm.nih.gov/pubmed/26806216>) This study used the Modified Fatigue Impact Scale for fatigue and reported that “patients with SPG4-HSP had more severe fatigue than controls”.

There has also been research undertaken in assessing fatigue in Multiple Sclerosis (a common misdiagnosis for HSP) including development of the Neurological Fatigue Index. The Brief Fatigue Inventory also appears to be used in a number of different conditions, including cancer. My questionnaire therefore asked respondents to complete:

- Neurological Fatigue Index (NFI-MS, a 9 question survey)
- Modified Fatigue Impact Scale (MFIS-5, a 5 question survey)
- Brief Fatigue Inventory (BFI, a 9 question survey)

There were 163 responses for the Neurological Fatigue Index questions, 157 responses for the Modified Fatigue Impact Scale questions and 159 responses for the Brief Fatigue Inventory questions.

Neurological Fatigue Index - MS

The Neurological Fatigue Index (NFI-MS) asks people to select how much they agree with each of 9 questions, selecting from; Strongly Disagree, Disagree, Agree and Strongly Agree. Details of the survey can be found here: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2834659/>. The overall score is the sum of the nine questions, and can range between 0 and 27. The table below shows the results.

NFI-MS Results

Mobility Score	Respondents	Minimum Score	Average Score	Maximum Score
0-1	30	3	16.6	26
2-3	41	7	15.4	24
4-5	52	9	17.5	27
6-7	13	9	17.0	22
8-9	27	10	19.5	25

These results show that the average and maximum scores are generally independent of mobility although the average rises slightly with decreased mobility. Those who do not use mobility aids (mobility score 0 or 1) have lower minimum scores than those who use mobility aids (mobility score 2 or more).

Modified Fatigue Impact Scale 5

There are two versions of the Modified Fatigue Impact Scale (MFIS) scale, a full questionnaire with 21 questions and a shorter version with 5 questions, asking people to select how often fatigue has affected them. Details of both versions of the MFIS survey can be found here (along with a number of other questionnaires associated with Multiple Sclerosis):

http://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/MSQLI_-_A-User-s-Manual.pdf. The overall score is the sum of the answers across all questions and can range between 0 and 20. The table below shows the results.

MFIS-5 Results

Mobility Score	Respondents	Minimum Score	Average Score	Maximum Score
0-1	27	0	11.0	20
2-3	39	0	9.7	17
4-5	53	2	12.7	19
6-7	11	2	11.9	19
8-9	27	7	14.1	18

These results show that the average and maximum scores are generally independent of mobility although the average rises slightly with decreased mobility. It is only those in wheelchairs all or most of the time (mobility score 8 or 9) who consistently have a higher minimum score.

The MFIS scale allows us to look at the different areas of fatigue. The results show that physical factors make the greatest contribution to the fatigue score across all levels of mobility, scoring slightly more than cognitive factors. The psychosocial factors contribute the least. From this, we can see that both physical and cognitive factors play an important part in the fatigue of people with HSP.

The analysis of respondents with SPG4 shows results similar to the full dataset, whereas those with SPG7 tend to have a higher level of fatigue. The MFIS-5 questionnaire shows similar results to the Brazil results, in that the physical score contributes the most to the overall fatigue level and the psychosocial score contributes the lowest level.

Brief Fatigue Inventory

The Brief Fatigue Inventory (BFI) has 2 sections. The first section has three questions and asks people to rate their fatigue right now, their usual level of fatigue and their worst level of fatigue. They are then asked to rate how their fatigue has interfered with six aspects of life. Details of the BFI are here: [http://onlinelibrary.wiley.com/doi/10.1002/\(SICI\)1097-0142\(19990301\)85:5%3C1186::AID-CNCR24%3E3.0.CO;2-N/full](http://onlinelibrary.wiley.com/doi/10.1002/(SICI)1097-0142(19990301)85:5%3C1186::AID-CNCR24%3E3.0.CO;2-N/full). The overall score is an average of the results for each question and can range between 0 and 10. The table below shows the results.

BFI Results

Mobility Score	Respondents	Minimum Score	Average Score	Maximum Score
0-1	26	0.7	5.5	9.0
2-3	40	0.3	4.8	8.2
4-5	54	2.0	6.0	9.3
6-7	12	0.6	4.8	7.3
8-9	27	1.7	6.5	9.4

These results show that the average and maximum scores are generally independent of mobility although there is a slight upward trend on the average score with decreased mobility. There is no clear pattern in the minimum score.

The Wiley link above contains classifications for mild, moderate and severe fatigue in cancer patients. I have defined these similar ratings for fatigue in HSP;

- Score less than 3 – Mild fatigue
- Score between 3 and 7 – Moderate fatigue
- Score greater than 7 – Severe fatigue.

The table below shows the number of respondents with mild, moderate and severe fatigue, along with the proportion of that mobility score group:

BFI Fatigue Rating

Mobility Score	Respondents	Mild Fatigue	Moderate Fatigue	Severe Fatigue
0-1	26	3 (12%)	15 (58%)	8 (31%)
2-3	40	6 (15%)	31 (78%)	3 (8%)
4-5	54	6 (11%)	28 (52%)	20 (37%)
6-7	12	2 (17%)	9 (75%)	1 (8%)
8-9	27	1 (4%)	15 (56%)	11 (41%)
Overall	159	18 (11%)	98 (62%)	43 (27%)

Around 90% of people with HSP have moderate or severe fatigue.

Fatigue Summary

166 respondents answered the question about which fatigue survey they preferred. Most (80%) had no clear preference. Of those who expressed a preference, most preferred the NFI questionnaire.

There were people from across the range of mobility scores who preferred the NFI and MFIS-5 questionnaires, whereas people who preferred the BFI tended to have less reliance on mobility aids. The MFIS-5 questionnaire shows that whilst the physical factors of HSP contribute the most to fatigue there is also an important cognitive aspect. Those with SPG7 tend to have a higher level of fatigue than those with SPG4. The BFI questionnaire shows that around 90% of people with HSP have moderate or severe fatigue.

Bladder Issues

There have been a number of papers examining bladder issues in those with HSP. *Bladder dysfunction in hereditary spastic paraplegia: a clinical and urodynamic evaluation*, by Fourtassi and others in 2012 (Pubmed ID [22289900](#)), reports urgency being the most common complaint affecting 72% of people, followed by increased frequency (affecting 66%), incontinence (affecting 55%) and hesitancy (affecting 52%). The study examined 29 patients and was carried out in France. These results are similar to *Bladder dysfunction in hereditary spastic paraplegia: what to expect?*, by Braschinsky and others in 2010 (Pubmed ID [197226407](#)), which reports incontinence being the most common symptom, affecting 69%, followed by hesitancy (affecting 59%), increased frequency (affecting 55%) and urgency (affecting 51%). The study examined 38 patients with urinary symptoms out of 49 patients. The study was carried out in Estonia.

The various texts on HSP often describe having overactive bladders (OAB). I reviewed different short form questionnaires for overactive bladders, and found the International Consultation on Incontinence Modular Questionnaire (ICIQ). I used the ICIQ overactive bladder survey <http://www.iciq.net/ICIQ.OABmodule.html>. There are four questions in this questionnaire, and users select their answers from pre-determined answers, with overall scores being a sum over all questions and ranging between 0 and 16. These questions were answered by 165 respondents. The following table gives a summary of the results;

Bladder Results

Mobility Score	Respondents	Minimum Score	Average Score	Maximum Score
0-1	30	0	5.4	10
2-3	41	0	4.4	14
4-5	53	0	5.6	12
6-7	13	0	7.5	14
8-9	28	1	7.1	16
Overall	165	0	4.6	16

This shows that there are people in each mobility band who do not have any bladder symptoms, and there are people within each mobility band who have many bladder symptoms. Given that the score ranges between 0 and 16, for the purposes of this analysis I am grouping scores as follows;

- 3-6 = mild effects, things occur “occasionally”,
- 7-10 = moderate effects – things occur “some of the time”
- At least 11 = severe effects – things occur “most” or “all” of the time.

Using this scoring system, around two thirds of people with HSP have no or mild bladder effects, and around one third have moderate or severe effects. There is a general trend that the milder effects tend to be with those with lower mobility issues, and the bladder effects tend to be more severe with those with higher mobility issues. However, looking at the different factors, the results appear to be broadly in line with two previous studies examining bladder issues in people with HSP, from France and Estonia.

- The key bladder symptoms appear to be frequency and incontinence, affecting the greatest proportion of respondents.
- Passing urine 4 to 6 times per day is normal. Just under half of respondents do this, just over half go more often.
- Passing urine no more than once a night is normal, two thirds of respondents do this, one third go more often.
- A third of respondents have to rush to the toilet most or all of the time, with a further quarter having to rush sometimes. Two fifths do not have to rush.
- Urine leakage most or all of the time occurs in one fifth of respondents, a further third have this sometimes. Overall, half of respondents are affected by incontinence, one fifth of respondents are not affected and three tenths are affected occasionally.
- The level of bother is generally above that expected by symptoms. Many respondents are bothered quite a lot by these symptoms.

Bowel Issues

There does not appear to be any papers examining bowel issues in those with HSP. Several reports describe bowel or sphincter issues, but from the abstracts available none appear to quantify this.

I selected the Incontinence Modular Questionnaire (ICIQ) bowel questionnaire. The ICIQ website indicates that the bowel surveys are not finalised, however there are several other references to the survey, e.g. <https://www.kingstonmaternity.org.uk/media/187024/bowl-function-questionnaire-icq-b-uk-english-.pdf>. There are twenty two questions in this questionnaire, with users selecting their answers from pre-determined lists. I decided that I would ask nine of these questions in order to get a picture of bowel function. The overall score is a sum of the answers for these 9 and ranges between 2 and 37. These questions were answered by 155 respondents. The following table gives a summary of the results;

Bowel Results

Mobility Score	Respondents	Minimum Score	Average Score	Maximum Score
0-1	28	2	8.6	16
2-3	39	4	8.0	15
4-5	51	4	9.8	20
6-7	11	5	10.4	16
8-9	26	5	11.8	19
Overall	155	2	9.5	20

This shows that there are people in each mobility band who have no symptoms or minor symptoms, and there are people within each mobility band who have several symptoms. The minimum and average scores both generally increase as mobility issues increase. Given that the score ranges between 2 and 37, for the purposes of this analysis I am grouping bowel scores as follows;

- 4-11 = mild effects – things occur “rarely”
- 12-20 = moderate effects – things occur “some of the time”
- At least 21 = severe effects – things occur “most” or “all” of the time

Using this scoring system around two thirds of people with HSP have mild bowel effects, and around one third have moderate effects. A few people, who don’t use mobility aids, have no effects at all, and no people showed severe effects. There is a general trend that the milder effects tend to be with those with lower mobility issues, and the bowel effects tend to be more severe with those with higher mobility issues.

- The key bowel symptoms are urgency and hesitancy, affecting the greatest proportion of respondents.
- Opening your bowels between three times a week and three times a day is normal. 95% of respondents do this, 5% go more often.
- It is not normal to open your bowels during the night. Nearly 90% of respondents do not need to do this, but just over 10% do need to go in the night.
- A sixth of respondents have to rush to the toilet most or all of the time, with a further third having to rush sometimes. Half do not have to rush.
- A third of people with HSP have to strain to open their bowels most or all of the time, with a further third having to strain sometimes. One third do not need to strain.
- Wearing pads and/or staining underwear more than once a month occurs in about a quarter of respondents. Less than three fifths of respondents do not have this problem, and less than one fifth have this less than once a month.
- One fifth of respondents have bowel accidents 'sometimes' and a small number have accidents 'most of the time' or 'always'. More than half do not have this problem, and a quarter have it rarely.
- The level of bother generally increases in line with symptoms. Those with more symptoms tend to have higher levels of bother.

HSP Information Sources

I asked respondents where they got their information on HSP. 160 people gave answers to these questions, although some answers were partial. Most people get their information about HSP from social media, doctors and neurologists. Medical websites, support groups, physiotherapists and friends/family with HSP form another important group of information sources.

The sources which people regarded as most trustworthy were neurologists, support groups and physiotherapists. Social Media and friends/family with HSP form another important group. Of sources used by more than half of respondents, the ones with people being most unsure were doctors and other medical professionals.

Overall; people need to be selective in what they believe on social media – and check out the author. Support groups can be a good source of information. People may need to work on relationships with doctors so they understand people's situations better. Talking about your situation with friends/family with HSP may be useful for you and them.

Adam Lawrence

Two legs bad, two wheels' good

I thought you may be interested in how my life has changed for the better in the past 2/3 years.

My legs were deteriorating as predicted and I started using a wheelchair full time, even though I can still stand and walk 10mtrs with sticks, so a wheelchair was a must and a blessing. It turned my life around, the tiredness was greatly reduced.

I had my house opened up into wheelchair friendly place so now use an electric chair indoors which means I have a hand free to carry things, meals, drinks as well as other

daily items. I use a manual chair when I go out, it is so comfortable so my mantra is now "two legs bad, two wheels good".

I decided to get fitter and started to attend my nearest MS centre so that I could use their hand cycle machine thus improving my upper body for the manual wheelchair use.

After just a few weeks I noticed an improvement and decided to take this further, I scrolled through the internet and discovered the British Wheelchair Athletics Association who are based at Stoke Mandeville.

I attended a training weekend in January 2016, they were so helpful even to new members, so I was trying seated throwing with the shot putt.



Maurice throwing the shot putt from a chair

When I was younger this was my event becoming All England junior champion in 1973, so 43 years later here I was trying it again!

I was training regularly and then decided to cash in my pension and had a small gymnasium built at home along with a therapy pool.



Maurice working hard in his gym

It was after this was completed I took the decision to come off medication. My Neurologist (Dr O.C.Cockerill) was wary initially but did support the sentiment, 3 years ago I was on 3600mg of Gabapentin and 60mg

of Baclofen both were daily doses, I weaned off them to try Sativex spray, this was better and muscles got softer but not for long and was increasing the number of sprays up to 8 a day (I had to self fund this at a cost of £430 per Month).

It took 6 weeks to come off the Sativex so since March 2016 I have been drug free all coinciding with hard work in my gym, I have a neuro physio visit once a week along with a masseur who unlocks the twisted legs and back, also once a week and have at least 3 sessions in the therapy pool

In April I attended a classification medical team for an athletics career, three persons, all very friendly and helpful had read all my medical reports etc which had been sent previously and after a couple of hours I was classified as a F34 (same as cerebral palsy) as HSP is a progressive condition I have to be reviewed every two years.

The BWAA host a Grand Prix series during the season consisting of 5 meetings, all at Stoke Mandeville, I threw in all 5 along with a few other meetings around the country, I have thrown and trained with many Paralympians.

During the year I also discovered Sportability and attended an indoor Sky Dive with them at Milton Keynes, great fun and gave me a buzz for days afterwards.

I can also recommend the Disabled Ramblers Group of which I am also a member, great to try off road scootering (you can hire one at a minimal cost), they have rambles all year all around the country.

In summary, please try sport of some sort, it has given me a whole new purpose in life and can honestly say that I feel human again and that my life is now the best it has ever been, something which would have seemed ludicrous to say 8 years ago when first diagnosed.

Maurice Charge

HSP Group Grants

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. The maximum grant available has recently been raised. Completion of one year's membership is a requirement for applicants. If interested, please request a grant application form from a committee member.

Collect Stamps for HSP

Don't forget to collect your good used stamps for Phil Burton to sell to raise funds. Pass them on to branch meetings, the AGM or anyone who can get them closer to the Regions 1 & 2 meeting where Phil can pick them up.

**RESEARCH
WITH
PLYMOUTH
UNIVERSITY**

Falls Survey 2017

A group of researchers based at Plymouth University are conducting a survey into falls in people with Hereditary Spastic Paraparesis. In older age and in other neurological conditions falling is a frequent problem that can potentially limit what people do and can cause injury. Falls are a great concern for the NHS with more clinical and research resources directed to preventing falls over the last few years. There is currently no published information about falling in people with HSP within the UK or abroad.

The research team is interested in answering questions such as "how frequently do people fall?", "when do falls occur and what are the causes of falls?" and "are there any factors that can predict falls?". Rebecca Chapman and Jon Marsden at Plymouth University have worked with members of the HSP South West support group to develop a survey of people's symptoms/characteristics and a falls diary. The diary is intended to record every fall or "near miss" over a 3 month period. The survey and the diary can be sent via post or e mail depending on people's preference. The team are hoping to involve as many people

with HSP above the age of 18 years across the UK regardless of whether they fall or not. This way they obtain a true indicator of the frequency of falls and importantly why some people fall and some people do not.

If you are interested in the study, there is an information sheet providing more detail at the end of the newsletter. The information sheet explains the study and provides the contact details of the research team if you want to discuss the study in more detail or volunteer for the study. The study will be launched on 06/03/17.

Rebecca Chapman & Jon Marsden School of Health Professions Plymouth University

Members' Letters

Hi folks,

My name is Heather McRobb and I am 37 years old and a mother of a five year old son.

I was given a tentative diagnosis of HSP, following around a year of the usual tests.

I am probably like many of you - always told to stop being lazy and 'pick my feet up' as a child, always clumsy. It wasn't until around 2005 when working as a recycling operative that I realised there was a problem, I started getting severe pain in my hips and lower back and was told by physio that I had a bad back.

It wasn't until over a year ago that I went back to physio and it was then I was referred to neurology - we know where it goes from there so I won't bore you with the details!

I consider myself very lucky that I am where I am. I still have a full time job and have most of my mobility, although walking any distance can be tiring and I use a stick.

I have been a member of the Facebook group for a while and it can be really humbling reading others' stories and seeing how people in a really bad place can still keep getting up off the floor. It was then that I realised that I had to do something to help out, instead of feeling sorry for myself.

As a child, myself and my family had many summer holidays in the Lake District, and I have very fond memories of the area. I

remembered climbing a hill called Cat Bells and decided that this would be my challenge! My son, Joe and partner, John were with me for support. We started early, to get a space in the car park and so it would hopefully be pretty quiet.

The first few steps nearly turned me back - it was like walking up big, uneven, stone steps - a thought that I imagine strikes fear into most of your hearts! Then, I told myself I could do it, took a firm hold of my sticks (with flexifoot ferrules!), and started up the hill.

We had such a beautiful day for it, we were lucky, if it had been wet I would have had to turn back without a doubt.

Towards the top, it became clear that I was going to have to lose the sticks, it was a case of scrambling up the rocks on hands and knees. Again, I almost turned back but remembered all the sponsors I had got and how disappointed in myself if I had to turn back. I, therefore, struggled to the top and the sense of achievement was overwhelming. I have never experienced anything like it.



Heather and 5 year old son Joe, at the summit of Cat Bells

The trip down was painfully slow, and painful. One false slip with the flexifoot and I was a gonner!

Once we got almost to the bottom, John went to get the car, it was such a struggle to keep putting one foot in front of the other. I was so proud of young Joe - only 4 when we did it, he was so well behaved, and also so proud of John, I would not have been able to do it had he not kept an eye on our flighty four year old.

I managed to raise over £1000 for the HSP Group which, Ian tells me, is going to be used to part fund a university scholarship which will help research into the condition.

I just want to say this, everyone's 'Cat Bells' is different - for some of us it is climbing a hill, for others it is getting out of bed in the morning. Whatever it is, keep doing it. Keep getting up when you fall, keep going to work, keep putting one foot in front of the other, you will feel better for it in the end.

Thanks to Ian, Della and all of my other Facebook friends and most of all, thanks to John, may you always be there to give me that push.

Heather McRobb

I was watching Vikings on TV (brilliant btw) and there was a discussion between a father, Ragnar Lothbrok and son, Ivar the Boneless regarding Ivar's disability.

Whilst these people did actually exist (historically) I'm pretty sure that this conversation never took place, but it still struck a chord with me.

Ragnar: "I thought (when you were born) your legs were a weakness. Your legs have given you a strength that even your brothers don't have. You are like a deaf man whose eye sight is sharper than anyone else. You are special, not in spite of your legs, but because of them."

What I took from this was that having become disabled has given me strengths in other areas.

I think that strength is measured in tolerance not mass, so although my body may be weaker, my inner strength is increased as I learn to tolerate and grow out of the things this condition has punished me with.

May seem melodramatic?

How many of us live in fear of a fall? Are in constant pain? Fear for our futures? Feel vulnerable in public? Are self conscious and feel like a burden? Suffer depression and anxiety?

Through these negative experiences we face every day, we grow to face those fears, deal with our pain and overcome our physical and

psychological barriers and limitations despite them. Only a sufferer truly understands our daily battles with ourselves.

We overcome and grow in strength and mettle, we have insight and tolerance beyond non-sufferers and so are able to be more objective and deal with life's other woes in a way they cannot.

I hope you feel as I do? That despite this condition weakening my body, it has helped me grow in inner strength.

Don't fear though, I'm not about to send out a raiding party!

Sean Constable

Regional News

Colchester Branch Meeting

Our meeting at Feering was well attended and we were very pleased to welcome two new members who live locally. We look forward to seeing them again.

A big thank you goes to Jenni Preston for inviting our guest speaker, Kate Prowse, to join us. Kate practices a complementary therapy called vibromuscular harmonisation technique or VHT. She told us that the technique was originally developed with horses and, as the results were good, its use was extended to humans.

VHT apparently works on the connective tissue which links all the other parts of our bodies – the muscles, organs and so on. The idea is that the gentle movements that the practitioner makes on various parts of the body set up small vibrations which travel through the connective tissue. The effect of this is believed to be that the flow of blood and lymphatic fluid through the tissues is increased, resulting in the delivery of more oxygen to the body and the removal of more waste products from the tissues – a detox. VHT is not trying to cure problems in specific parts of the body but takes a holistic approach, working on the whole body. Kate made no claims for cures or relief of symptoms but said that clients enjoy it, sometimes feeling effects a few days later.

Steph Flower led the way and Kate gave a demonstration of the technique while Steph lay on Kate's treatment table. VHT is given while the person is fully clothed and consists of a series of calm and gentle, but firm, movements in different parts of the body. Kate explained that if any part of the body is tender, the movements can be as "light as a shadow". Three other members of the group had treatments while seated and Kate answered questions.



She told us there are other therapists scattered around the country and said that an initial session would last about an hour and would cost about £50. The number of repeat sessions would depend upon the individual. Kate also said that it is possible to go on a course to learn the basics of VHT so that the technique can be used at home on a family member with HSP, as and when it is needed. One of our younger members often asks for a short session at home and she seems to feel the benefits. If anyone is interested in finding out more, the web address is

www.vhtworld.com

We shall be meeting again on Sunday, 19th March 2017 from 3-5 pm at Feering Community Centre, near Colchester, Essex, CO5 9QB. As always, everyone is very welcome to join us.

Hilary Croydon

Midland's Region 7 Meeting

We had a super get-together again at the Kenrick Centre in Harborne in October. It was so nice to meet up with some new friends and to catch up again with old ones.

June invited our guest speaker for the afternoon, Professor Steve Sturman, who is a Consultant Neurologist with the Neurology and Rehabilitation team at the Queen Elizabeth Hospital in Birmingham.

We shared a really happy and informative afternoon together. Professor Sturman is a really super guy and his talk was given at a very easy level for everyone to understand.

He started by explaining what different types of HSP there are and went into some of the diagnostics of dominant and recessive inheritance and how the genes cause the disease. Although for some of us it was known information, for many of us there were different elements that I (for one) hadn't been aware of and new angles of approach to the complexities of the condition.

The second session was given to diagnosis and then treatment, finishing with support systems like benefits and driving assessments.

After 3 hours we had to draw things to a close. Professor Sturman shared with us our frustrations about funding for research. He let us take a copy of the information sheet that he was working from, which had some very good visually simple and clear points about everything discussed. We scanned and later emailed this out to the group.

It was great to have lots of questions asked and information and experiences passing so readily, both ways. Everyone appeared to be very relaxed and confidences seemed to be built on. Steve was very interested in and impressed with our newslink letter and said that it had been a 'privilege' to come and talk at our group.

We'll be meeting up again in the Spring-time, next year, so please do get in touch if you'd like to join us.

Penny Cohen

Region 5 meeting

Group 5 met again at Meadow way, Chapel rooms on 15th October, with tea and biscuits. We had a chat over health and other problems.

We were lucky to have Corin Germany, a travel consultant, who gave us details of a company who provide holidays for disabled people. We were given a leaflet with information on cruise and hotel holidays.

We will be meeting again on March 11th. I hope to see new members there.

Barbara Jones

A November Afternoon

In November Regions 1 and 2 enjoyed Steph and John Flowers, with Canine Partners Elmo and Merlin, treating us to a demonstration of the tasks these amazing dogs can do. Their demonstration was preceded by a film which emphasised how the Canine Partners help with so many tasks which are vital to everyday living. After their display Steph also told us about the spinal stimulator she had implanted to help lessen her neuropathic pain.

We are always so delighted and pleased that members travel from all areas of the South East to join us, but this was emphasised in November. Not only had been a warning about severe weather conditions, understandable for a day in November, but part of the M3 was closed due to bridge demolition. Milford is not that close to the M3, but with that major roadway being closed, local roads that eventually feed into the M3 were very heavily congested, if not at a standstill, by the end of our meeting. With true stalwart HSP mentality, new routes were found and nobody complained.

Our afternoon included time at the beginning for Carer's and tea at the end, to ensure everyone has refreshment before starting their journey home, but there was the added benefit that Terry Duffy and friends brought a wide selection of gifts. This had double advantage in that we could buy in readiness for Christmas with profits being donated to HSP.

Thanks to you all for the stamps and raffle prizes you regularly contribute. We look forward to seeing you in April.

Jane Bennett

Forthcoming Events

Afternoon tea Regions 1 & 2

Saturday April 8th 3pm – 6pm
The Clockhouse Milford, GU8 5EZ
Call Jane Bennett on: 020 8853 4089

Region 3 Meeting

September 2nd 2017 1.30pm – 4pm
The Orange Tree Public House
100 Stevenage Rd, Hitchin, SG4 9DR
Contact Della Brookman: 07710 637 941

Region 4 get together

Saturday April 1st 2pm onwards
The Dartmoor Lodge Hotel, Ashburton
Call Ian Bennett on: 01202 849 391

Norwich Meeting

Saturday March 11th 2pm
Meadow Way Chapel NR6 5NU
Call Barbara Jones on: 01603 423 267

Colchester Meeting

Sunday, March 19th 3 - 5pm
Feering Community Centre
Feering, Essex, CO5 9QB
Call Hilary Croydon: 01284 728 242

Region 9 Meeting

Saturday 18th March, 2 - 5pm
Mickle Head Beefeater
Eurolink, St Helens, WA9 4YR
Call Irena Pritchard on: 01524 261 076

Region 7 Meeting Birmingham

Saturday 8th April, from 12 noon - 3pm
The Kenrick Centre, Mill Farm Road,
Harborne, Birmingham, B17 0QX
Contact Penny Cohen: 07818 288 738
Email: pennycohen57@hotmail.com

Coffee Social (Stoke on Trent)

Temple Street Methodist Church
Stoke on Trent
ST4 4NW
Saturday April 8th 2-4pm
Contact Shaun Wall: 07732 803 363
Email: shaunwall2003@yahoo.co.uk

Potato Pants Music Festival

Saturday 3rd June 2017 from 2pm - 11pm
£5 entry – pay on arrival
High Mead Farm
Ham Lane
Ferndown
BH22 9DR

HSP Support Group AGM 2017

Saturday July 1st
Tally Ho Conference & Banqueting Centre,
Persore Road
Birmingham
B5 7RN
Full details in next Newslink

New Members

We welcome the following new members:

Carina Thurgood
Essex
Region 5

Graeme Anderson
Edinburgh
Region 11

Louise Donaghy
Darlington
Region 10

Christine Nelson
Melton Mowbray
Region 8

Kerry Goodwin
Brightlingsea
Region 5

Maree Murray
Bristol
Region 4

Dean Fowler
Pontyclun
Region 6

Kevin Mills
Brecon
Region 6

Shaun Wall
Stoke
Region 7

Margaret Swierkocki
Dalton in Furness
Region 9

Yvonne Thompson
Stotfold
Region 3

If you are interested in contacting any of the above new members, please contact the relevant area coordinator, or the membership secretary.

Appendix I



Participant Information Sheet

Version1 Date 19/12/16

Study Title : Falls in Hereditary Spastic Paraparesis: An Observational study of falls characteristics and predictors of falls and long lies

You are being invited to take part in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

This study is a survey looking at falls in people with Hereditary Spastic Paraparesis. It aims to survey as many people with Hereditary Spastic Paraparesis whether or not they commonly fall. It aims to identify how frequently people with Hereditary Spastic Paraparesis fall and to describe the characteristics of falls such as where people fall and what were they doing at the time. The survey will also assess whether there is a relationship between people's reported symptoms, such as weakness, muscle stiffness and fatigue and the presence or absence of falls.

Why have I been chosen?

You have been chosen because you are a member of the HSP Society group with a diagnosis of HSP. Your details have been kept confidential by the HSP Society and have not been released to any third party. To participate in the research, you would need to contact the research team directly using the address provided at the end of this sheet.

Do I have to take part?

It is up to you to decide whether or not you will take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part, then you are still free to withdraw at any time and without giving a reason. A decision to withdraw during the study, or a decision not to take part, will not affect your medical care or inclusion on any future research projects.

What will happen if I choose to take part?

If you are interested in volunteering for this study, please contact Rebecca Chapman using the phone or e mail address listed at the end of this sheet. Rebecca can then answer any questions you may have about the study. You will firstly be sent by post or e mail (depending on your preference) a consent form to indicate you are willing to participate in the study. You will also have a questionnaire about factors such as your age, diagnosis and family history, previous falls as well as your current symptoms and their perceived severity. Once you return these forms via post or e mail you will be sent diary packs. These will be used to indicate your falls and their characteristics on daily basis. This method of recording falls is preferred to recalling falls over 3 months as people often forget minor falls and the detail of the events associated with it. The falls diaries will ask about how you fell, what you were doing at the time and the perceived cause of the fall. Every 2 weeks you will need to return the falls diary sheets or an indication that you have not fallen in that period. We will collect the falls diary over a 3 month period. If we do not receive the diaries after 2 weeks we will send a reminder via telephone, e mail or text depending on your preference. We may also contact you if there are some missing responses or answers that need clarifying.

What would be expected of me if I agree to take part in the study?

You will be asked to complete an initial questionnaire and keep a falls diary over a 3 month period.

Are there any side effects?

There are no side effects.

What are the possible risks and benefits of taking part?

There will be no risks in taking part. Falls can cause injury and be distressing. If there are any issues that concern you during or after the study, please contact the research team using the contact details at the end of the form.

Appendix I

Will taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Jon Marsden, the Project Supervisor, will be responsible for the security of the data. You will be provided with a unique code. We will keep your name, contact details and code together in a locked filing cabinet for the duration of the trial. This allows us to contact you and for you to withdraw your data if you so wish. At the end of the study any personal information will be destroyed and the data will be stored using a unique code only. You will not be identifiable in any way from any publication arising from the study. Data will be stored at Plymouth University either within a locked filing cabinet or on encrypted, password protected computer drives.

Withdrawal from the project

Your participation in the study is entirely voluntary. You are free to decline to enter or to withdraw from the study without having to give a reason. At the end of the study (September 2017) we will destroy personal information and your data will be stored using a unique code only. After this time we will not be able to identify individuals and your data cannot be withdrawn from the study.

What if something goes wrong?

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about this study, you should contact the project supervisor Prof Jon Marsden using the address provided at the end of the document.

What will happen to the results of the research study?

The study is being completed by the researcher as part of his Master's degree in Neurological Rehabilitation at Plymouth University and results will therefore be written up to form their thesis. The results of this study aim to be published in 2018 and presented at relevant national and local conferences. We will also present the results at regional and national HSP support group meetings. We will ask if you want to be sent a copy of the final study summary

Who has reviewed the research?

Ethical approval has been gained by the Faculty of Health and Human Sciences, Health Student research ethics subcommittee.

Contact for further information please contact :

Rebecca Chapman
MSc student (MClinRes)
School of Health Professions
Faculty of Health and Human Sciences, Plymouth University
PL6 8BH

Email: rebecca.chapman@postgrad.plymouth.ac.uk

Telephone number: 07710650565

Professor Jon Marsden at Plymouth University who is the study supervisor can also answer questions on this study. His contact details are:

Jon Marsden
Professor of Rehabilitation
School of Health Professions
Faculty of Health and Human Sciences, Plymouth University
PL6 8BH

Email: jonathan.marsden@plymouth.ac.uk

Telephone number 01752 587 590

You should be given a copy of this information sheet and a signed consent form to look at in your own time.

Thank you for reading this and considering whether to take part in the project