HSP Newslink

The Newsletter of the Hereditary Spastic Paraplegia Support Group

Issue 41 – May 2017

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

No BREXIT for HSP

I'm delighted to confirm that the UK HSP Support Group is now a member of Euro HSP. This will further improve our relationships with the following European HSP organisations who are also members:

- Denmark, Foreningen for ATAKSI / HSP
- France, Association Strümpell Lorrain or A.SL-HSP France
- Italy, Associazione Italiana Vivere la Paraparesi Spastica Onlus
- The Netherlands, Vereniging Spierziekten Nederland
- Norway, Norsk forening for Arvelig -Spastisk Paraparese/-Ataksi
- Spain, Asociación Española de Paraparesia Espástica Familiar
- Switzerland, HSP-Selbsthilfegruppe Schweiz
- Sweden, Hereditär spastisk parapares

EURO-HSP is an international, non-profit association registered in Paris on July 2010 with the following objectives:

- Keeping up with and supporting medical research on HSP and related conditions.
- Central processing of information on such research and passing it on to the members of EURO-HSP
- Promoting and improving contacts between practitioners concerned and persons

affected by HSP and other related conditions.

- Investigating social, political and cultural matters connected with the welfare of people affected by HSP and related conditions, as well as promoting and improving the exchange of information on such matters.
- Promoting co-operation on an international level between national associations for people affected by HSP and related conditions.
- Co-operating with or being members of other national and international organisations and institutions that have the objective of furthering the welfare of individuals affected by a physical disablement and, inter alia, those with a neuromuscular condition.
- Gathering funds and collecting, managing, using and distributing contributions, legacies and donations or their benefits, for the purpose of stimulating and promoting both medical research into HSP and related conditions and the welfare of people affected by them.
- Serving as a meeting point for any and all implicated groups (people with HSP, their families, investigators and scientists, doctors, nurses, health care workers, etc) where all aspects of dealing with optimal maintenance of health can be sought, including alternative methods with rational basis.
- Participating in media and media events in order to keep the general public as well as public and private institutions, European or International, aware of HSP issues and concerns.
- Other activities not specifically contemplated in these statutes that may favor the promotion, support, and social and labor inclusion of people affected by HSP and / or related conditions.

Further information can be found on the Euro-HSP website: http://www.eurohsp.eu/

We'll be seeking a representative to manage and oversee our EURO-HSP connections, so if this is of interest please let us know.

Chairman's Column

This will be the last time this column is called 'Chairman's Column'. At this years AGM I am standing down but I will continue to be very involved, probably remaining on the committee as Membership Secretary. I'll continue to edit the Newsletter so the column heading will simply be amended to 'Editor's Column'.

I have thoroughly enjoyed my time as Chairman and thought this would be a good opportunity to discuss some of the highlights. I've chosen the following ten:

1) Since before I was Chairman, a charity that is very close to my heart, called FSDP (Flying Scholarships for Disabled People) has sponsored ten of our members (including myself) to undergo flight training in a light aircraft. This can make a huge difference to someone's self-esteem and confidence and this has certainly proved the case for some of our members. Incredibly, FSDP have spent approximately £100,000 on our members, their generosity is beyond belief.
2) I have been lucky enough to attend HSP meetings in Spain and in Germany during my time as chairman. Developing good relationships with the HSP societies of other countries and making friends with with HSPers around the globe has been very interesting and enjoyable. On my latest visit to Madrid, I was proud to be part of a team involved with developing a new HSP logo for worldwide use. I am delighted with the result and it's great to now see it in use on the websites and letterheads of other HSP Groups around the world.
3) Although I'm not pretending it isn't hard work, it's been a pleasure to organise AGM's and provide an opportunity for our members to get together and learn more about what's going on within the world of HSP. One

of the highlights of this process for me was at last years AGM when our very own member, Amber Miekle-Janney (aged 16) delivered an excellent presentation on her skiing activities.

4) With the help of others, I've enjoyed being involved with trying to get local meetings started in various regions around the country including the South West, Norwich and the North West. It's brilliant for me to see how many people now enjoy regularly attending the Ashburton meetings and long may they continue. It's fantastic to see so many regional meetings taking place and I thank all the co-ordinators and other individuals who do all the hard work to arrange these very important events. Please keep up the great work.

5) Nine years ago I created the Facebook Group called 'Hereditary Spastic Paraplegia's Unite and it's come as a huge surprise to see how well used it is by people with HSP from all over the globe. It now has over 1400 members who happily discuss problems or seek advice from one another on a day to day basis. I had no idea what an important facility it would prove to be and I thank the members who've helped me to run it. If you're not already a member, I would strongly recommend that you join.

6) With the help of fundraising in my local community, presenting both Steven Foot with an all-terrain mobility scooter and Alice Parsley with a Power Chair were two huge privileges which I will never forget. It's so good to have subsequently discovered that both of them are using their new equipment regularly, if not daily and in both cases they have found it life changing. Both were unaware of what we had been up to and seeing the look on their faces when presented with their new mobility aids in a packed pub, was priceless!

7) I have to say that organising the Potato Pants Music Festival is great fun. I have found it overwhelming / emotional / unbelievable at how many people have jumped on board to support it at little or no cost to our charity. I have to say well done and thank you to Lori in Austria for coming up with Potato Pants in the first place. As those of you who attended last year's festival will realise, the people who filled the specially made trousers with potatoes and raced each other, had without question a whale of a time. It certainly proved to be a fun way to raise money, while at the same time giving the public an inkling of what it may be like to be affected with HSP. The music is pretty good too!!!

8) Working with a very strong committee has been a privilege and we are very lucky to have such a dedicated, efficient team running our charity.

9) On occasions there have been bad days. Usually because of fatigue and very occasionally because of an unhappy individual, I've found myself questioning why I get so involved. However, on the rare occasions when this has occurred, the postman delivers the perfect antidote in the form of a letter or a card from a member expressing thanks for help or advice. When this has happened, the smile has immediately returned and it has suddenly been made very clear why I like to be involved.

10) At times I have introduced members and as a result there are a few very special friendships around the country. You'll know who you are and it's a privilege to have been involved. I have also made some great friends who'll be friends for life. I certainly never expected this when I first joined the Support Group nearly 15 years ago.

I'm now going to focus more on fundraising and particularly The Potato Pants Music Festival which I'm hoping can become a larger event. As I mentioned earlier, I will continue to produce the newsletter but as always, your help with content is very important and much appreciated, so please keep those articles coming in.

I look forward to seeing many of you at this years AGM on July 1st in Birmingham. Please bring any spare DVD's so that we can raise a few pennies for HSP. The article on the final page explains all.

Thank you all for putting up with me as Chairman.

Ian Bennett

Adam's Column

HSP Falls Study

Readers will have noticed at the end of the previous NewsLink the letter from Plymouth University about their study to understand more about how many people with HSP fall and what makes them fall http://hspgroup.org/images/Newslink/March2017.pdf. Ian has also sent similar e-mails on this topic. I've not had a fall due to HSP and I contacted them to find out if my data would be useful. It turns out that it will and I have signed up to participate. I encourage you to do the same!

The study aims to survey people with HSP, whether or not they commonly fall. It aims to identify how frequently people 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. Such understanding will help to raise the awareness of the condition with other healthcare professionals, determine what interventions may be useful and drive future research.

There is an initial questionnaire gathering information about participants (factors such age, diagnosis, family history as well as current symptoms and their perceived severity) and any falls you may have had in the last three months.

The second part of the study records any falls or "near miss" falls over a three month period. You will be sent diary packs, used to indicate your falls and their characteristics on a daily basis. The falls diaries will ask about how you fell, what you were doing at the time and the perceived cause of the fall. These diaries are returned over a 3 month period.

Misdiagnosis Comparison

My experience with looking at the results of my surveys is that everyone with HSP is unique, the number and severity of symptoms vary extensively from person to person and from year to year. To help me understand how difficult it must be to diagnose HSP and similar conditions correctly (in the absence of a genetic test) I have looked at the common symptoms of HSP and of conditions which are often misdiagnosed as HSP. The table below shows symptoms for conditions, mostly taken from the NHS website, supplemented with UK support group websites.

I've abbreviated each of the conditions in each column; Pure HSP (PHSP), Complicated HSP (CHSP), Friedreich's ataxia (FA), Spinocerebellar ataxias (SCA), Motor neurone disease (MND), Duchenne muscular dystrophy (DMD), Becker muscular dystrophy (BMD), Spastic cerebral palsy (CP), Multiple sclerosis (MS), Arthritis (Arth), Charcot-Marie-Tooth disease (CMT), Diabetes (Diab), Vitamin B12 deficiency (B12), Peripheral neuropathy (PN)

	PHSP	CHSP	FA	SCA	MND	DMD	BMD	CP	MS	Arth	CMT	Diab	B12	PN
Weak legs/walking issues	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Stiffness/cramps	✓	✓	✓	✓			✓	✓	✓	✓	✓			
Balance/co-ordination		✓	✓	✓	✓				✓					✓
Weak grip					✓									
Learning/memory issues		✓		✓		✓		✓	✓				✓	
Swallowing		✓	✓	✓				✓						
Vision/hearing issues		✓	✓	✓				✓				✓	✓	
Speech issues		✓	✓	✓	✓	✓		✓						
Bladder issues	✓	✓		✓					✓			✓		
Fatigue	✓	✓							✓			✓	✓	
Pain										✓				✓
Bruising/Itching/Wound healing		✓										✓	✓	
Numbness/sensation/tingling hands/feet	✓	✓	✓	✓					✓		✓		✓	✓
Diabetes			✓									✓		

Study of Effects of HSP

I found a research paper from 2016 which looks at the differences between people with HSP and a control population to evaluate the burden of HSP. The study was undertaken in Norway, comparing 108 people with HSP against an age and gender matched sample from a study of 46 thousand people.

The paper is called “Health survey of adults with hereditary spastic paraparesis compared to population study controls”, by Krister W. Fjermestad, Øivind J. Kanavin, Eva E. Næss, Lise B. Hoxmark and Grete Hummelvoll. You can read the full paper here: https://ojrd.biomedcentral.com/articles/10.1186/s13023-016-0469-0

The study is a broad survey of health and everyday life domains among persons with HSP, including life satisfaction, mental wellbeing, social support, problems with sleep, memory, pain, gastrointestinal/urinary functioning, and ability to perform activities of daily living (ADL).

The HSP sample more frequently lived alone. Overall, the HSP sample reported lower life satisfaction, lower mental wellbeing and lower social support, as well as poorer memory and sleep, compared to controls. Furthermore, the HSP sample more frequently reported musculoskeletal pain, constipation, and urinary incontinence compared to controls. There was no difference between samples in frequency of physical activity and alcohol and tobacco use. Men with HSP reported higher impact of HSP, lower life satisfaction, and less ability to perform activities of daily living compared to women with HSP.

Adults with HSP experience disease burden on a larger number of areas than previously documented, and men with HSP may represent a particularly vulnerable group.

Activities of Daily Living Scale

There is another study you can participate in, which seeks to learn about rates of disease progression in patients with motor neuron diseases and learn about clinical characteristics that

patients report which influence this rate of progression. They seek to try out a new daily living scale, identify if patient reported features can predict progression and compare their scale with other scales. You answer questions on-line, there is an initial survey about your diagnosis and history, and then a shorter (15 question) monthly survey for 12 months.

To take part you need to sign up to the CReATe group (**C**linical **Re**search in **A**LS and Related Disorders for **T**h**e**rapeutic Development) of the The Rare Diseases Clinical Research Network (RDCRN) https://www.rarediseasesnetwork.org/cms/create. I had signed up to this site in 2016 and was e-mailed about partaking in the study, and I am now completing month 4 of the survey. If you are not contacted by them about this, then use the contact page to e-mail them about study 8003 "A Patient Centric Motor Neuron Disease Activities of Daily Living Scale".

Adam Lawrence

Useful Information

The Jumbulance Trust

The Jumbulance Trust exists to make travel possible for adults and children who are disabled or have a serious or complex health condition. We offer the opportunity to groups and individuals who wish to go on holiday, take short breaks or a day out.

Further information can be found on their website: http://www.jumbulance.org.uk/

SPG 11 Families

SPG 11 Families

Our son, Tim, who is 24, has SPG 11 which is one of the complex, recessive SPGs so that he is the only member of our family to be affected.

SPG 11 is very similar to SPG 15 and they have a wide variety of additional symptoms. We find it has been very helpful to be in email or phone contact with other families who are living with the conditions. By talking to others we can all benefit from shared knowledge which means that we can support our young people more effectively.

We are in touch with six other families, so far, who are now also in contact with each other as a result. The affected members of the families also often talk to each other on Facebook.

Even the experts don't know how many SPG 11 and SPG 15 Families there are in the country – perhaps we can find out.

I'm sure there are other families out there! If you are part of an SPG 11 or SPG 15 Family and would like to be able to talk to other families for mutual support and to exchange experience do, please, give me a ring on 01284 728242.

I would like to hear from you very much.

Hilary Croydon

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!

Raise Funds 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.

100,000 Genome Project

Hi all

At my recent consultation with my neurologist, we discussed my diagnosis of Hereditary Spastic Paraplegia, with added symptoms of Parkinsonism. I have no known cases of either of these disease's in my family, so do not at this time, know the SPG that caused them. They could be two totally different gene's causing this or one gene which is causing both symptoms. Because i am responding well to Levodopa, which changes into Dopamine in the brain, my neurologist says, because of my age onset of the Parkinson's, it is very likely to be genetic and if I only had the Parkinson's symptoms, my diagnosis would definitely be 'Parkinson's disease'.

So! as you can imagine, I asked about doing some blood tests again for other gene's. (I was tested for the 7 most common SPG's) which, came back negative... Dr Morrow mentioned the '100,000 genome project'. Initially, I was turned down because of having no family history of HSP. Dr Morrow informed me that they are now taking HSP patients, with no family history and who have been diagnosed by ruling out other conditions. You do not now have to have a genetic diagnosis.

I am being referred by my neurologist and am waiting for an appointment to begin the process. This could take about a year to hear anything. No one has received any results yet. The project runs until 2018. Everyone could see their results at the same time. I will tell you a bit about it. Here is the link, if you wish to take part or have an interest in the project.
https://www.genomicsengland.co.uk/the-100000-genomes-project/

The project will sequence 100,000 genomes from around 70,000 people. Participants are NHS patients with a rare disease, plus their families, and patients with cancer.

The aim is to create a new genomic medicine service for the NHS – transforming the way people are cared for. Patients may be offered a diagnosis where there wasn't one before. In time, there is the potential of new and more effective treatments.

The project will also enable new medical research. Combining genomic sequence data with medical records is a ground-breaking resource. Researchers will study how best to use genomics in healthcare and how best to interpret the data to help patients. The causes, diagnosis and treatment of disease will also be investigated. We also aim to kick-start a UK genomics industry. This is currently the largest national sequencing project of its kind in the world.

Most of us have heard of genetics, the study of the way particular features or diseases are inherited through genes passed down from one generation to the next. But the more we learn about genes, the more we understand that the old idea of having a single gene for this, or a single gene for that, which determines your fate is not – except in the case of unusual inherited diseases – a good way of describing the complexity of genes. In fact, groups of genes work together and their activity is influenced by a huge variety of environmental and other factors. And we now know that the DNA between your genes is also very important.

You have a complete set of genes in almost every healthy cell in your body. One set of all these genes, (plus the DNA between the genes), is called a genome. Genomics is the study of the whole genome and how it works but has also come to have a broader meaning to include the way that the genome is interpreted and the technologies that have been developed to help do this.

When the first draft of the whole human genome was announced it was claimed that it would revolutionise medical treatment. It had taken 13 years and over £2 billion to laboriously read every letter of the human genetic code. It took such a long time because the DNA sequence of humans is very long – 3 billion letters – and because the sequencing machines available at the time were so slow and laborious. Now a human genome can be sequenced in a few days for less than £1000. It's the leap in the speed and cost of technology that has opened up the

potential of genomics and brought it within reach of mainstream healthcare.

But haven't we already got a good understanding of genetics? One of the great surprises from the Human Genome Project was that there were only about 20,000 genes– about the same number as a starfish. The role of the remainder of a human's genome – in fact a staggering 95 percent of it – was a mystery. Now we know that the remaining DNA is not irrelevant as was once thought but that much of it has a critically important role, influencing, regulating and controlling the rest. That's why it's necessary to sequence the whole human genome (rather than just looking at the 20,000 genes currently used for diagnosis in medicine) if we are to really understand the role of genes in health and disease.

But people are very different, so studying only a small number of genomes would not be enough to give doctors and scientists a true picture of our genes and their relationship to disease. Another key point is that by itself, a genome can't tell you very much. To make sense of it, it is essential to know much more about the person who donated it; details like their symptoms and when they first started, along with physiological measurements, such as heart rate or blood pressure (this sort of information is provided by clinicians and called phenotypic data). Another set of information which may be important in interpreting genomic data comes from their past medical records and would include such things as previous illnesses, medications and birth weight.

And this is where the NHS comes in. The way in which the NHS is able to link a whole lifetime of medical records with a person's genome data and the fact it can do this on a large scale is unique. The richness of this data can help to understand disease and to tease apart the complex relationship between our genes, what happens to us in our lives and illness.

So what can genomics do? You can use it to predict how well a person will respond to a treatment or find one that will work best for them – so called personalised medicine. A good example in use already is whether or not a woman's breast cancer is HER2 positive. If it is, Herceptin will be very effective for her but not for someone who doesn't have HER2. You can also use genomics to test how well a cancer might respond to radiotherapy. For some that can mean far fewer radiotherapy sessions. Or use it to find the 30,000 people who currently use insulin for their Type 1 diabetes but would do better on simple tablets. Genomics can be used to track infectious disease, precisely pinpointing the source and nature of the outbreak through looking at the whole genomes of bugs. The potential of genomics is huge, leading to more precise diagnostics for earlier diagnosis, new medical devices, faster clinical trials, new drugs and treatments and potentially, in time, new cures.

The supersonic age of genomics has begun. And just as the NHS has been at the forefront of scientific breakthroughs before, we want the NHS to be at the forefront again, with its patients benefiting from all that genomics offers, becoming the first mainstream health service in the world to offer genomic medicine as part of routine care for NHS patients

Privacy and confidentiality issues

Any relevant information about a patient will be returned to their doctor. For other medical researchers and companies to gain access to Genomics England's data services they will have to first pass a rigorous ethical review and have their research proposal approved under policies being devised by Genomics England's Ethics Advisory Committee. Insurers and marketing companies will not be allowed access.

Oversight by the Genomics England Data Advisory Committee will ensure that any researchers wanting access to data will go through rigorous identity checks and their use of the data will be closely supervised. No raw genome data can be taken away. The data will be kept within Genomics England's data structures and will be constantly under its control. Genomics England commits itself to constant testing and re-testing of its security systems to ensure data safety.

While Genomics England has the data, patient identifiers (such as NHS number or postcode are removed) to reduce the risk of re-identification of clinical and genomic information with a particular individual. Only when data is used for a patient's own care will identifiable data be made available to the patient's doctor and medical team. Patients are told that participant anonymity cannot be absolutely guaranteed as in theory, any non-trivial piece of health records data can be re-identified by someone who already has access to sufficiently detailed information about an individual. In practice, this is very hard to do and harder still to achieve undetected. Genomics England can't promise that no researcher would be able to do this but what it can promise is that it will be made so difficult that there would be far easier ways to achieve the same goal.

Genomics England is talking constantly to patients about their concerns to make sure that any issues they may have are addressed at an early stage. Patients have been involved from the outset and are at the very heart of this project. In particular, the commitment to consent is of paramount importance.

When the project ends, the NHS will need to be ready to use genomics as part of its routine care, so it is vital that more scientists, geneticists and doctors are trained to interpret the data and understand what it means for a patient's medical condition. In parallel with Genomics England's work, a skills and training programme for workers in the NHS is currently being set up by the organisation responsible for doing this – Health Education England.

The 100,000 Genomes Project will use the generosity of patients and the outstanding skills and talent found in the medical and the life sciences' sectors in the UK to help deliver this project. Genomic England's legacy will be a genomics service ready for adoption by the NHS, high ethical standards and public support for genomics, new medicines, treatments and diagnostics and a country which hosts the world's leading genomic companies. It is a bold ambition with benefits for all.

There is much more information online and your neurologist should be able to outline the project and if you're interested, will be able to refer you. It would be a great help to the project and research, if as many HSP patients could get involved, to help research and hopefully get a genetic diagnosis. That's my reason for taking part in the project.

Della Brookman

HSP Can't Stop You From Doing the Duke of Edinburgh's Gold Award!

About two years ago, I wrote a piece in the Newslink about our son Tim's quest for the Gold D of E Award because we were finding it very difficult to put together a team to do the expedition element and we hoped that someone might be on the same journey.

So, I thought I would let you know what happened. We were in touch with The Bendrigg Trust which is based on the edges of the Lake District and the Pennines. As well as providing activity holidays for people of all ages with disabilities it also organises specialist expeditions which comply with the D of E requirements at Bronze, Silver and Gold levels. They were scouring the country for young people interested in doing an expedition for the Gold Award because they knew that Tim was running out of time as he had to complete the Award by his 25th birthday. Finally, they found four other people and the expeditions went ahead in 2015.

None of the others had a physical disability but they were quite severely autistic so that the expedition was a considerable challenge for them. As far as Tim was concerned, it was a challenge for all sorts of reasons. Tim has SPG 11 which is one of the complex HSPs and it affects him in many different ways, but including in his upper body. This meant that he couldn't use a manual off road chair on the hills of the Lake District but the D of E is flexible and they allowed him to use a power chair. We bought a Storm 3 for the purpose and it was excellent. Bendrigg Trust had a large wheelchair accessible tent and, in view of Tim's circumstances, the D of E allowed a

variation from the normal continuous journey with camping in a new place each night. Instead, the team was able to camp in one place for all three nights and travel out and back each day. They did a mix of walking (or power chairing, in Tim's case!) and canoeing on Derwentwater and Bassenthwaite Lake. A young man who was supporting one of the other lads offered to give Tim a hand as necessary on the personal side if his SPG 11 was creating a barrier to him completing the expedition.

Tim enjoyed it all very much, despite appalling weather for the practice expedition in April and quite a bit of rain at night during the qualifying expedition in August. They climbed hills, enjoyed wonderful views and Tim loved canoeing on the lakes.

For Tim, the expeditions were the last part of the Award as he had done everything else some time before, so he sent in the paper work, the award was granted and then he waited for a place at one of the presentations.

Finally, eighteen months after finishing the expeditions Tim was presented with his Gold Award at St James' Palace in London in February this year.

Tim proudly holding his D of E Gold certificate

The certificates are presented by an invited guest but the Duke of Edinburgh spends a few minutes talking to the group as part of the presentation. He made a point of speaking to Tim, asking him how and where he had done the expedition. The D of E team made it a really special occasion, stressing what an achievement it is.

Tim did the Bronze Award when he was 14 years old at school so this has been a 10 year journey, interrupted by the diagnosis of SPG 11 when he was 19 years old. It hasn't been an easy journey at all but it has been well worth all the effort put in.

The D of E team have been excellent. While ensuring that it remains a challenge for each individual they are flexible about how the expeditions are done. We cannot praise Bendrigg Trust too highly. Without their team, the expeditions could not have happened and Tim could not have gained the Award. They were the only organisation offering specialist Gold expeditions at the time.

So, I would really encourage anyone with HSP who is between the ages of 14 and 24 to go for the D of E Award. At each stage you have to do some volunteering, take part in a physical activity and learn a skill as well as completing a practice and a qualifying expedition. For the Gold you also have to take part in a residential activity away from home with people you don't know – Bendrigg also offer these. The length of time for which you do all these elements increases through the awards. The scheme gives people the chance to try new things, meet new people, have fun and prove themselves to themselves –a wonderful way of improving self confidence and self esteem.

Check out the D of E's website for more information on the scheme http://www.dofe.org/ and Bendrigg's for information on their activity holidays as well as on the D of E expeditions and residentials that they offer http://www.bendrigg.org.uk/ .

Do give it a go. You will have so much fun!

Hilary Croydon

Members' Letters

Hi everybody

My name is Kevin Mills and I was diagnosed with HSP a few months ago (even though I have had it for years).

I moved from Scotland down to Brecon in Wales twenty years ago, to be with my girlfriend (now my wife) and we had twin boys a few years later.

The reason that I am writing this is firstly and most importantly to introduce myself and say hello to my new co-members of the support group, but also to contact other members to discuss social meetings and gatherings because I find it quite uplifting to discuss this condition with people who know things about it. We know about the Facebook page but for different reasons my wife and I prefer not to use social media. Due to that reason I would love to contact and be contacted by members to talk about upcoming social gatherings and meetings.

Kevin and his wife Suzanne at his nephew's wedding on the banks of Loch Lomond

My wife and I went to have some lunch and a chat with the nearest members that we could find and found them to be very nice and very informative, so thanks to Peter and Sandra for that.

So just to sum up, I would just like to say hi and ask that some members contact me just either to say hi or let me know about any gatherings, or even just for a chat.

Best Regards

Kevin Mills
kevinmills944@gmail.com
01874 622727/07762756981

Regional News

Colchester Branch Meeting

We met, as usual, at Feering Community Centre, between Colchester and Chelmsford. We had a record attendance this time of 29 including two new members, one of whom turned out to be related (unknowingly) to another member!

We began with informal chat as we caught up with old friends and introduced ourselves to new members. Then, once we were all supplied with tea, coffee and cake, we had a discussion as a group on a number of topics.

We found that most members present do not have a genetic diagnosis. We agreed that might be because their gene is not known yet or because it has been identified since they last saw a geneticist. It seemed that most had been clinically diagnosed a long time ago and so it was felt that it might be worth requesting a referral to a geneticist to see if a genetic diagnosis could be achieved. We thought this was important for a number of reasons including the possibility of benefiting from new treatments, as and when they become available.

A number of members do not see an HSP specialist at the moment. We talked about our nearest HSP Clinics which are at Addenbrooke's Hospital in Cambridge and at the National Hospital for Neurology and Neurosurgery in London. One of our members pointed out that hospital transport to and from appointments is available, based on need.

Again, not everyone has the benefit of regular meetings with a neurophysiotherapist. We discussed the fact that funding constraints prevent neurophysios from visiting patients regularly to deliver the physio in person. We agreed that their role is to create an exercise programme, to teach the patients or carers (in some cases) how to do the exercises and to monitor progress and adjust the exercise routine as necessary. I think we were agreed that physio is so important and that it is very beneficial to see a neurophysio from time to time for a review of the exercises.

We also talked about the right to request an assessment of needs by a social worker who can create an individual care plan. Carers are also entitled to an assessment of their needs.

Finally, Carina Thurgood told us the inspirational story of her family's journey with SPG 15. One family, acting alone, has achieved so much.

We were still talking when the caretaker arrived to lock up but we will be meeting again on Sunday, 15th October from **2.30** – 5 pm at Feering Community Centre, near Colchester, Essex, CO5 9QB. As always, everyone is very welcome to join us. Please note, though, that we are starting at the earlier time of 2.30 pm.

Hilary Croydon

Forthcoming Events

HSP Support Group AGM

Saturday 1st July 10am - 4.30pm
Tally Ho Conference Centre
Pershore Road
Birmingham
B5 7RN

Mobility Roadshow

1st -3rd June
NAEC Stoneleigh, Warwickshire, CV8 2LG
10am-5pm Thursday & Friday
10am-4pm Saturday
Venue website: www.naecstoneleigh.co.uk

Norwich Meeting

Saturday July 8th 2pm
In Barbara's lovely back garden
For further details:
Call Barbara Jones on: 01603 423 267

Region 3 Social Meeting

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

Morecambe get together

Saturday October 7th 2pm - 5pm
Midland Hotel, Marine Rd W, Morecambe LA4 4BU
Contact Irena Pritchard on: 01524 261 076
Email irena.pritchard@btinternet.com

Region 7 Meeting Birmingham

Saturday 14th October, from 12 - 3pm
The Kenrick Centre,
Mill Farm Road, Harborne,
Birmingham, B17 0QX
Contact Penny Cohen: 07818 288 738
Email: pennycohen57@hotmail.com

Colchester Meeting

Sunday, October 15th 2.30 - 5pm
Feering Community Centre
Feering, Essex, CO5 9QB
Call Hilary Croydon: 01284 728 242

Region 4 get together

Saturday October 28th 2pm onwards
The Dartmoor Lodge Hotel, Ashburton
Call Ian Bennett on: 01202 849 391

Afternoon tea Regions 1 & 2

Sunday November 12th 3pm – 6pm
The Clockhouse Milford, GU8 5EZ
Call Jane Bennett on: 020 8853 4089

Potato Pants Music Festival

Saturday 3rd June 2017 from 2pm - 11pm
£5 entry – Pay on arrival at the gate
High Mead Farm, Ham Lane, Ferndown, Dorset, BH22 9DR
Request disabled parking (much closer)

New Members

We welcome the following new members:

Ellen Caddy Cheam Region 2	Caroline George Altrincham Region 9	Richard Croft Gawsborough Region 8
Robert Haacke Diss Region 5	Jim McCarroll Co. Antrim N Ireland	David Hutchinson Wakefield Region 10
Tracey Aggett Tiverton Region 4	Liz Wheatley Guildford Region 1	Diane Love Norwich Region 5

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 2017 AGM Details

Saturday 1st July

The Tally Ho Conference & Banquetting Centre
Pershore Road, Birmingham, B5 7RN

Directions to the Tally Ho Conference Centre:

Please do not rely on SatNav to navigate you – using 3 separate systems, it has misdirected folks, leaving them half a mile from the venue.

Using the Edgbaston Cricket Stadium **(B5 7QU Edgbaston Road)** as a marker, please continue as follows:

In Edgbaston Road, with the Cricket Stadium to your right, and Cannon Hill Park to your left, continue for approx 100 yards to a major set of traffic lights at the crossroads they share with Pershore Road (A441).

Turn left into Pershore road (signposted Redditch, Kings Norton & Stirchley). The driveway to the Tally Ho is approx only 100 yards from those lights on your left.

There will be HSP signs and hopefully red balloons at the driveway entrance.

Drive to the end of that driveway, and the Tally Ho is on your right (a single-storey building) - with its own Car Park to the front and side.

The Tally Ho Conference Centre Tel No: 01216 268 228 - should there be any emergencies!

AGM Agenda

10.00	Coffee & Welcome
10.30	AGM
11.15	Dr Nicola Siân Cooper Different modes of inheritance in HSP, the benefits, pitfalls and limitations of genetic testing
12.00	Break
12.15	Professor Andrew Crosby from Exeter University Current Research
1.15	Lunch
2.30	Professor Jon Marsden and Rebecca Chapman from Plymouth University Falls Survey
3.30	Coffee and social time
5.00	Close

Thank you to June Masding and Penny Cohen for the following great idea:

A GREAT CHANCE FOR EVERYONE TO HELP WITH

FUND-RAISING!!

Please, please, please!!

Bring along any of your unwanted DVD's to the AGM on 1st July, and donate them to help raise funds

Bring them to June & Penny

who will arrange and man a table on the day

where you will be able to purchase any DVD of your choice for just £2 each!!

All money raised will be for our HSP Support Group

Recycling & Fund-raising together!!

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Looking forward to seeing what a great selection we get - Thank you!!