



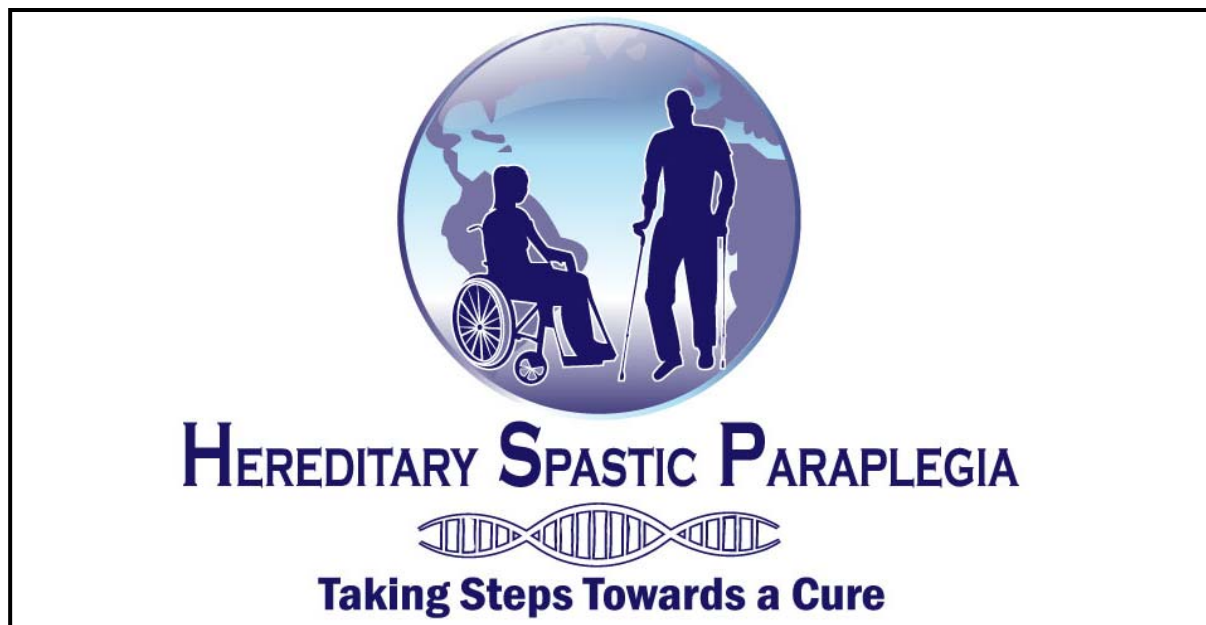
HSP Newslink

The Newsletter of the Hereditary Spastic Paraplegia Support Group

Issue 38 – May 2016

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

New International HSP Logo



Our new logo and tagline

Last June I attended a meeting in Madrid where leaders of many HSP organisations around the world were in attendance. This meeting was organised by Frank McKeown who is the president of the Australian HSP Research Foundation. It was a very interesting three days and I made new friends meeting HSP'ers from USA, Spain, France, Switzerland, Italy, Denmark, Sardinia and the Netherlands.

Research was a major topic under discussion and particularly how all of our international groups can work together to help future research.

During conversations, we all agreed that it would be a good idea to have a global identity for HSP support organisations and people with HSP everywhere. It will help with public recognition and demonstrate global unity in the quest to find effective treatments for the condition.

A working group of six was formed and we held two online competitions. One was to compile a tagline and one was to design a logo. There were hundreds of entries to both competitions and the tagline 'Taking Steps Towards a Cure' was unanimously selected as the winner. The working

group whittled the logos down to our favourite six and then members of HSP organisations globally were invited to vote for their choice.

The winning design does not replace our existing logo but will be used alongside it. It will be shown on our website and future letterheads, newsletters and flyers. You may also notice that it is already displayed on the Australian website and I'm sure it'll become a familiar sight.

Thank you to all who voted. I personally think it was an excellent idea and I'm delighted with the result.

Chairman's Column

I can't believe that it's May already, the year seems to be passing by very quickly. I haven't noticed much of a Spring to date but thankfully the weather forecasters are promising that warmer weather is on the way. The cold damp days and nights certainly don't help my mobility but as always I'm happy to use various mobility aids to enable me to get out and about.

I've had to admit to myself that I can't manage the garden any more so I have taken on a gardener who is doing a brilliant job. Maybe I should have done it sooner because I love my garden and I'm much happier when it's neat and tidy. I spend many hours relaxing outside when I'm fatigued and find it very therapeutic.

Our AGM will be here soon (June 25th) and you'll find details on the final page of this newsletter. I'm sure you'll agree that it should be another very interesting day and a good opportunity to meet up with friends old and new. As I said in the last newsletter, I'm not intending to stand as Chairman this year for a couple of reasons. Firstly, I have done five years and I strongly believe that organisations such as ours need new people on the committee with fresh ideas, to ensure continued good progress is made. Having said that, I do feel that our current committee is very strong and we are very lucky to have these individuals volunteering their time and skills for our cause. The other reason I'd like to lower my workload is simply because I'm

not quite as mobile and don't have the same energy levels as in years gone by.

I'm very happy to continue editing the newsletter and hope to remain as Membership Secretary.

I know that many of you are aware of the music festival I'm organizing down here in Dorset and thank you to all who've shown an interest, many of whom I know are intending to attend. Plans for the **Potato Pants Festival** at High Mead Farm on June 4th are progressing very well. I have eight musical acts/bands entertaining us throughout the day and there will of course be a bar and a few food sellers and other stalls. Activities for children are being planned and there will be a bouncy castle and candy floss. The bar will be stocked by a local award winning brewery which of course I've tried and tested (the things I do for HSP). I'm having some special garments made that can be stuffed full of potatoes and members of the crowd will be invited to participate in some crazy races in between the musical performances. The Wimborne Town Crier is hoping to join us and if so, he will be starting these races and introducing the musicians. There is a whisper that AFC Bournemouth want to get involved with the crazy potato activities, but I haven't had this confirmed yet.....Fingers Crossed!

I must say that I've been extremely fortunate to have lots of help from some amazing people with the organisation, it's certainly surprised me what's involved with organising such an event. There is a website for this event: www.potatopantsfestival.co.uk and there is a Facebook event page simply called 'Potato Pants Festival'. Please contact me if you are interested in attending, the postcode for the event location is: BH22 9DR.

You will find AGM notification papers enclosed with this newsletter. Please note that attendance at this year's AGM can now be paid for using BACS and I hope that our secretary receives some new nominations for committee positions.

I look forward to seeing many of you either at the Potato Pants Festival or the AGM (or both).

Ian Bennett

Adam's Column

This article presents the results of my third survey, launched in September 2015. The survey covered modifications at home, depression and quality of life. Respondents also answered questions about their mobility allowing trends to be spotted with level of mobility. For more details please visit my blog <http://hspjourney.blogspot.co.uk/2016/02/2015-survey-results.html>. There were 109 respondents who completed the survey, predominantly from the USA and the UK. Respondents indicated which mobility aids they used, and I have grouped these into an “HSP mobility score” which allows me to cross-reference mobility against the other questions in the questionnaire.

Table 1 – Overview of mobility aids used

Mobility Aids Used - Overview:	Respondents	Percentage	Mobility Score
Those without aids	23	21%	0-1
Those who use mobility aids some of the time	20	18%	2-3
Those who use sticks most/all of the time	27	25%	4-5
Those who use frames most/all of the time	22	20%	6-7
Those who use chairs most/all of the time	17	16%	8-9

This shows that there is a significant variation in the mobility of the respondents to the questionnaire, which would appear to cover the full range of mobility expected by those with HSP.

1 Modifications around the home

I wanted to find out what types of modifications people had made around the home and asked a set of questions about modifications in different areas of the home. Overall, there were 99 respondents who answered these questions.

There were 31 respondents who indicated that they had made no modifications to their properties. These fell into two general groups;

- those that had not made modifications yet, and
- those who didn't need to make modifications because they had moved into an accessible property which meets their needs.

Plans to move properties reflect a range of attitudes of people, with some people preferring to stay in their current home and make whatever modifications they need to, with others planning to move properties as the effects of HSP on their lives change. Different respondents gave answers suggesting that moving property would be something which they would expect to do in the near future whilst others were planning to move in the longer term.

The overall conclusion of this appears to be that as HSP progresses modifications will need to be made to properties, and many respondents indicate that living in a single storey dwelling makes life much easier. The requirement to move to a single storey dwelling will depend ultimately on personal situations and preferences and the progression of HSP, and there will be plenty of other factors in any decision to stay or to move house.

Respondents did not indicate if they owned or rented properties which will have a bearing on the ability to make modifications. One key factor will be the practicality of making modifications, with modifications potentially being more difficult in older or smaller properties. A key factor in both modifications and moving home will be the affordability and the ability to pay.

There were 22 different types of modifications which were mentioned by more than one respondent, as shown in the following table. As these questions were free-form answers I have had to make a few assumptions on what respondents have meant in some cases, and therefore there may be a small amount of variance in the data in this table.

Table 2 –Modifications by more than 1 person

Modification	Mobility 0-1	Mobility 2-3	Mobility 4-5	Mobility 6-7	Mobility 8-9	Total Answers
Total number of respondents	20	18	24	21	16	99
Grab rails (all data, in any location)	3	7	8	13	8	39
Ramps (external or internal)	1	2	5	4	5	17
Grab rails (within the shower or bath)	2	5	3	3	1	14
Accessible/raised toilet	2	2	2	2	4	12
Stair lift	0	3	0	3	5	11
Bath seat/shower seat/bath board	2	1	2	2	4	11
Conversion of bathroom to wet room	2	1	0	3	4	10
Hospital/power/electric/adjustable bed	0	0	1	2	4	7
Widening of doorways	0	0	0	4	1	5
Making the level of the bed lower	2	0	1	2	1	6
Modifications to the kitchen*	1	0	1	3	1	6
Grab rails/toilet frames/toilet handrail	0	1	1	0	3	5
Conversion of bath to shower	2	0	1	1	1	5
Adjustment to external steps	2	1	0	2	0	5
Use of a Bed Rail	0	0	1	0	4	5
Making the level of the bed higher	0	1	1	1	2	5
Electric/hydraulic/power doors	0	1	0	1	2	4
A lifting/raising chair	0	0	1	0	2	3
Making the level of the sofa higher	0	1	0	1	1	3
Use of a commode	0	1	0	0	2	3
Height adjustable tables	0	0	0	0	2	2
Having a second banister/stair rail	0	0	1	1	0	2

I have presented a commentary on each of the most common modifications made, i.e. those with 10 or more respondents. The parts of properties that are modified the most after the inclusion of grab rails are the bathroom/toilet with a range of different modifications made. Adjustments to beds are relatively common. Modifications in other parts of properties are made less frequently. This would appear to reflect the importance of different activities – using the toilet and keeping clean are important as is getting sleep.

Grab Rails

Grab rails are by far the most common modifications that are made around homes, and are present in some homes at all levels of mobility. The majority of grab rails are installed in bathrooms/toilets although respondents also included them by doors, in bedrooms, kitchens, hallways, garages and other rooms.

The reasons for installing grab rails fall generally into two groups, one group includes reasons around helping to keep balance and move around, and the other group includes reasons around helping to get up/down in/out off/on from things like showers/baths/chairs/beds and getting up/down stairs. Reasons for installing are often following similar incidents or being increasingly unable to do something.

Advice for others includes “Definitely help to keep you on your feet and preventing falls”, “it is a small step to take but it makes life so much easier”, “Safety is more important [than] decor or vanity”, “more confidence while showering”. Several respondents mention talking to occupational therapists about this.

Ramps

Ramps are also a common modification, again made by people at all levels of mobility. There are two general types of ramps mentioned, the larger scale purpose built external ramp used for access to the property, and smaller portable ramps which may be for use either outside or inside the property.

Whilst many of the respondents include in their reasons for installing ramps that it gives them wheelchair access to parts of their property, other respondents indicated that they have ramps because of their issues getting over/up/down steps when walking. Most of the ramps are used by respondents who rely on mobility aids of one kind or another all or most of the time.

Advice for others includes looking on Amazon to purchase directly and purchasing second hand ramps. “Worth doing provided you can” and “Very good, not too expensive.”

Raised/Accessible Toilets

This modification includes toilets that were described either as raised or accessible and has been made across the full range of mobility. Generally, this was described as making it easier to stand up/sit down from the toilet and was installed because people were finding it difficult to do so.

Advice for others includes “Really makes a big difference” and “Make sure that the height of the [seat] suits you”.

A couple of respondents who had been having work done on their bathrooms had elected to install a taller toilet in preparation for expected future changes to their mobility.

Stair lift

The stair lift tends to have been installed by respondents who rely more frequently on mobility aids, although a few respondents have had one installed earlier.

Stair lifts are reported as giving access to otherwise inaccessible parts of the property or, installed because it makes access easier to parts of the property by people who have difficulties getting up or down stairs.

Advice for others includes “Best thing I did! I’m not the only one who uses it!”, “Do it- though ugly and expensive my back is better for it” and “It is beneficial if you struggle to get upstairs”. Of those with lower mobility scores, the reasons for installing are “Used a lot of energy and time”, “Assessment by Occupational Therapist” and “to make life easier and safer”.

Bath seat/shower seat/bath board

This modification covers several things. Some respondents describe having a seat, chair or stool in their bath or shower and others describe having a bath board – i.e. a board which spans the bath which you can sit on. This modification has been made by people across the range of mobility.

What is not clear from all of the descriptions is if these seats are fixed to wall/bath or if free standing seats have been added. From the descriptions some clearly are permanent. These are described as helping people keep from falling, prevention of dizziness, helping get in/out of the bath/shower, relieving fatigue. These are installed in showers generally when people are no longer able to stand, or after a fall. Advice for others includes “makes showering much more enjoyable” and “Just do it. It helps so much”

Conversion of bathroom to wet room, or conversion of bath to shower.

The wet room modification has been made by a number of respondents across the range of mobility. Some have specifically referred to this modification as a wet room whereas others have described it as having a shower level with the floor.

The main reason for making this modification is enabling the respondent to shower because getting in/out of the bath has become difficult or impossible. Advice for others includes “It has made bathing so much easier.” “it helps so much”, “Strongly consider keeping a bath as laying in the bath reduces stiffness.” “Bathroom mods are expensive. Get professional advice and plan carefully if you need to modify an existing bathroom.” These comments show that the decision to make this modification may be difficult for some.

Bedroom Modifications

There are four main modifications described in the bedroom. There is the contrast between the first group of people who have made their beds higher against the second group of people who have made their beds lower. The third group is people who have bought hospital or power beds, which I take to mean are at least electrically adjustable in height. The fourth main modification made is the use of a bed rail.

In all cases, the modification is made due to difficulties getting in or out of bed. Some people were struggling to get up from a low bed whilst others were finding it hard to climb into a high bed. Those with electric beds report that these make them more comfortable and help with pain, and they make the transfer in or out of bed much easier. Some respondents’ power beds include a massage option, a heated mattress option and are able to let them sit up. Others with hospital beds report that guard rails prevent them from falling out of bed. The bed rail group have rails on/near their beds to help them get in/out of bed or to sit up whilst in bed.

Advice for others includes “morning stiffness of muscles is a nuisance when getting out of a low bed”, “put your bed on the right height, take a good mattress” “For those with severe HSP symptoms I recommend this [hospital bed] to help carers with transfers and changing.” “Make sure your bed is the right height to enter”

Kitchen Modifications

Relatively few respondents indicated that they had made modifications to their kitchens. The main modifications made are to do with changing the heights of things so that they are accessible from a wheelchair, including appliances, sinks, cupboards and worktops. Some are raised and others are lowered, some are made to be roll-under. Others are replaced with differing sizes or with easier to clean versions, such as induction hobs and auto-defrosting fridge/freezers. Controls are moved to the front. Taps are sometimes changed for lever taps.

Some respondents also describe smaller modifications that they have made, including “serving spoon with holes, able to drain water from food”, “kettle tipper, safer for me to boil the kettle”. Some respondents have added extra chairs or stools in their kitchen to allow them to take the weight off their feet whilst there. One respondent indicates their chair is able to raise/lower allowing them to access higher cupboards/things.

Modifications Conclusions

There is a wide range of modifications that people have made around their properties and the approach depends heavily on personal preferences. Modifications tend to be made after a change in

mobility/symptoms has been noticed, particularly after an incident/accident. Although, some people are planning for future changes in mobility. I asked respondents for the length of time that they have had these modifications, but there is sufficient information from the mobility scores to establish the general pattern.

Frequently the first modifications made are the installation of grab rails within the property, and these are often fitted in the bathroom first. Subsequent modifications are made depending on the rate of progression of HSP. The parts of properties which are modified the most after the inclusion of grab rails are the bathroom/toilet with a range of different modifications made. Adjustments to beds are relatively common. Modifications in other parts of properties are made less frequently.

Some people prefer to make modifications within their existing property whilst others prefer or have to move into accommodation which has been or can be set up to meet their needs. Some people are designing and building their own property to their own specification. Other key factors in modifications and moving home are practicality and affordability.

2 Depression

I included the two question Patient Health Questionnaire-2 (PHQ2

http://www.cqaimh.org/pdf/tool_phq2.pdf and

<http://www.apa.org/pi/about/publications/caregivers/practice-settings/assessment/tools/patient-health.aspx>) in my survey, and followed the scoring given for these questions. This tool is a screening tool which can be used to identify a need for further assessment. The total score for an individual ranges between 0 for least likely to be depressed and 6 for greatest need for further assessment.

The survey sets a cut-off score of 3 or more at which there is a recommendation for further assessment, although some other analyses suggest using cut-offs of 2 or 4 for other reasons.

Overall this study shows 63% of respondents having some symptoms of depression and 37% without those symptoms. Additionally, it suggests that around one quarter of people with HSP may require further assessment for depression, particularly those who are using walking frames all or most of the time to get around.

Looking at the highest scores, where people have “Little interest or pleasure in doing things” and/or “Feeling down, depressed or hopeless” nearly every day, it is my hypothesis that this seems to occur at the beginning of peoples’ journeys with HSP and at the point where people are beginning to lose the ability to walk. These highest scores are not seen in those who have accepted the use of walking sticks and are not often in those who have accepted the use of a wheelchair, and perhaps the acceptance of these mobility aids relieves the depression. I repeat, this is just my hypothesis and I accept there is not much to back this up.

My conclusion is that the responses to this survey show that people with HSP appear to suffer from depression more than the general population.

3 Quality of Life

Respondents were asked 3 questions about physical functioning and 2 questions about social functioning from the Patients Like Me Quality of Life survey (<https://www.patientslikeme.com/>). In the full survey there are 11 physical functioning questions, 8 mental functioning questions and 5 social functioning questions. The questionnaire is used across many conditions and I selected a few general questions as a sample. In total 102 respondents answered this question.

The physical functioning results show that over 60% of respondents score good or best when using no mobility aids or when they are used some of the time (mobility score 0 to 3). There are no clear differences between these mobility bands. Once mobility aids are used most or all of the time (mobility score 4 to 9) the physical functioning score lowers, with around 30% of respondents scoring good or best. Again, there are no clear differences between these three mobility bands. There may be an upturn in physical function for those most affected by HSP, perhaps as they have

optimised their lives to their mobility's. This sample analysis appears to show that a step change in quality of life occurs at the point when mobility aids are needed to be relied on more often.

The social functioning results, show that before mobility aids are needed (mobility score 0 or 1) around 90% of respondents score good or best for social functioning. Once mobility aids need to be used (mobility score 2 to 9), the percentage of respondents scoring good or best drops to around 75%. Within this, the proportion of respondents scoring best drops from 50% with no mobility aids to around 20% when some are needed. Once mobility aids are used the social functioning score does not change significantly, and this sample analysis appears to show that a step change in quality of life occurs at the point when mobility aids are needed.

The conclusion I draw from this is that HSP does affect quality of life and there appear to be two step changes, the first step change is a reduction in social functioning at the point when mobility aids are needed and a step change in physical functioning when mobility aids need to be relied on most or all of the time.

Drug Repurposing for Rare Diseases

Findacure Conference 29th Feb 2016

On 29th Feb I had the pleasure of going to the Findacure Drug Repurposing for Rare Diseases conference which was held at the Royal Institution in London. Drug re-purposing is taking an existing drug and demonstrating that it is effective for a different group of people. Well known examples include:

- Aspirin - 1899: Pain - 1970: Myocardial Infarction and Stroke - 2010: Cancer.
- Viagra - Originally: Erectile dysfunction - Now: Pulmonary arterial hypertension

Drug re-purposing is quicker, cheaper and less risky than conventional drug development. For every approved drug, there are another 23 drugs which have entered pre-clinical trials but not made it that far. Conventional drug development takes some 4-9 years and costs 1.8 billion, but drug repurposing takes some 1-4 years and costs 0.3 billion. Some 90% of drugs on the market already have secondary uses, and often the secondary uses are more effective than the original use. The proportion of drugs entering the pre-clinical trial stage is low, perhaps 10%.

Hidden Costs

I think that the most powerful presentation was the "hidden costs of rare diseases" from Matt Hammond:

- Psychological
- Time (travelling, seeing professionals etc.)
- Finance (travelling)
- Missing out (on other activities and events)
- Form filling (it seems there a lot of forms in some cases)
- Loneliness (being the only one in your situation)
- The need to plan everything (because of the effects of the disease)

Ataxia UK

Ataxia UK appears to be similar to the HSP Support Group - a patient led research charity, supporting patients with a helpline, magazine and branches. Ataxia is similar to HSP in that it affects movement, there is no cure and treatments focus on symptom alleviation. They give talks on ataxia and its impact and have a patient registry assisting with trials/studies. The group focuses on raising

funds for projects which; Improve diagnosis, Run Clinical and Pre-clinical trials, Give Symptom alleviation. They promote collaboration between patient groups, pharma companies, clinicians and specialists. The group organised a conference in 2015 which was attended by 43 people from 20 countries. The conference was aimed at sharing knowledge/information/care/treatment and was viewed as a success.

Drug Repurposing for Mosaic Overgrowth Disorders

Innovation is needed in organising trial for rare diseases. An example was given for a UK drug repurposing trial for mosaic overgrowth disorders - the elephant man had mosaic overgrowth. Patients were scattered across the UK, so collaboration was needed in the trial design, and this sounds similar to how trials might work for HSP. NHS trusts have no capacity to undertake blood tests, and GPs need approvals to do so. Therefore, the trial had to be designed to minimise the study interventions (blood tests), and private sector involvement was needed. Funding was the next challenge. Trial costs include: Staff time, a database for the results, the drug itself (and any placebos), shipping costs for the drug, imaging and blood test costs, insurance and pharmacy fees. Pfizer agreed to provide the drug free of charge, they determined that the database could simply be a spreadsheet, and it was cheaper for them to get insurance for 3 separate trials in single locations than a single policy for a multi-centre trial. Overall, the costs were reduced from an initial estimate of £150k down to £60-70k.

Drug Repurposing

In terms of drug repurposing, I understand the process that is gone through. I hadn't realised quite the extent of drug re-purposing, and this is done because repurposing is cheaper, quicker and less risky. Although, there doesn't appear to be quite the same incentive to do this as there is for developing a new drug. The main thing to take away is the need to collaborate, most of the papers described that collaboration was needed between the different people involved in the chain. There are several steps:

1) Identify a need.

Firstly, it is necessary to define a need for a new drug. This is where the collaboration between patients, patient groups and clinicians is important. There needs to be sufficient interest in an issue for researchers to look at it, and this is where patient groups can come in very useful by keeping on top of research activities and knowing about patients with condition to (potentially) have a sample of real-world patients who are interested in taking part in research trials.

2) Look for solutions.

With a need in mind it becomes necessary for researchers/clinicians to look for solutions to the need. Several different approaches were described. At one end of the scale the knowledge of the clinician about the need can be used to look through existing information to identify candidates. At the other end of the scale computers are used to search through database libraries of molecules/drugs for candidates. It is a positive that the drug companies/pharma are getting involved with sharing their libraries of molecules/drugs with researchers. In terms of drug repurposing it is perhaps useful to see unsuccessful trial results to allow the safety/function of drugs to be evaluated for other purposes, but these are not often published.

3) Gathering evidence.

The candidate drugs/molecules then have to be examined to ensure that they are safe and if so, tests and investigations can be made to identify the ones with the greatest potential. If the evidence does not demonstrate improvements in patients then it is necessary to set up a trial.

4) Trials.

Often a trial is needed in order to provide evidence that the drug is safe to use and gives results. Sometimes there will need to be a balance struck between improvements gained and negative side effects. Depending on funding and other constraints the trial may be large or small. Issues with trials revolve around getting the right population of patients to take part and their distance from the research centre. Trials for rare diseases have to trade between; Small number of subjects, requirements of randomised controlled trials (RCT), high attrition rates and long study durations. Judgement is needed in trial design to make use of real world experience. Focus on the patient is key. An RTC may not be required.

5) Treatments.

Once successful trials are reported, this informs the medical community and the treatment can spread. Prescribing a drug outside of its normal/approved use is called an “off-label use”. Sometimes it is a combination of therapies which gives good results. Routes to off-label drugs in the UK is either through GP or hospital, but this varies throughout the UK.

Data Sources

I was interested to hear about the different work on data sources, with different tools extracting information from papers in order to allow them to be searched in a database. Two different examples were given, and I particularly like the healx one:

<https://rareomics.healx.io/disease/spastic-paraplegia-hereditary>

Funding

Naturally, researchers need to be paid to work, and there is the issue of funding for such work. There are not the same commercial drivers for funding as there are for new drug discoveries, and that is another aspect where collaboration is needed. Often, the patient groups raise money and provide funding, and often deals can be done with the drug manufacturers to get the drugs needed and information about them for trials at a reasonable price (or free). Various research organisations and drug companies are joining forces to be able to run/organise/fund research projects.

Summary

In conclusion I found the day really useful, and thanks to the group for paying for my ticket! There were also lots of interesting people to talk to in the coffee breaks and it was good to find out more about what happens. Many of the companies present at the event were based in Cambridge, which is my home town! I think that the role of patient groups in understanding what research is being done and sharing that information with their members is important, as is feeding back real world experience/problems to the researchers so they can potentially capture some of this in their research design. Social media seems to be a very important resource for promoting and sharing information, and I'm pleased to report what I heard and saw in order to share this information with you.

Interested readers can see my full conference write-up on my blog:

<http://hspjourney.blogspot.co.uk/2016/04/drug-repurposing-conference-london-29th.html>

http://hspjourney.blogspot.co.uk/2016/04/drug-repurposing-conference-london-29th_20.html

http://hspjourney.blogspot.co.uk/2016/04/drug-repurposing-conference-london-29th_21.html

<http://hspjourney.blogspot.co.uk/2016/04/my-views-on-drug-repurposing-conference.html>

Adam Lawrence

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.

HSP Research

It was great to hear that the German HSP group were awarded 10,000 EU by the Google Impact Challenge, for a project – Participation despite HSP.

While voting for them, I looked on their website and with a bit of help from Google translate, have found out that they have 22 business sponsors, from a mixture of business types. My first thought was, what could we learn from the great work that the Germans have done?

We have over 300 members. Do we have any, with experience in marketing or an enthusiasm to help the HSP community? Do we have people to help raise awareness of HSP in the UK with business people and for them then to donate money? Do we have people, who have networks with business contacts or commercial sponsorship experience? If so, it would be good to form a Research Fundraising Circle/sub-committee of people who feel they could help.

A short summary from St. Helen's meeting in October 2014, attended by Dr. Siva Nair.

The research into HSP is mainly centred on genetic research, i.e. the causes of HSP and little on treatment or cures. In the last 10 years there have been 300+ research projects in HSP genetics and only 11 on treatment. In comparison there were 200 times more research projects on treatment of Multiple Sclerosis. Dr Siva Nair suggested that we, as a group, perhaps need to be little more vociferous in influencing research projects. It is not an easy process, he acknowledged.

However, the funding for research is changing and priorities are also about to change. The Government are encouraging "user control of research".

I would be happy to help co-ordinate the set-up of the group, but feel that I cannot be the lead.

Please email me if you feel you can contribute, whether as a committee member, committee lead or with any ideas/suggestions on how to enhance our research sponsorship from businesses.

"Get involved and let's make the impossible possible"

You can email me at irena.pritchard@btinternet.com.

Looking forward to hearing from you.

Irena Pritchard Region 9

Fundraising Made Easy

We are thinking of setting up a new fundraising scheme in association with Utility Warehouse - The Discount Club.

What is the new scheme? A new and easy way to generate a regular income for us, and save money for yourself at the same time.

Who's behind it? Utility Warehouse - The Discount Club provides savings on essential utilities to over 500,000 customers. They also provide additional benefits, including other great ways to save money. Utility Warehouse is part of Telecom Plus plc, a major UK company, listed on the London Stock Exchange.

What's in it for them? Utility Warehouse doesn't spend money on adverts on TV or in the national press...they rely on recommendation. This saves them millions of pounds every year, savings they pass on to their customers by charging less. It truly is win-win.

- Utility Warehouse gets a new customer
- You save money
- We generate much needed funds

Every time you use a service (Phone, Broadband, Mobile, Gas, Electricity) we raise

money and you save money. The Unique "Double the Difference" Price Promise from Utility Warehouse guarantees that you will save money when you switch all your services to them, or they will give you back "Double the Difference".

The UK's most generous Cashback card from more than 40 High Street retailers and another 2,000 online retailers.

- Earn 3% to 7% Cashback at leading retailers on your shopping and petrol.
- It's not a debit or credit card - it's a pre-payment card. Just top it up, shop and save.
- Access a retailer through the Utility Warehouse website and you can earn up to 20% Cashback on your order.
- Your Cashback is paid as a credit on your monthly Utility Warehouse statement.

How does the scheme work?

- We tell you about the scheme.
- You call a freephone number, and
- Join the Utility Warehouse Discount Club, who donate up to 5% of your utility statement to us, every month.
- We carry on raising funds for as long as you remain a customer.

That's it.

For more information, call Edwin Linnell on 01798812151 or go to his website www.edwin-linnell.co.uk

More about Edwin. He is a friend of Joyce, who some of you will know. She has attended our meetings in Milford, Surrey for several years. Edwin will also earn a small, monthly commission on the business generated by the HSP Support Group but he has offered to pay this in to our bank account as a donation.

Edwin Linnell

SS Great Britain

A few weeks ago we were staying overnight near Bristol and treated ourselves to a visit to Brunel's ship the SS Great Britain.

When she was launched in 1843 she was the biggest iron hulled ship in the world and was fitted with an innovative steam powered propeller. She was built to make the Atlantic crossing to New York but in the early 1850s began carrying emigrants to Australia. She also carried troops to the Crimea in 1855 and the England cricket team to Australia in 1861. She later became a cargo ship and was, finally, scuttled in the Falkland Islands in 1937. A salvage operation was begun in 1969 and in 1970 she was returned, with difficulty, to the dry dock in Bristol where she had been built and where she remains after major restoration.

I had long wanted to explore the ship, partly because of its history and the tale of its restoration and partly because my great great grandmother travelled on the Great Britain from Liverpool to Melbourne in the 1860s to visit two of her brothers who had emigrated to Australia. I had assumed that a tour of the ship was out of the question because such a ship, surely, wasn't going to be wheelchair accessible.

But, yes, it is totally wheelchair accessible from the separate, "no cobbles" entrance gate to the reception desk (carer goes free), the museum and, finally, the ship itself. There is an external lift going down into the dry dock, below the "waterline" so we were able to enjoy the full glory of the beautiful shape of the hull. The lift then took us back up to the weather deck which was fully accessible. Then, another lift – inside the ship's funnel, no less – took us back down through the various decks which were also fully accessible. The lifts are large enough to take a manual wheelchair user and one other person and, we were told, can accommodate smaller mobility scooters (best to check sizes in advance, I should think).

Despite all this the staff are looking to improve accessibility. They have noticed that many wheelchair users now travel alone so they intend to install push button or sensor operated doors. We haven't been

to any museum where accessibility is so much at the forefront of planning and in such difficult circumstances.

They are about to start building a new museum so best to check on that too, in case they are in between museums at the time.

Both the museum and ship (sounds, smells, the lot) were superbly presented and very interesting. There is a choice of three different free audio guides, First Class, Steerage and Technical. The first two tell stories of life on the ship in the words of passengers but aren't so strong on information. The Technical one was informative without being too technically detailed.

Don't miss it!

www.ssgreatbritain.org

Hilary Croydon

Unwanted equipment

Hi lovely people. I've been meaning to do this for a long while. You see, I have a pair of walking crutches that are hiding in the cupboard, under the stairs. I have no use for them, because I find them awkward and clumsy. I prefer my walking sticks. I do not walk far, so the need for the crutches is nil.

So! I am bringing them along to the AGM in June. They are free to anyone who wants them. Total waste being under the stairs! I am thinking, it would be a shame if HSP's wanted to try walking aids, only to buy them, then relegate them to the cupboard somewhere. I will, of course take them home with me, if there are no takers... They also, have flexyfoot ferrules.

There will be an area put aside at the AGM for unwanted walking aids/equipment. To be given away, free of charge, to anyone that might want to take them. Might save someone the expense.

PLEASE NOTE, IF NOT CLAIMED BY THE END OF THE DAY, MEMBERS WILL HAVE TO TAKE THEIR ITEMS HOME AGAIN.

Not sure if this is going to work, as I know it is difficult for members to transport equipment that they no longer use.

Anyway, the crutches are free to anyone that wants them. Or, if wishing to pay something. A donation to the group is always welcome. Every penny helps.

Della Brookman

VERY Long Hike for HSP

There was an article in the February edition discussing my friend Stuart Montrose's forthcoming challenge for HSP. Stuart is walking from Lands End to John O'Groats for four charities, one of which is HSP.

This is a massive undertaking and Stuart would appreciate all the help and support he can get. He is particularly after somebody with HSP to join him for a few strides while he walks over a bridge in Glasgow. The local television station is going to cover this so if you can help, please let Stuart or myself know. He is planning to be in Glasgow on 8th and 9th June. Stuart is setting off from Lands End on May 21st and plans to walk about 30 miles per day.

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

If you can help or support in any way, you can contact Stuart directly, his mobile number is 07752 499 688.

Ian Bennett

Regional News

Region 4 meeting

Forty members attended the Ashburton meeting on April 10th. It was great to meet two new members and I believe they both found the meeting to be very worthwhile. We simply chatted amongst ourselves and some of us met some new friends and we all shared useful information. It's great to see so many members attending who have been coming regularly for years, some of whom were present at our first meeting about 12 years ago. We were joined by Derek Weeks who's recently walked from north to south Wales (188 miles) and raised

nearly £700 for HSP. It was good to meet Derek and see some of his photos from the trek. Our usual raffle set a new record, £140 was raised which once again covered all meeting costs with plenty left over to go into the HSP account.

There were four trustees present so immediately after the meeting we took the opportunity to have a committee meeting in a quiet corner of the bar.

Twenty four members stayed in the hotel overnight we all sat down and enjoyed dinner together in the restaurant followed by one or two beverages in the bar

The next Region 4 meeting will be at the same venue on October 15th.

Ian Bennett

Midlands Region 7

The Kenrick Centre, Harborne 12/3/2016

We had a super turn-out - it was great to see our regulars again, and so lovely to be able to welcome several new members too (there were 11 HSP members present).

We invited my Consultant Dr. Hani BenAmer to join us, with whom I have a good relationship, and who is a Neurologist & Honorary Clinical Senior Lecturer at Birmingham University. I asked if he would like to come along to meet us all, as I am the only HSP patient on his books, and I was hopeful that this might give him a better benchmark for any research into HSP.

He was very pleased to have been invited to our group, was very engaging, and lead a very interesting chat with us all on Genetics, explaining how difficult a process it is. He also said that to have to investigate outside of the initial 7 Genes, could cost anything up to 10's of thousands of £'s!!!

We had a super, very informal, and very open discussion with him, with many questions being able to be asked, and lots of answers given.

Dr. BenAmer is kindly asking other medical professionals at the Queen Elizabeth hospital if they might be interested in

coming along to meet us. We are a very positive little group, and most of us are very happy and willing to help with any research, questionnaires, or just being asked anything about our conditions.

We are hoping that he might have some news for us sometime after Easter. He said that unfortunately a condition like ours, has only a small voice in the medical world, but if each one of us can do as I had done, it might just help to make our voice be better heard.

There was quite a buzz over our coffee cups after he had gone, and then we settled down to a more general discussion.

Everyone says how wonderful, and so very valuable our Newslink is, and Des Williams wondered whether a little quiz page (like you have in a newspaper) could be considered to be added to it??

We came to a close at 3pm, everyone said they'd enjoyed the meeting, and we plan to meet again in September, most probably again at the Kenrick Centre, but we will confirm all the details just as soon as possible.

With kindest regards to all,

June Masding & Penny Cohen

East Anglia Colchester Meeting

Our spring meeting at Feering Community Centre proved popular and we were very pleased to welcome three members who are new to the HSP Group. We missed a few regulars, struck down by sickness, but will look forward to catching up with them in the autumn.

Hugh Beavan started the meeting off by telling us about his experience with stasis eczema which has had a serious impact on his mobility over the last few months. He was told that it may be associated with HSP because it is caused by poor circulation in the lower leg which is made worse by reduced movement.

Hugh also drew our attention to an MS Centre, called Joseph's Court, which he

attends in Colchester. It is run by MS UK and provides a number of services such as highly specialist exercise equipment, physiotherapy and massage. Another member attends a similar one called Charms Therapy Centre, in Chelmsford, which is an independent charity. It offers massage, hyperbaric oxygenation therapy, occupational therapy, counselling and other services. Both centres offer the use of FES equipment to build muscles and are open to people with other neurological conditions such as HSP. It seems that there are other centres scattered across the country.

We then moved on to discuss our chosen topic which was Personal Budgets under the new Care Act. It seemed that only one member present had a Personal Budget for social care though we have another member who has recently obtained a Personal Health Budget. Other members were interested in obtaining budgets and it might be that more people could benefit from them, if more information was available.

After a break for our usual coffee, cakes and chat we had a more general discussion covering a number of areas including the HSP Registry, motability and adaptations in the workplace.

We shall be meeting again on Sunday, 9th October 2016 from 3.00 - 5.00 pm, at Feering Community Centre, CO5 9QB and, as always, everyone is very welcome to join us.

Hilary Croydon

Region 5 meeting

Some members of Region 5 met on Saturday 12th March at The Oaks Restaurant at the Norwich Airport Premier Inn. Over teas and coffees, we chatted and were given advice by the physiotherapist Rekha Srinivasan. We are so lucky that she attends our meetings. We hope to have a further meeting in July in an empty room where she can help us with exercises.

Barbara Jones

Forthcoming Events

The Mobility Roadshow

Fully accessible and free admission

May 26th – 28th

Opening times: 10am-5pm Thurs 26th & Fri 27th May, 10am - 4pm Sat 28th May
Silverstone Racing Circuit, Northants
MM12 8TN

Afternoon tea Regions 1 & 2

Sunday November 20th 3pm – 6pm

The Clockhouse Milford

Call Jane Bennett on: 020 8853 4089

Region 4 get together

Saturday October 15th 2pm onwards

The Dartmoor Lodge Hotel, Ashburton

Call Ian Bennett on: 01202 849 391

Norwich Meeting

Saturday July 16th 2pm

Meadow Way Chapel NR6 5NU

Physiotherapist Rekha Srinivasan will be advising us on correct use of mobility aids.

Call Barbara Jones on: 01603 423 267

Colchester Meeting

Sunday, October 9th 3 - 5pm

Feering Community Centre

Feering, Essex, CO5 9QB

Call Hilary Croydon: 01284 728 242

Region 9 Meeting

Saturday 15th October, 2 - 5pm

Meeting Rm, St Helens South Premier Inn

Eurolink, Lea Green, St Helens, WA9 4TT

Call Irena Pritchard on: 01524 261 076

HSP Support Group AGM

Saturday 25th June

10am - 4.30pm

Trident Technology and Business Centre

Leamington Spa, CV34 6SW

Region 7 Meeting Birmingham

Saturday 15th October, from 12 - 3pm

The Kenrick Centre, Mill Farm Road,

Harborne, Birmingham, B17 0QX

Contact Penny Cohen: 07818 288 738

Email: pennycohen57@hotmail.com

Potato Pants Festival

Saturday 4th June 10am - 11pm

High Mead Farm, Ham Lane, Ferndown

BH22 9DR

New Members

We welcome the following new members:

Christine Lilley London Region 2	Karen Winter Canvey Island Region 5	Mike Featherstone Newcastle Region 10
Julia Miles Isle of Wight Region 1	Kenneth Lilley London Region 2	Neil Brookes Manchester Region 9
Karen Johnson Preston Region 9	Mandy Reid Kidderminster Region 7	Peter Nall Wrexham Region 9

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

HSP Support Group 2016 AGM Details

Saturday 25th June

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

10.00	Coffee & Welcome
10.30	AGM
11.15	Georgie Powell from Flexyfoot
11.45	Break
12.00	Debra Gordon & Lauren Moore from Coloplast Continence – What does it mean to you?
1.00	Lunch
2.15	Dr Paul Taylor from Odstock Medical Functional Electrical Stimulation (FES) – How it may help HSP
3.15	Coffee
3.30	Amber Meikle-Janney HSP Can't stop me!
4.30	Close

Georgie Powell from Flexyfoot Ferrules will be present throughout the day with a range of their products for trial or purchase.

Debra Gordon and Lauren Moore from Coloplast will be present throughout the afternoon and set up an area where members can view some of the Coloplast products and chat privately about any continence issues.

Dr Paul Taylor from Odstock Medical (FES) will be able to give members an FES trial.