

HSP Newslink

The Newsletter of the Hereditary Spastic Paraplegia Support Group

Issue 53 – March 2022

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

Let's help Emily get the wheelchairs she needs



Emily (No 28), doing what she loves, competing in a wheelchair basketball match

Hi my name is Emily, I'm 16 years old and live in Dearham. I live with my Dad, Mam and little brother Lewis who is 11 years old.

My Dad, was diagnosed with Cerebral Palsy when he was 18 months old, he was able to walk short distances until he was in his early 20's and since then has had to rely on a wheelchair for all aspects of his daily living. From an early age it was evident that I was having very similar problems, I had poor balance, constant pain in my lower limbs and when I tried to walk, could only do so on my tiptoes.

At first Doctors thought that I might also have Cerebral Palsy, however, when I was 3 years old, whilst My Mam was pregnant with Lewis, and following months of tests, they found out that my dad and me both had Hereditary Spastic Paraplegia (HSP). This is due to a faulty gene which causes the long nerve in the spine, which controls muscle tone and movement, to deteriorate.

At six years old I was relying on a wheelchair most of the time, underwent a Tenotomy operation, which involves cutting through the tendons to allow a greater range of movement. Unfortunately it didn't make a

major difference and I still have to use a wheelchair for getting around.

When I was 7 years old, I started having five monthly Botox injections and was required to go into casts every 3 months which elongates the muscle in the back of my legs, to enable me to walk on the flat of my feet rather than my tip toes. Every time these were removed, I had to have intensive physiotherapy to teach me how to walk again but when I was 8 years old it was agreed that these weren't having a positive effect and all agreed they should be stopped.

My dad has always had a very positive attitude towards life, when I was diagnosed he was very keen to provide me with a role model as I was growing up, teaching me that anything is possible, even when living life with a disability. He often found accessing leisure and recreational activities with his able bodied friends difficult, with the most realistic sport available being swimming. However, he became a member of Cumbria wheelchair sports club, and fell in love with wheelchair basketball

My Dad took me, my mam and Lewis to watch him play in games and training and that's when I become interested and very keen to try it. I loved it and it was quickly acknowledged that I had a natural talent for the sport and was signed up the junior league team of The Cumbria wheelchair sports club, but sadly that club pulled out of the leagues. However, my dad found another club called The Lancaster Bulldogs and both me and my dad have been there ever since they are a great bunch of people. The Bulldogs encourage both disabled and non-disabled members, therefore the set-up allows complete integration, and as a result, several of my able bodied friends have attended training with me to play the sport alongside me, on a totally even level, and it was great to be involved in sports with my friends instead of just watching them at school.

Alongside me playing for Lancaster Bulldogs I am currently playing junior league and women's league for Wakefield Whirlwinds. During playing for Wakefield in the woman's league I was spotted and approached to play for East London Phoenix, in the first ever professional women's league which is being run by British wheelchair basketball. I will be training and playing with some of the best players in the country including Paralympic players.

I recently played for the England Orange team in the 2021 School Games

<https://www.schoolgamesfinals.org/sports/wheelchair-basketball/>

I also played in the junior league final 2019 for Lancaster spinners and came away with a silver medal.

I have has been using the same chair since I was 11 and it does not fit me anymore and it's holding me back. To progress in the sport, I desperately need an up-to-date sports chair, which would be tailored to my needs and classification and also take into account all aspects of my disability. I have been measured and quoted for a custom RGK Elite X Basketball wheelchair which costs £6,547.00, a substantial amount, but these specialist chairs are expensive.

Due to the travel and loading of the car and lifting etc, I'm also needing a new day chair which I will also be getting from RGK. I need something more lightweight and easier to transport. I spend 95% of my time in my day chair so having a new lightweight one would make my life a lot easier.

Any extra funds I get from gofundme, I will be using to put towards an RGK Sub4 day chair.

Any funds after that will be used for maintenance costs/spare parts and travel.

I'm studying in 6th form at Energy Coast UTC Lillyhall, they have been amazing and are helping me all they can with my sport. This year I also recently had an interview for the British wheelchair basketball sports science diploma and I was successful in that so my life is pretty full at the moment.

If anyone could help me and continue my journey and help me get the chair I need It would be greatly appreciated.

You can support me at my fundraising page:

<https://www.gofundme.com/f/help-emily-get-her-wheelchair-basketball-chair?qid=3d8a8fdb947344850b50f1184bba39a8>

Many thanks for taking the time to read my story

Emily Branthwaite X

Chairman's Column

Happy 2022

Happy new year everyone! Although that is my first message of the year, I'm writing at the end of February as the legal Coronavirus restrictions in England are being lifted. I'm hoping that this means we can get back to having face-to-face meetings enjoying the company of others. I know that each of you will need to take your own views on behaviours, balancing the freedom of being in charge of your own decisions against minimising the risk to yourself, those who are close to you and others.

Joined Neurological Alliance

The HSP support group has recently joined the Neurological Alliance - <https://www.neural.org.uk/> The neurological alliance is an umbrella organisation which aims to: "ensure that every person with a neurological condition has access to high quality, joined up services and information from their first symptoms, throughout their life." The alliance is focussing on neurological conditions, and seeks to raise the voice of those with neurological conditions. There are more than 80 members of the alliance, including the charities which support conditions which are frequently misdiagnosed for HSP.

At the same time, we are continuing with our membership of Genetic Alliance - <https://geneticalliance.org.uk/> - whose work is similar, but have a wider remit looking at genetic conditions. Both of these organisations seek to influence policy and improve care. They regularly publish useful information, and I encourage you to spend a few minutes browsing their websites.

Welcome to new members

I am always pleased to hear about new members joining us. I am happy to welcome them to our friendly supportive community, hoping that they don't feel quite as lonely or isolated as they did before finding out about us. For me, our community is key to what we do, and this leads quite naturally into me thanking our meeting organisers, everyone who contributes to our newsletter, everyone who helps with raising awareness or money, and those who help the group in every other way! These connections, stories and activities really help people's wellbeing and give useful information.

Looking for Help

If you have looked at our website recently you may have seen our page about how people could help the group: <https://hspgroup.org/want-to-be-able-to-help-the-group/>. As you know we are a small charity, and we rely on people giving us their time to achieve all of our work. I encourage you all to speak with your friends, family or colleagues and see if any of them might feel like giving us some of their time and energy to help the group. If you ask someone to help the group, your personal connection with them and with HSP is much more likely to make them say yes!

Paralympics

As I write this the winter Paralympics are underway. I went to see if I could work out which athletes are competing for team HSP, and there appears to be two. Arthur Bauchet is a French skier who has won (at the time of writing) two Golds in the Alpine skiing, and Griffin LaMarre has competed in the USAs ice hockey team. Well done!

EuroHSP

You may recall back in April 2021 we announced a new HSP research award with the prize funded by EuroHSP, to be awarded at the Tom Wahlig HSP symposium in November. The award was looking for research papers into treatments for HSP. I am pleased to let you know that there were eight papers

submitted, and the winning paper was 'Spastin recovery in hereditary spastic paraplegia by preventing neddylation-dependent degradation', by Dr Francesca Sardinia and her team in Italy. They are investigating treatment options for SPG4, and our group put some funding into this study. Click here for the paper: <https://www.life-science-alliance.org/content/3/12/e202000799> Click here for an award report on the EuroHSP website. As a member of EuroHSP we made a contribution to the prize fund, and participated in deciding which of the papers to make the award to. This award is likely to be back in 2022.

Rare Disease Day

Hopefully you all know that the last day in February is rare disease day, which we like to celebrate as HSP is a rare disease. I choose rare disease day to publish the results of my annual HSP survey, which you can read more about elsewhere in this newsletter. You can read the full version on my blog here: <https://hspjourney.blogspot.com/2022/02/2021-survey-results.html>

Adam Lawrence

Editor's Column

Apologies that it's taken so long to get this edition of Newslink to you. The main reason is the shortage of material that I've received from members. I host a meeting on Zoom on the first Wednesday of every month and I've been requesting material there but not as much as I'd hoped was submitted. Many thanks to those of you who have contributed and hopefully your interesting articles will inspire others to do the same. I can only make our newsletter as interesting as the material I receive from members. This is the 53rd edition of our Newsletter that I've compiled, please help me make the 54th edition a simpler task.

Another excuse I have for being a bit slow in producing this Newslink is that life's been a little hectic recently. The main reason for my busy life is the arrival of my second grandchild. On January 9th my granddaughter, Violet was born and it's amazing now having a grandson and granddaughter. I'm so lucky because they only live five houses along the road so I get to see them on an almost daily basis.

The local music scene here in Dorset also continues to take up plenty of my time. I really enjoy putting my weekly radio show together but to do this well, I have to go to plenty of gigs. It's a hard job but someone has to do it. I've been doing this for 3 years now and have made many very good friends

who are musicians. This proves to be really handy when organizing the Potato Pants music festival, which for new members who are unfamiliar with this, raises money and awareness for HSP. I'm so lucky to have so many musicians who are willing to donate their time and talent to support our cause. I can now confirm that the next festival will be on September 3rd at the same venue as the last event. I'm delighted to have booked a band that I've been trying to get involved ever since the first festival back in 2015. This band will headline and I'm confident they'll significantly add numbers to the crowd. Tickets for this will remain at £10 and I'll have plenty more information for you in the coming months but in the meantime, keep your eyes on the Potato Pants Festival Facebook page and please give it a like while you're there.

As many of you know, at our last AGM I stood down from my position as a trustee of the HSP Group. I remain a trustee for just one more year for the incredible charity, Flying Scholarships for Disabled People, following 17 years of involvement. This is all an attempt to reduce my workload but I don't seem to be very good at this because I'm good at taking new things on. However, I'm going to make a serious effort from now on to reduce workload as I'm certainly not the spring chicken that I once was.

Try not to laugh, but having just discussed my ongoing efforts to reduce my workload, I have

to confess that I'm considering entering the Bournemouth half marathon in my wheelchair again later this year. I'm sure I have one more attempt left in me. I continue to exercise daily in my wheelchair often completing four or five miles. I'm also very conscious that I must do as much walking as possible to maintain that ability for as long as possible. For this reason, I make a point of walking with crutches or a rollator on a daily basis, but I have to confess, it doesn't get any easier.

I hope you've managed to avoid Covid in recent months, although I appreciate that won't have been easy. The Omicron variant, has been so transmissible, I've known loads of people who've been affected recently, including my wife. Luckily, like many, she only had very mild symptoms.

I've really enjoyed hosting the meetings for all members that we hold on the first Wednesday of every month, using the Zoom platform. It's been great witnessing members learning so much from other members and also discovering that members have met up in person as a result of these on-line meetings. You'll read about this later when you read Lu Browns article. The Wednesday Zoom meetings will continue indefinitely.

I hope that you, your friends and your family manage to stay as healthy as possible in the challenging covid and HSP world that we all live in. Hopefully I'll get to see you either on Zoom or in reality in the coming months. If it happens to be in reality, lets hope it's over a g&t or similar.

Ian Bennett

Amazing opportunity at The Calvert Trust

Some of you may remember our former Chairman David Pearce. On the front of the August 2006 newsletter David wrote an article about how much he enjoyed a stay with the Calvert Trust. For those of you who don't know, the Calvert Trust is an organisation with three locations around the UK, where they provide many exciting challenges for disabled people. These challenges include horse riding, kayaking, sailing, archery, cycling and abseiling to name but a few. I can remember

David telling me what an incredible experience this was and he'd be delighted to know that some of our members have recently discovered for themselves how much fun and uplifting a Calvert trust break can be.

Sadly, David Pearce passed away in 2018 but he very generously left us some money in his will. Some of this was used for research but we wanted to use some for a purpose that we knew David would fully approve of. For this reason, we decided to pay half the cost of a Calvert Trust experience for any member. This is limited to one holiday per member every two years. We have allocated a certain amount of money for this and when it's gone, it's gone.

Please check out the Calvert Trust's website and if you like what you see, get yourself booked in. The HSP Group will refund half the cost.

For more information on this contact Ian Bennett

bravoechonovember@btinternet.com

Fundraising News

Thanks to all who have raised funds for us using Easyfundraising.

If you ever shop online and are interested in supporting the HSP charity, please register for this or get in touch. Use the following link and follow instructions:

<https://www.easyfundraising.org.uk/causes/hspsupportgroup1/>

We are also registered with Amazon Smile so you can now raise funds for the group when shopping at Amazon. To use this go to:

<https://smile.amazon.co.uk/ch/1181539-0>

and that will help you select the group as your charity. The difference from normal Amazon shopping is that you need to remember to do your shopping from

<https://smile.amazon.co.uk/> so that the donations come through.

Ian Bennett

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 is currently £1000. Completion of one year's membership is a requirement for applicants. If interested, please request a grant application form from the Secretary Dave Harris, details at the end of this newsletter. There is also an online form available via our website.

Members' Letters

Help! I'm going to be needing a wheelchair

(Written by someone with an irrational fear of being in a wheelchair)

I joined the HSP Support Group once I felt that I could no longer deny to myself or others that there was anything wrong, although I had my diagnosis a couple of years previously. I knew that I would degenerate from falling too often and difficulty walking to being in a wheelchair. I only knew one other person with HSP, my brother. He is much older than me, lives in the States (with a different healthcare system) and lives in a large adapted house. Some time ago he did suggest that I couldn't have the same condition as "it was so rare". However, he didn't consider the importance of the word 'Hereditary'!

The zoom support group introduced me to other members but seeing faces not actions doesn't provide the full picture. It is at the end of the day and everyone seems tired. Tired from work or tired of HSP?

I felt that I needed to redress the balance and so asked Ian at one of these monthly zoom meetings if he could recommend anyone for me to meet. He kindly obliged and put me in touch with Carrie.

Carrie mostly spends her days in her wheelchair but that doesn't hold her back. I wasn't sure if I would be meeting someone with horns or in Gromit's wrong trousers. My mother had a fear of wheelchairs and would not use one later in life, even though we were all begging her to do so. I inherited this fear and had thought that wheelchairs were only for those in their 90s in care homes (other than Paralympian basketball players)



Caroline Begg enjoying activities at her waterski club

Anyway, Carrie didn't have horns but was able to whizz confidently round her flat and turn on a sixpence. She made everyday chores such as finding me (I got lost) seem so easy that I realised that there was hope. I hadn't thought through dealing with everyday tasks such as making cups of tea and washing up. It seemed that her bathroom was adapted but nowhere else. Then she outlined plans for her proposed skiing trip. She is already a member of a water-skiing group which she joined seven years ago.

Positivity oozed out of every pore and she doesn't let anything get in her way. I realised that it would be possible to have a good life after all.

She explained that she probably has had HSP since she was a young child but, not being diagnosed and growing up as part of an active family in South Africa, she was pulled up hills and did not receive any favours.

The main lesson from Carrie was that of positivity. If she can go snow-skiing, then I

can make the most of my holiday to Finland to see the Northern Lights. As to using a wheelchair – maybe it won't be so bad. But my search for HSPers doesn't end with Carrie and I'd love to meet some or all of you soon.

If you have met one person with HSP, you have only met one person with HSP

The above quote has been taken from a saying about dementia, but it equally applies to HSP.

Lu Brown

Watch out for the DVLA!

Recently I became a "hands only" driver. I've had a driving licence for 40 years and driven many conventional cars of different sizes and makes. From around the year 2000 I recognised that my HSP, specifically my legs, meant that I must always drive an automatic car. On that basis I drove happily and safely for two decades. But my family noticed that my use of the accelerator and brake was becoming increasingly imprecise and my youngest son was very blunt in telling me I wasn't a safe driver. I took an assessment in a conventional car organised by Herts Ability, the organisation in Hertfordshire which deals with many disability related issues, and sure enough I failed.

I then took lessons in driving a hands only car and became good enough to pass the assessment, again organised by Herts Ability, which meant that I could drive a "hands only" car on the road. Once again, I have wheels! At once my freedom increased, and so too did my wife's, because she didn't have to drive me everywhere. Even better, I didn't need to buy a new car; I had a "hands only" kit installed in my own Vauxhall Corsa.

However, one important point emerged. IF YOU USE A HANDS ONLY CAR YOU MUST INFORM THE DVLA. I must say the DVLA's website could be more explicit about this. I only knew because I was told by my driving instructor, specifically trained to teach people how to drive "hands only" and other adapted vehicles. He told me that if you were capable of driving an ordinary car but chose to have an adapted car, you didn't need to inform the DVLA. However, if you can only drive an

adapted car, you must inform the DVLA so they could alter the coding on your driving licence. Herts Ability gave me a copy of their favourable assessment for me driving a hands only car. I sent this to the DVLA along with my driving licence and a form called D497. This form confirmed the type of adaptations I would be using.

My instructor also told me to be sure to inform my motor insurers of the change. He said they would not increase my insurance premium and this turned out to be correct.

I have written this article because at one of Ian Bennett's monthly zoom meetings I got the impression that people in the HSP community did not know all this and some may indeed be driving adapted vehicles not reported to the DVLA. If that's the case, don't delay; get in touch with the DVLA.

Mike Horsman

Regional News

Scottish Zoom 31/10/2021

This was the third Zoom meeting we have held and we were pleased to see some new faces of all ages, some who watched and some who stayed for part.

It was useful to get a teenagers perspective. Indeed some had common interest, although they lived some hundreds of miles apart.

We had a speaker (Lindsey) about the physio service available in a small part of Glasgow and it was surprising how it is important for the patient to take time to have their say in the assessment process.

Lindsey gave a presentation with slides to those who wanted them.

Lindsey then went on to a questions and answer period covering Hydro Therapy and services by Postcode lottery.

She gave us some handy websites and undertook to tell us SOME neurophysios in Scotland.

We discussed some elements of what happened in the Holyrood Cross Party Group and the next meeting (rescheduled for

January 2022). We also discussed how individuals can help.

We also discussed some possible locations when we are able to meet in person and the requirements of a venue. Originally the physical meeting was arranged for the Holiday Inn Express in Stirling, which is a long way from SW Scotland.

There is still a need for a Zoom meeting for those in more remote parts.

Mike Cain

Birmingham Zoom Chat 16/10/2021

Everyone welcomed. Only four people this time. We welcomed our newcomer.

We talked about:

Botox

It was shared - where in the body injections had been received, benefits from etc. Some had in upper thigh, others in feet/ankles/toes.

It is at The Rehabilitation Centre in Selly Oak, Birmingham where Botox is given, and would appear that not very much assessment is being given following treatments. It was suggested that they should assess the results more regularly and compare them every few weeks to be able to get a better picture/assessment of how the treatment is working – which they don't do at present.

Two members have received Botox in different parts of the body, which they find have helped to relax the spasticity.

We all agreed that exercise was essential too – use it or lose it!

Walking aids/Wheelers/Rollators etc

We found we all used a variety of walking aids to help us every day, each one of us find some things better than others – we are all unique!

We shared the different types we all used and hope that when we can get together for a meeting, that we may be able to try each other's out.

The Rehabilitation Centre in Selly Oak, Birmingham does have several walkers/wheelers/wheelchairs that one might be able to 'try out' – but one has to have a

referral to the centre from their GP/Consultant in the first instance to be able to attend.

FES

We found that at some point we had all tried this, with different results/opinions – again, we are all unique and have different needs. It was really good to share.

Families with HSP

We shared with each other, that other members of our families are also affected by HSP – some of us with several/many members, others with a few or none. We found that although there may be a few in one family, that each were differently affected – some greatly, others not so much, and all at varying times of our lives.

We concluded our meeting with the hopes for our next meeting to be a face-to-face at the Kenrick Centre in Harborne in Spring 2022 - Covid permitting.

We will advise John Mason who will be sending email details to all within the 50-mile radius – and please do look out for details on our website or Newslink.

Kindest regards to all

Penny & June

Family Chat Zoom Meeting 18/11/21

The Meetings Committee have been wanting to get parents & carers of children, young people & dependant adults with HSP together for a long time. Being scattered throughout the UK, we understand that it's difficult to get everyone together in one place, what with travelling etc, it can be a challenge for even the most organised of families.

With this in mind, we decided, at very short notice, to arrange a zoom 'family chat meeting'. It was advertised about three days before on the HSP Support Group website <https://hspgroup.org/hsp-support-group-meetings/>

and Hereditary spastic Paraplegia support for UK HSP'rs Facebook page <https://www.facebook.com/groups/731239283741617/?ref=share>

and sent to all members by the HSP Support Group e-mail facility.

We were pleased to welcome four people to the family chat and there were eight others that expressed interest in joining the chat, but couldn't make the November family chat because of work and other commitments.

One lady hadn't met any other HSP'rs. It was her first time and appreciated the help, support and experience from other parents, plus sharing the experiences she had gained through her HSP journey.

Many subjects were covered including wheelchair services, personalising wheelchairs etc, social clinics, FES, suitable cars/mobility equipment, HSP clinics/consultants, plus obtaining the referrals/medical help needed.

All felt the meeting had been successful and were keen to meet again in December. It was agreed that an evening would be best. So, we've arranged to hold the next 'family chat' on Wednesday 8th December @ 8pm.

We hope to welcome you to the next one.

Della Brookman

Wales/Bristol area zoom meeting

Sun 10th October 2021

The meeting started at five pm (as advertised) but I was quite disappointed that only one member showed up, even though the meeting was well advertised and John Mason sent out 42 invitations. Although one other member actually took the time to email me and tell me that he would have been there but he would be travelling at the time. The thing is I was just about to find out that it doesn't matter how many people attend because you can have a more detailed discussion with fewer people although at the same time your views and ideas can reach more people with a better turn out, so a meeting with one member or ten members has its own merits.

Informative and detailed discussion on a couple of matters and I found his input to be very useful. (I just hope he found my input just as useful). I will be holding another meeting soon.

Kevin Mills

East Anglia Zoom Meeting

11/11/2021

Although face to face meetings are held in Norwich and at Feering, near Colchester, in non-covid times, this zoom gathering was expanded to include the whole of East Anglia to give people who can't normally travel to a meeting the chance to meet others. We were joined by some of these, as well as by old friends, in a very relaxed and informal get together.

We shared experiences of covid and of vaccines and their side effects. Most had been able to book their covid booster and their flu jabs. However, some had found that the facilities available at vaccination sites were not always fully described on the online booking site, for example, giving the impression that there were no disabled toilet facilities when, in fact, there were.

Our discussions covered swimming, gyms and physio. The options of three wheeled bikes, electric bikes and static bikes were considered as well. The joys of a mobility scooter combined with a Motability car, with a hoist in the back to lift the scooter in and out, were clear. We shall look forward to seeing it in action once face to face meetings can start again. One member had had a very positive experience with an online falls prevention course provided for those in Cambridgeshire and Peterborough

(<https://healthyyou.org.uk/services/falls-prevention/>).

Several people shared experiences of using Functional Electric Stimulation (FES) to assist walking though, in some areas, funding for this can be an issue. It seemed that the availability of Blue Badge parking spaces is reducing in some town centres and pedestrianised roads are forcing people to walk further than is comfortable for them. The majority of us were still waiting for a genetic diagnosis despite some having been members of the 100,000 Genomes Project from the very beginning. However, it was encouraging that more people are being told that reviews of their PIP entitlement will be deferred, sometimes for extended periods.

We talked about the pleasure we get from our gardens and from the variety of bird life we see in them.

We plan to meet again at 2.30 pm on Sunday, 10th April 2022. This will either be face to face at Feering Community Centre, Feering, near Colchester, CB5 9QB or by zoom. Watch out for the publicity nearer the time and we hope you'll be able to join us!

Hilary Croydon

Milford Zoom Meeting

November 2021

Catching up with those who usually join us at Milford was a pleasure, plus welcoming a new couple.

A couple of the discussions included how we manage fatigue and when/ what age did we know there were activities we couldn't do, in relation to when we were diagnosed.

Fatigue

In 2018, an occupational therapist, Beth Williams, included some key factors in her presentation on managing fatigue:

- Raise your own awareness to your energy levels
- Listen to your body and take ownership
- Learn to say **NO**
- Leave time for doing important, pleasurable activities
- Explain fatigue to your family and friends
- Learn to manage your fatigue.
- Plan ahead
- Prioritise activities
- Organise your environment.

Activity Limitations

Some people had physical difficulties during childhood with HSP not being confirmed for a couple of decades later. This could have been unable to do certain school sports and activities. We agreed that this could easily be because HSP is a rare disease and has only recently been more well known.

We all agreed being able to do some exercises daily, be it physio guided or Pilates type, is beneficial, especially to ease back discomfort.

As always, great to see those that were able to join us, but sorry for those that couldn't make the connection. We appreciate that if people can't attend the Milford meetings, be it in person or using Zoom, they let us know. As many have known each other for a number of years, updating others that all is well and they have other commitments gives peace of mind.

Looking forward to meeting again in April, be it in person at Milford or using Zoom.

Jane Bennett

SPG 11 and SPG 15 Zoom Meeting

4th November 2021

You may wonder why we would have a separate meeting for these two types of HSP. It's because, although they are very similar to each other, they are very different, in some ways, from other types of Hereditary Spastic Paraplegia.

Although they share symptoms, such as mobility and bladder issues, with other types of HSP, they have some 'add ons' which make them rather different. You might be interested to read a blog written by the father of an adult child who has SPG 11 here <https://hspgroup.org/a-parents-perspective-of-complicated-hsp-spg-11/>

This was our first meeting for all those in the UK who have or who support someone who has SPG 11 or SPG 15. These two types of complex Hereditary Spastic Paraplegia are particularly rare and we are all scattered across the country so meeting up in person isn't a realistic option for us. The HSP Support Group's Zoom platform is the perfect solution.

We chatted for a couple of hours, getting to know each other better and each of us sharing advice based on our own experiences. We talked about: when symptoms first showed themselves; the difficulties and time it had taken to get a diagnosis; genetic testing of wider family members; and the fact that changes in NHS guidance in recent years have made testing more restricted. We also

covered symptoms, as well as medication and physiotherapy aimed at reducing their impact. We discussed the equipment supplied by occupational therapists to make life easier and the different options for activities to make life more enjoyable. We talked about the need for supported living placements for some, the difficulties in finding the placements and, yet, how successful these can be. We touched on the stress and lack of sleep that tends to be associated with the conditions – for all concerned. And, of course, we talked about PIP applications... We also chatted about baking, football and motorbikes – it wasn't all HSP!

We plan to meet again at 7 pm on Wednesday, 26th January and, if you have SPG 11 or SPG 15 in your life, and would like to join us, please get in touch with me by email so that I can send you the joining details. I'd love to hear from you.

Hilary Croydon

SPG 11 and SPG 15 Zoom Meeting

26th January 2022

We have a separate meeting for these types of HSP because, although they are very similar to each other, they are very different, in some ways, from other types of Hereditary Spastic Paraplegia, most (but not all) of those affected being young adults dependent upon their parents.

These two types of complex Hereditary Spastic Paraplegia are particularly rare and the few affected families are scattered across the country so Zoom gatherings work very well for us.

Seven people, both affected young people and parents, were able to come along and others dropped by to say 'Hello', even though they had other commitments that evening. We met new people and caught up with old acquaintances, chatting for over two hours, getting to know each other better and sharing experiences.

We talked about symptoms such as pain and the different medications people have been offered, though a number of people didn't experience pain along with the spasticity,

which was good news. We discussed the various activities available and the limits imposed by fatigue. Some play wheelchair sports, even if they are not wheelchair users, while others feel sport isn't for them. We covered the impact covid has had on progression and mood. We talked about the variable provision of physiotherapy and also about the problems arising from continence issues. One family had found the Just Can't Wait Card

(<https://www.bladderandbowel.org/help-information/just-cant-wait-card/>) to be helpful and many found carrying a radar key to be very useful (<https://www.disabilityrightsuk.org/shop/official-and-only-genuine-radar-key>). Some people have moved house and others have adapted their homes to ensure the accommodation, including the bathroom, is accessible.

We discussed the need to plan in great detail when travelling, whether in this country or abroad, and the frustrations that can arise, even with the best of planning! Some had managed to fly, while others had restricted themselves to holidays in the UK because of the complexities of international travel. Even in this country people had found it difficult to locate accessible accommodation. The general sense was that everyone could do with a proper holiday!

Inevitably, we talked about PIP but it did seem as though most people were getting the right decision in the end. We also discussed research and selective dorsal rhizotomy, a surgical procedure to release spasticity, which we believe is not yet available in the UK for HSP.

Finally, the young people, themselves, are arranging to meet up through Facebook.

We plan to meet again on Zoom, so if you have SPG 11 or SPG 15 in your life, and would like to join us, please get in touch with me by email so that I can send you the joining details, when we have a date. I'd love to hear from you.

Hilary Croydon

Forthcoming Events

Lancashire

April 3rd on Zoom

Contact Estelle Marshall for further information

estelle.marshall@hotmail.co.uk

A meeting for all members

Simply a natter to catch up with old friends and maybe make some new ones

The first Wednesday of every month 7pm, online using Zoom

Zoom details are emailed to all members or

Contact Ian Bennett: 01202 849 391 or

bravoechonovember@btinternet.com for info

Birmingham/West Midlands

April 9th 3.00pm – 5.30pm on Zoom

pennycohen57@hotmail.com or

june_masding@hotmail.co.uk for further details

Colchester/Essex

April 10th 2.30pm

Contact Hilary Croydon for further information Tel: 01284 728 242

tohiti@btinternet.com

Milford/Surrey

April 23rd 3.00pm

Contact Jane Bennett for further information
02088 534 089

New Members

We welcome the following new members:

Christine Batcheler
Cambridge

Angela Durndell
Sutton Coldfield

Joanna Hahessy
London

Gary Axten
Haverfordwest

Andrew Thomas
Swansea

Jane Matthews
Leeds

Leila Manion
Exeter

Jenny Lindsay
Scotland (North East)

Philip Jones
Somerset

Steven Dixon
Bristol

John Pysden
Cumbria

Phyllis Clements
Norwich

Jane Hardie
Southampton

Dennis Roberts
Great Yarmouth

Nathan Dalgarno
Newcastle

Lindsey Dalgarno
Newcastle

Sarah Murphy
Benfleet

Hannah Kendell
Cardiff

If you are interested in contacting any of the above new members, please contact our membership secretary, Mitesh Patel (miteshpatel59@hotmail.com)

2021 Survey Results - An on-line Survey for People with HSP

This article is an abbreviated version of the full results. If you wish to read a more complete version of the results please see my blog <https://hspjourney.blogspot.com/2022/02/2021-survey-results.html>. There were 565 respondents who completed the survey, predominantly from the USA, Germany, Brasil, and the UK. There were 60 responses (11%) from the UK. Thanks are due to all the respondents in many countries who took time to respond to this survey, without these excellent answers this analysis would not be possible.

Wellbeing

543 respondents answered the Warwick-Edinburgh Mental Well-being scale (WEMWBS) question, with their average score of 46.0, which is broadly the same as the average scores of 47.4 in 2019 and 45.9 in 2017 and 2018. The average score in 2020 was 42.9, most likely a result of Coronavirus. To aid highlighting larger effects, scores that could be significantly different from the average have been shaded yellow or light green, and those that are likely to be significantly different from the average are shaded orange and green.

Mobility Analysis

Just over half of respondents use walking sticks/poles/crutches/ canes, two fifths use wheelchairs/mobility scooters and just over a quarter use walking frames/rollators. Functional Electrical Stimulation (FES) is the mobility aid used by the least number of people, with a take-up of 5%. These results are similar to previous years. Table 9 shows these results, including the percentage of respondents. These add to more than 100% as some people use more than one type of mobility aid.

Table 1 – Use of mobility aids

| Mobility Aids Used - Summary: | Respondents | Percentage |
|--------------------------------------|--------------------|-------------------|
| Using sticks/poles/crutches/canes | 290 | 51% |
| Using Wheelchair/Mobility Scooter | 246 | 44% |
| Using Walking Frame/Rollator | 168 | 30% |
| Using Orthotics/AFO/Insoles | 138 | 24% |
| Using FES | 29 | 5% |

Relationships

This section included questions about relationships with other people to explore feelings around how their HSP impacts on life in a more general sense

Exclusion from invitations to social events

There are 560 respondents who answered: Have you ever been excluded from invitations to social events by family or friends? Around three in five people with HSP feel they have not been excluded from social events, one in five feel they have, with one in five not sure. Those who feel they have not been excluded have a higher wellbeing, and those who feel they have been excluded have a significantly lower wellbeing.

Comfortable discussing HSP issues with partner/family

There are 559 respondents who answered: Do you feel comfortable discussing issues relating to your HSP with your partner/family? Around two thirds of people with HSP are

comfortable discussing HSP issues with their partner or family. Less than 10% are not comfortable, with the remainder comfortable discussing some of the time. Those who are comfortable discussing have a higher wellbeing, and those who are not comfortable discussing have a significantly lower wellbeing.

Comfortable discussing your HSP in a new romantic relationship

There are 518 respondents who answered: In a new romantic relationship, how comfortable would you feel discussing your HSP and its impact? Around two in five with HSP would be comfortable discussing HSP issues in a new romantic relationship. Less than 10% are not comfortable and would not discuss. About half would discuss this, but would feel uncomfortable. Those who are comfortable discussing have a higher wellbeing, and those who are not comfortable discussing have a significantly lower wellbeing.

My family understand the consequences of my health problems

There are 560 respondents who indicated how much they agreed with the statement: “My family understand the consequences of my health problems.” Two thirds of people with HSP agree or strongly agree with this statement. About one in five neither agree or disagree, with the remainder disagreeing or strongly disagreeing. Those who perceive their family understands the consequences of HSP have a higher wellbeing, and those who perceive their family does not understand have a significantly lower wellbeing.

My family can sometimes make me feel like I am exaggerating about my HSP

There are 552 respondents who indicated how much they agreed with the statement: “My family can sometimes make me feel like I am exaggerating about my HSP”. Over half of people with HSP disagree or strongly disagree with this statement. About one in five neither agree or disagree, with the remainder agreeing or strongly agreeing. Those who think their family feel like they are exaggerating have a likely significant lower wellbeing, and those who think their family do not feel they are exaggerating have a higher wellbeing.

My family think I can do more than I feel able to

There are 558 respondents who indicated how much they agreed with the statement: “My family think I can do more than I feel able to”. Almost half with HSP disagree or strongly disagree with this statement. About a quarter neither agree or disagree, with the remainder agreeing or strongly agreeing. Those who perceive their family thinking they can do more than they are able have a lower wellbeing, and those whose do not perceive this have a higher wellbeing.

Acceptance and Stigma

Acceptance

Part of the journey with a progressive condition like HSP is accepting that you have HSP. Respondents filled out the Acceptance of Illness Scale (AIS) which is tool to measure acceptance of any disease. There are 8 questions, and the total score ranges between 8 and 40. A low score indicates that the person does not accept their illness whereas a high score indicates greater acceptance.

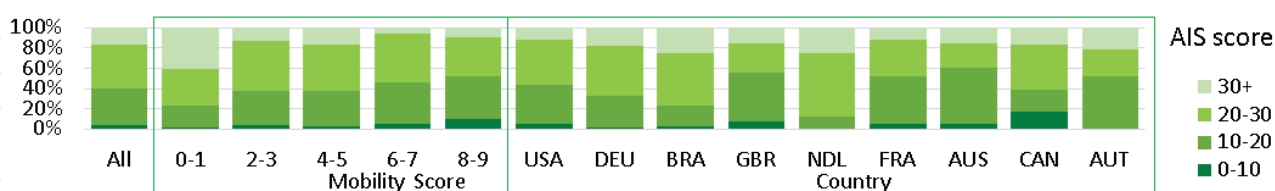
For this analysis scores of 30 points and above are considered to be good acceptance, scores between 20 and 30 points are considered moderate acceptance, and scores below 20 are considered low acceptance.

There were 511 answers to these questions, and the overall average score is 21.7, which is around the point between low and moderate acceptance. Scores covered the full range

between 8 and 40, and the distribution across countries is shown in table form and graphically.

Table 2 – Acceptance of Illness Scale

| AIS | All | USA | Germany | Brasil | UK | Netherlands | France | Australia | Canada | Austria |
|---------|------|------|---------|--------|------|-------------|--------|-----------|--------|---------|
| Answers | 511 | 122 | 84 | 44 | 57 | 41 | 42 | 20 | 18 | 19 |
| Score: | 21.7 | 20.9 | 22.8 | 24.0 | 20.2 | 25.3 | 19.1 | 20.3 | 20.5 | 21.9 |
| <20 | 40% | 44% | 33% | 23% | 56% | 12% | 52% | 60% | 39% | 53% |
| 20-30 | 44% | 43% | 49% | 52% | 28% | 63% | 36% | 25% | 44% | 26% |
| ≥30 | 16% | 12% | 18% | 25% | 16% | 24% | 12% | 15% | 17% | 21% |



Brasil and the Netherlands have the greatest proportion with good acceptance. Australia and the UK have the greatest proportion with low acceptance. Acceptance of illness is lower when mobility aids are used all or most of the time, and is higher when mobility aids are not used.

Acceptance and Wellbeing

There is a strong link between acceptance and wellbeing. Those who have a low level of acceptance have a wellbeing score of 38.4, more than 7 points below the average and those that have a high acceptance have a wellbeing score of 55.9, almost 10 points higher than the average.

Stigma

Respondents answered the extent which they feel stigma round their HSP. 503 respondents answered this question. Over half (55%) say they feel a little stigma on account of their HSP. About a quarter (28%) feel no stigma at all, and the remainder (17%) feel very much affected by stigma. Overall, nearly three quarter (72%) are affected by stigma, either a little or very much. The patterns are similar between countries. People identified the factor which they believed to be the greatest cause of stigma:

Table 3 – Greatest cause of stigma

| Stigma cause | Respondents | Percent |
|---------------------------------------|-------------|---------|
| Lack of understanding about HSP | 166 | 35% |
| The symptoms of HSP | 140 | 30% |
| The invisible nature of HSP | 107 | 23% |
| Because HSP is a nerve/brain disorder | 39 | 8% |
| Misconceptions or myths about HSP | 12 | 3% |
| The name HSP | 8 | 2% |

People identify a lack of understanding about HSP and the symptoms of HSP to be two main causes of stigma they feel about having HSP, these factors being chosen by about two thirds of respondents.

Bladder

Respondents were asked details about urinating. Around 550 people answered these questions, with some people not answering all of these questions.

Table 4 – Overactive Bladder Score Results

| Overactive Bladder Effect Bands | Respondents | | Wellbeing |
|---------------------------------|-------------|-----|-----------|
| All respondents | 544 | - | - |
| 0-2: No effects | 96 | 18% | 48.0 |
| 3-6: Mild effects | 230 | 42% | 46.8 |
| 7-10: Moderate effects | 171 | 31% | 45.3 |
| 11+: Severe effects | 47 | 9% | 42.9 |

This table shows that more than 80% of people with HSP have some degree of bladder issues. The majority (42%) of people with bladder effects have mild effects, with less than one in ten (9%) having severe effects. Wellbeing scores decrease with increasing bladder effects.

The survey sought to identify how people manage their bladder problems. People were given a picklist of eight options to identify if and/or how they manage their bladder problems, and were given the opportunity to identify if they used other methods than those in the list or to report that they used more than one option.

Table 5 – Bladder problem management

| Main method for managing bladder problems | Respondents | | Wellbeing |
|---|-------------|-----|-----------|
| Do not have bladder problems | 90 | 17% | 48.8 |
| Take no action to manage | 133 | 25% | 46.0 |
| Medication to relieve spasticity | 126 | 23% | 44.0 |
| Drink less fluids | 85 | 16% | 43.7 |
| Train bladder muscles | 53 | 10% | 47.9 |
| Use an intermittent catheter | 33 | 6% | 46.8 |
| Botox injections in bladder | 10 | 2% | (48.7) |
| Use a catheter which stays in place | 9 | 2% | - |

Comments were made by 179 people who mostly described either one method in more detail or using more than one method. Of methods listed that were not in the pick-list choices, the most common are:

- 32 people use an incontinence pad
- 14 people plan their drinking – mostly drinking more in the morning and less in the evening
- 12 people use incontinence pants or nappies
- 6 people use a urinal, bottle or similar
- 4 people use Sacral Nerve Stimulation (SNM), also known as a bladder pacemaker

Wellbeing Conclusions

Throughout this report the factors shown to have the greatest association with people's wellbeing have been identified. The HSP symptoms covered in this survey with greatest potential impact on wellbeing are walking distance and needing to rush to the toilet. As these factors change over time there can be decreases in wellbeing. People can review their situation with their neurologist, physiotherapist or doctor to ensure their exercise routines and medications are appropriate for their stage of HSP, and be confident that they are managing their changes over time as well as they can.

Within the HSP sphere other potential areas where changes could be made include:

- Balance/strength exercises or modifications at home/work to reduce falls
- Checking that mobility aids are still appropriate
- Techniques to help manage bladder issues
- Reviewing factors affecting depression

The two areas with the greatest change are measured with the Acceptance of Illness Scale (for acceptance), and the PHQ2 scale (for depression). Those who have low acceptance of their HSP have significantly lower wellbeing and those with good acceptance have significantly higher wellbeing. This level of wellbeing change is also seen with the PHQ2 score for depression. People could consider counselling or taking/changing treatments for acceptance or depression.

There are two key aspects covering the greatest wellbeing changes within relationships:

- Many of the questions are phrased around people feeling that their family or partners do not understand their experiences with HSP, sometimes making assumptions about HSP which don't reflect peoples' own perceptions.
- Secondly, there are some questions showing that people are sometimes not comfortable discussing their situations with important people.

Provided that people feel safe to do so, they could consider having conversations with these important people which initially feel difficult, but which can help everyone improve their understanding, recognise that situations change and be honest about concerns, difficulties and feelings. For some, those conversations may feel more appropriate with a counsellor or trusted friend.

Useful Contacts

| | Email | Telephone No: |
|--|--|---------------|
| Adam Lawrence - Chairman 18 Mayflower Court, Staple Hill, Bristol, BS16 5FD | adam@idios.co.uk | 07834 505 161 |
| David Harris – Secretary 18 Lodmoor Avenue, Weymouth, Dorset, DT3 5AF | dave@vadcar.org.uk | 01305 772 286 |
| John Mason - Treasurer 18 Sandringham Road, Trowbridge, BA14 0JU | john@jrmweb.uk | 01225 761 788 |
| Mitesh Patel – Trustee/Membership Sec | miteshpatel59@hotmail.com | |
| Ian Bennett – Newsletter Editor & Devon host 37 Wimborne Road West, Wimborne, Dorset BH21 2DQ | bravoechonovember@btinternet.com | 01202 849 391 |
| Jane Bennett – South / South East meetings host | luckyjane82@hotmail.com | 020 8853 4089 |
| Della Brookman – Herts meetings host | della_brookman@msn.com | 07710 637 941 |
| Penny Cohen – Birmingham meetings host | pennycohen57@hotmail.com | 07818 288 738 |
| June Masding – Birmingham meetings host | june_masding@hotmail.co.uk | 01214 445 095 |
| Mike Cain – Trustee & North West meetings host | michaelcain123456@yahoo.com | 0161 456 7531 |
| Hilary Croydon - Essex meetings host | tohiti@btinternet.com | 01284 728 242 |
| Barbara Jones – Norfolk meetings host | | 01603 423 267 |
| Kevin Mills – Wales meetings host | kevinmills944@gmail.com | 01874 622 727 |