

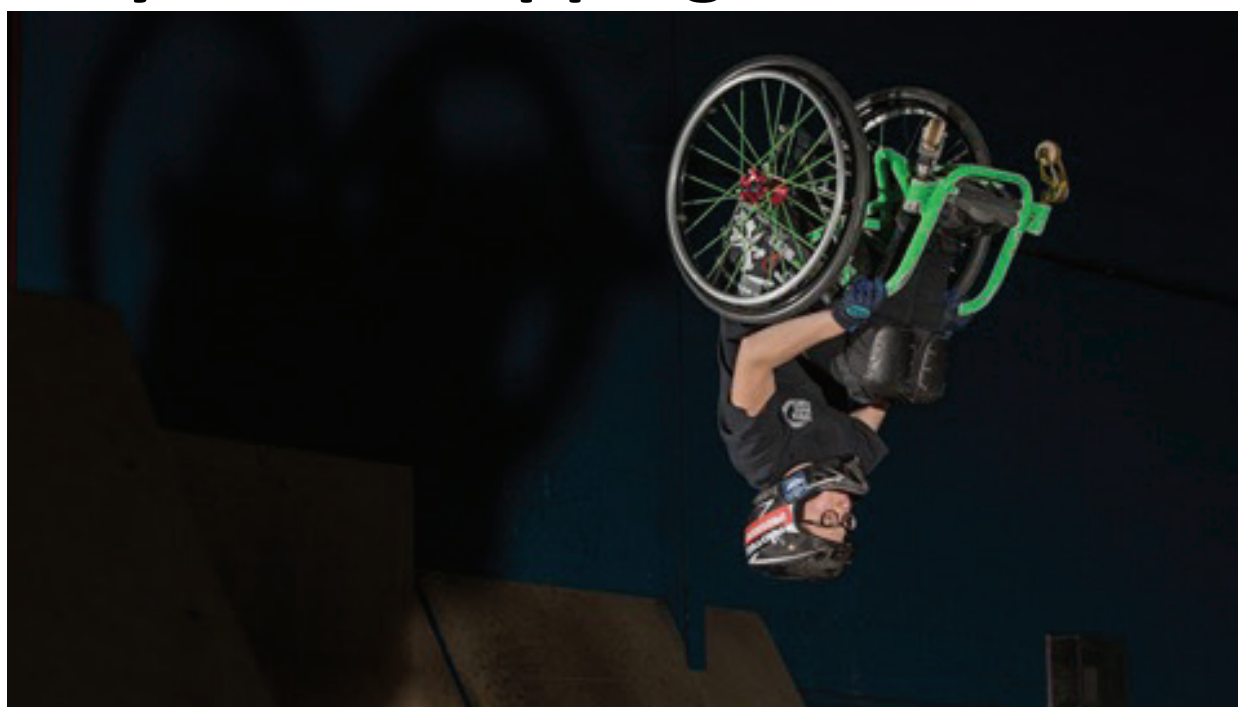
HSP Newslink

The Newsletter of the Hereditary Spastic Paraplegia Support Group

Issue 43 – February 2018

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

Lily Rice – Flipping Awesome!!



Lily performing a backward flip!

Hi, I'm Lily Rice, I've just turned 14 years old, I live in Pembrokeshire and I have HSP, but more importantly I am the only girl riding WCMX (wheel chair motor cross) in the UK. WCMX is a mix of BMX and Skateboarding and is practiced at skateparks. It is a relatively new sport, especially in the UK. In the last few years my condition has progressed whereby I now rely on a wheelchair. I've never let my condition hold me back or stop me from trying to achieve my goals.

I had the privilege of meeting the current world champion Aaron "Wheelz" Fotheringham at Nitro Circus in 2016. We stayed in touch and he donated his old wheelchair to me in February 2017. Since then I've been unstoppable.

My journey through 2017 has been incredible. It started in June with a demonstration in front of hundreds at my local skate park and I had an amazing response from the crowd. In July I performed another demonstration at the National Action Sports Show, this time in

front of thousands, to raise the profile of WCMX. I had amazing feedback from the organisers, competitors and spectators alike. I dropped a 10ft vertical ramp for the first time which was epic!

In early September Unilad contacted me to film a mini documentary on WCMX after seeing my video edits on my social media. I became the first person in the UK, first female in Europe and second female in the World to successfully land a back flip on a wheelchair. To date it's had over 2 million views online. The video of this went viral / worldwide and was featured on various BBC channels, ESPN American, Lightworkers and Buzzfeed. I entered a memorial competition in Cardiff and came 3rd in the under 16's against able bodied people.

As a result of my back flip I've worked with a number of TV production companies, played the part of a WCMXer in a children's TV drama and featured on Newsround. In November I filmed a music video with Tom Fletcher (McFly) for Christmas. The song and video had a powerful message about someone with a disability striving to achieve their goals.

In November I also received the Radio Pembrokeshire Young Inspirational Person award in recognition of what I have achieved.

Before Christmas I was invited to participate at a high level free sports demonstration for Toyota in Copenhagen. The International Olympic and Paralympic Committee were present as part of a project with the aims of including WCMX into the games.

I'm currently involved in working with schools and disability groups in England and Wales to talk about WCMX and encouraging others to have a positive outlook.

In April I will be the first person ever to represent Great Britain at the World Championships in California and I hope to compete in the Paralympics one day. I would like to travel the world demonstrating WCMX and inspiring others to show that having a disability, or using a wheelchair doesn't have to be life limiting. You can do anything that

you put your mind to, you just have to adapt and do it differently.

You can follow my journey on my social media; Facebook and Twitter Lily Rice WCMX and Instagram @hsp.me.

Lily Rice

Beyond Inspiring

I feel so honoured to have been able to work with Lily and Archie. I met them both through my book *The Christmasaurus* in which the main character, William Trundle, is a young wheelchair user.

I was trying to find someone to play William for a music video for one of the songs from *The Christmasaurus*, but all of our searches kept leading us to Lily, who had recently landed that unbelievable backflip in her wheelchair.

After hearing more about her story and the journey she'd been on, it felt so in line with the heart of *The Christmasaurus* that I knew we had to work with her somehow and she kindly agreed to star in the video and let us base the narrative on her own story.

Inspiring doesn't quite seem to say enough about the feeling you get when watching Lily do her thing. Firstly, skateparks can be fairly intimidating environments at the best of times and seeing Lily's fearless determination and pure enjoyment is beyond inspiring.



Tom Fletcher

I also have to say how wonderful it was to see such brilliant support from her family and friends who all went above and beyond to help us make that music video. The response we have received has been overwhelming.

A little after that I met Archie who was one of the three talented kids who played William Trundle in the live shows of The Christmasaurus throughout December. He is a smart, funny young man who constantly asked the most intelligent questions about the show, often pointing out the obvious mistakes us grown-ups had failed to see.

I'm so proud that through The Christmasaurus we've been able to create an opportunity for young wheelchair users to come and perform. They stole the show every night and it was an honour sharing the stage with them.

I wasn't aware of the coincidence of working with both Archie and Lily given that they both have HSP and that the condition is rare, affecting around one in ten-thousand. However, the chances of working with them both seem even more incredible as they are both one in a million.

I would absolutely love to work with Lily and Archie again and I look forward to seeing what they do next.

Tom Fletcher

Chairman's Column



Hello everyone. I hope that you all had an enjoyable Christmas and New Year. For me, Christmas is quite busy, we try and catch up with both my family and my wife's family, so there are (much to my boys delight) several "present opening sessions" in different parts

of the country. With the new year there has been a big influx of new people at the Pilates class I attend as people embark on new year resolutions of one kind or another. Such resolutions can be a simple way of improving your wellbeing. They don't have to be physical, meeting with friends more often, taking up or revisiting a hobby, or simply something like listening to your favourite music can all work well for this.

Those of you who read my [blog](#) may have spotted that at the end of the year I like to reflect on the year and work out what is different. For the group, this year I'm looking to thank two groups of people, those who raise money for the group and those who organise meetings. On the fundraising front there are several ways that money arrives with the group, including:

- Sponsored events/activities – You've read about some of these in other newslinks
- Raffles and sales of all sorts of crafted and other items
- Monthly donations – several people have set up monthly standing orders into our accounts
- Wedding, funeral, celebration party and individual donations

Looking to 2018, if you, friends, family, colleagues, sports clubs, or indeed anyone else is thinking of setting themselves a challenge, please consider the group as a worthy recipient for any funds raised. I want to thank all of those who have raised money, are thinking of raising money, and who have given to others raising money for the group. All fundraising amounts are welcome, the big and the small. We use the funds to help support you, and the act of raising funds helps to raise the groups profile and our cause to a larger audience.

Thank you also to those who invest time and effort organising the numerous meetings that happen regularly across the country. These meetings are an important part of the support network that this group provides. Thank you for your dedication to the group, and thanks also to those members that attend, making

these regular events. As has been said many times, two members having a coffee together could count as a meeting, and there are no requirements for what must happen or not happen. I understand that some people are nervous about going to meetings, but we are all in the same boat, and attending these meetings has led to life-long friendships being made between some group members.

The end of 2017 also saw two young HSPers in the news showing HSP doesn't have to be a disability. As you've just read, Lily Rice has become the first Brit to perform a backflip in a wheelchair – You can see a video of this on the [BBC news website](#). I also watched Tom Fletcher's [Afraid of Heights](#) single, with Lily and her story in it, and I agree it is a powerful message. Good luck with the WCMX. On this theme, Archie Blomfield was chosen to be [William Trundle](#) live on stage at the Hammersmith Apollo over Christmas. William Trundle is the wheelchair bound lead character in Tom Fletcher's Christmasaurus story, which is well worth a read for those liking Christmas and dinosaurs (like my youngest!).

Finally, for this column, during 2019 the group will celebrate being 30 years old. I'm looking at ways to celebrate this important anniversary. It's interesting to note that the group was set up before any of the genes associated with HSP were discovered. I'm interested in hearing from people with interesting stories or photos from any point in the groups past. Please drop me a line.

Adam Lawrence

Editor's Column

Happy New Year to every reader. For the first time ever, I've made some new year resolutions that I may be able to keep. I've decided to drink a little less beer and a little more water. I'm also trying to use my rollator a little more and wheelchair a little less, particularly when at home, to try to maintain mobility. The problem with this is that I notice that I suffer much more with fatigue when I make good use of the rollator so it's all

about getting the balance right. Another resolution I made is to stand on a vibration plate for 10 minutes followed by 20 press ups, on a daily basis. Hopefully these activities will improve my fitness and help me to keep on top of my HSP.

I know that many of us find the winter months depressing. January and February are my least favourite months because I enjoy getting out and about which isn't always easy when it's bitterly cold and dark so early. However, I try to get out whenever I can, often on my scooter, wrapped up in several layers. I find that getting out and about and meeting people is the best tonic for these winter months.

I hope you enjoyed reading the headline article written by Lily Rice. It's been a pleasure communicating with her and her family recently and learning about her amazing wheelchair activities. I've always said that a wheelchair isn't a negative thing and nobody makes a better job of proving this than Lily. My wheelchair dance moves on New Year's Eve are nothing in comparison to Lily's backward flips, but great fun nevertheless. Maybe Lily's activities will speed up some people's decision to take the plunge and start using a wheelchair. I certainly hope so!

Plans for the Potato Pants Festival are progressing well. I've been judging in a local music competition, the final of which is in April. It's for local musicians and one of the prizes for winning is to be the first musician on stage at the Festival. I spend many an evening checking out local musicians or supporting those who have supported us in the past. I love the local music scene and I honestly believe it's a great tonic for living with HSP and helps keep a smile on my face.

I've written to local banks and law firms to see if I can get some funding and I will be targeting a few other organisations. If I could persuade someone to sponsor the stage costs or cover the hire of the generator, the HSP Group would then make even more money.

This year's Festival will take place on Saturday June 2nd and we're 99% certain that we're also

going to have live music, food and refreshments on the Friday evening. I will confirm in the next newsletter and give full details. Please give me a call if you have any questions.

Our next Newslink has to be produced in May as it is posted/circulated together with the notice of our Annual General Meeting. A couple of members have already promised to submit an article but as always, I'm on the lookout for suitable content. If you have anything at all that you'd like to share with our readers that you think would be of interest, please get in touch with me. I can include photos, but to keep printing costs down, I have a general rule of one photo per article. Sometimes I break this rule where necessary. Unfortunately, there isn't one letter from a member within this issue, so please let's try to change this for the May edition.

I finished my column in last October's Newslink by thanking everybody who's recently or currently involved with raising funds for the HSP Support Group. I'll echo that sentiment but I'd particularly like to thank Michelle Brookes who spent 2017 walking 1000 miles for HSP. This was an outstanding achievement, physically, mentally and financially. Incredibly, Michelle raised nearly £4000 for our charity. I had the pleasure of joining Michelle a couple of times when she was walking in the south of England and it was lovely to meet her husband Neil and son Finnegan, both of whom are affected by HSP.

Still on the subject of fundraising, many of you are aware that my daughter, Jade, luckily managed to get an entry into this year's London Marathon in April. She already had a place in the Edinburgh Marathon which takes place the following month. Jade is conscientiously training most days and sometimes I join her and set the pace on my mobility scooter.



Setting the pace for Jade on my mobility scooter

I know some of you have sponsored her before, and I really don't want to be annoying, but Jade is raising funds for HSP by running in these two marathons. Please at least share her fundraising page with friends.

<https://uk.virginmoneygiving.com/JadeBennett>

I must tell you all about my first cruising experience. At the end of last October my family and my daughters' boyfriends went on a Royal Caribbean cruise from Southampton to Bilbao and Le Havre before returning to Southampton. It was a present from my daughters, a short cruise to find out if it was a holiday I should consider in the future.

I have to say that I was amazed! The experience was more than ten times better than I could have expected. Deciding to use my wheelchair at all times made all the difference as I had no idea how immense cruise ships are. We were on the Navigator of the Seas which has 15 decks. With loads of restaurants and bars, an ice rink, a theatre, several shops, three swimming pools and Jacuzzis, a casino, a cinema, a gymnasium, a basketball pitch etc etc. It's like a floating town. There's even a high street in the middle of the ship with a classic car parked on the road.

Accessibility was brilliant, there was nowhere that I couldn't go and the staff were, without exception, friendly and helpful. During the cruise I swam, played basketball, table tennis and mini golf. The food was fantastic and unlimited and the restaurant where we enjoyed our dinner was similar to a scene from Titanic, if not better, with a huge chandelier and three levels. People must put on weight when they do a world cruise.

My only slight moan was the cost of alcohol on board but we've since learnt that Royal Caribbean are one of the most expensive operators when it comes to booze. Ironically this probably made it more enjoyable because we all took the decision to drink frugally on board, but make up for it when we were on dry land. For this reason, there were no hangovers. I will certainly be cruising again and I would strongly recommend it.

In my role as membership secretary, I've had the pleasure of recently meeting a couple of new members who are local to me and I persuaded one of them to apply for a flying scholarship. Also, at the last Ashburton meeting I said a few words about Flying Scholarships and a member present decided to apply. There are actually four applicants for Flying Scholarships this year who have HSP and I wish the very best of luck to all of them.

As always I look forward to hearing from many of you, or meeting up at future events. Many thanks to those who've contributed to this edition and helped make it an interesting read.

Ian Bennett

Winging it with HSP

On the 14th September 2017 I did a wing walk for Flying Scholarships for Disabled People. A charity very close to my heart. But more importantly I did it for me and HSP.

We all know the feeling of stiffness, weakness and losing the sensation and true feeling in our limbs. Our mobility is slowly decreasing and so does our confidence. The only way forward is to test our nerve and continue to the very best of our ability to increase confidence and keep us there. I've always been an adrenaline junkie and I'm so glad that

hasn't left me. It's so much more of a challenge now, and a challenge we face every day, be it a trip to the shops, visiting friends never knowing what to expect. Will I get too cold? Will I be too stiff to walk? Is it uphill, how many trip hazards? Not feeling confident today....I'll just stay in.



Sherrill winging it!

But when you do push yourself and achieve even the smallest thing it helps enormously. So a wing walk...a big thing...Why not? The most difficult bit was climbing onto the wing as my very weak leg muscles won't allow me to push myself up anymore. It was daunting. Can I get up there? I'm here now and some wonderful people had travelled to see me. Damn right I was getting up there, and with some words of encouragement from those watching, I did. I confess I needed an assisted lift..Julie's hand on my backside to push up, and Marie, the lovely ex wing walker who strapped me in, guiding me up and putting out a hand to hold and steady myself. Once in....no fear. The fear was of not being able to do something physical now my body was failing on me. But I did do it. I could do it. I can do it. HSP, what a wicked game you play! My mind thinks I can and my body fools me into thinking I can't but with effort, determination and others, we all can. It's not a death sentence. It's a physical restriction...nothing more. So I had the time of my life and the adrenaline pumping through my veins gave me an extra shot of "can do". So never ever think you can't do something with a debilitating condition because you can. And every time you step out of your comfort zone a shot of "can do" is released into your system, and "can't" no longer exists. I hope next time any of you think today is going to be a struggle, remember how fortunate we mostly are.

Sherrill Semple

The Journey

2016 was quite a rollercoaster for our family, firstly our 15-year-old daughter Maddi, who was limping at the time, was diagnosed with late onset Krabbe disease which typically survival is between two and seven years after onset of symptoms. She was the only one in the UK with this form. We panicked and decided to travel to Pittsburgh to see a world's leading specialist in the disease who had met and treated teenage patients with the condition. In this hospital they offered a bone marrow transplant specifically for this type of disease to help save Maddi, so fundraising began in the UK to help support Maddi with what treatment was lying ahead, this was a horrendous time and we were shown round the transplant unit at the hospital. It was certainly devastating for Maddi as well as us. However, the specialist said she just wanted to rule out one other disease called Hereditary Spastic Paraplegia before the transplant could go ahead. The test was done and SPG15 (spastic paraplegia type 15) was found. The transplant was put on hold and we returned to the UK.

We had a meeting at Great Ormond Street with our team to discuss the new diagnosis, they informed us that SPG15 was in fact an even rarer disease. It appeared she was the only one in the UK and one of twenty or so reported cases worldwide. There is no treatment yet, but symptom management is offered as and when.



Maddi doing what she loves best looking after animals

After exhaustive research I realised that SPG15 is an extremely complicated form, as far as I am able to see with others worldwide the severity of symptoms vary considerably. There are also a few similarities to SPG11.

I decided that I would continue to pursue a treatment for Maddi, so we travelled to meet other great specialists around the world in Milan, Washington, Baltimore, Michigan and Montreal. Through discussions with these greater minds the opinion is that gene therapy or gene editing is the way forward for a potential treatment, but at that time there was no one working specifically with SPG15.

Once back home I was on a mission. I kept searching for a potential cure and managed to find out about the amazing work SITran were carrying out at Sheffield University with Sma, Parkinson's etc, I arranged a meeting with Professor Azzouz at SITran to see what the options would be for SPG15. Having done his own thorough research, he came back with a plan in the early part of last year and as a result, we now have a team working to develop a Gene Therapy Approach "proof of concept" for SPG15. This involves developing a viral vector that can deliver a good copy of the SPG15 gene (ZFYVE26) to the central motor neurons. At present this is being tested on fibroblasts and the SPG15 knockout mouse which arrives in Sheffield early Jan 2018. If this is successful, then the research can move forward to human clinical trials within time.



Alison Bushnell (her teenage son Josh has SPG15) came all the way from Boston to meet Carina (The Maddi Foundation) and Professor Azzouz at SITran, University of Sheffield

The work that is being done on SPG15 will be very useful as a potential therapy for SPG11 as both genes are very large and have similarities. SPG11 vector design will benefit from the knowledge that will be generated by the work on SPG15.

Fundraising began in 2016 mainly through social media, friends, family and live events to start the process of the “proof of concept”, which we engaged Professor Azzouz and his team to start back in June 2016. We have now obtained a charitable status for "The Maddi Foundation" in the UK (UK charity number 1174374). Fundraising efforts will continue, but further grants are critical to finishing the proof of concept phase. Being a relatively new small entity, we still need to raise more public awareness of this and other similar dreadful diseases.

Also, this year we have a new clinician (Thomas Bourinaris) at UCL who has recently started his PhD with Professor Henry Houlden (UCL). He would like to connect with SPG15/11 patients to help create a world registry as this would be important for any trials in the future. For more information please email me carina@themaddifoundation.com or go to our website www.themaddifoundation.com

Carina Thurgood

Fundraising

One of the joys of reading the newsletter and meeting members is learning how so many raise funds for our Support Group. We are lucky to have those who are able to achieve athletic or sporting goals whilst others make and sell goods. We cannot forget our annual music festival which combines having fun and socialising with increasing the awareness of our disability. Thanks to Phil Burton and Hilary Croydon's networking, many of us save our used stamps which we take to our local meetings and for Phil to sell.

For many, fundraising is limited as we cannot get to meetings or enjoy the Potato Pants Music Festival, but there are a couple of ways we can do so from our homes.

At the November Milford meeting Edwin Linnell explained the benefits of belonging to Utility Warehouse. There are some members that already belong and have found benefits, but, sadly, as they joined before Edwin set up the HSP Support Group connection we do not benefit. Edwin told us how it is possible for the Support Group to earn a monthly commission from Utility Warehouse, based on the utility bills of all our supporters who become members of the Discount Club. If anyone is interested, please email me, details at the back of this Newsletter, and Edwin will contact you. If you decide to join directly from the Utility Warehouse hosted site please use the following link:

www.utilitywarehouse.org.uk/L73858 . The last part is important as L73858 is our reference number at Utility Warehouse and it ensures that you become one of the Support Group's customers. At the top of the Utility Warehouse screen you will see Community Fundraiser: H S P Support Group to confirm that you are on the right page.

We all enjoy shopping and more of us are doing so on-line. The HSP Support Group can now have funding from Easy Fund Raising. This site raises free donations when you shop online. When you look on the site you will see familiar retailers such as John Lewis, Amazon, eBay and Apple. These are ready to help us raise more for our HSP Support Group when we shop with them. I know it is easier to use the link below when you receive the Newsletter electronically, but for those that don't, just put 'Easy Fund Raising' into your search engine. You have to register, but they even offer a 'Donation Reminder' so you don't forget when you are shopping! Friends and family members that shop on line can also register and help raise funds. <https://www.easyfundraising.org.uk/causes/hspsupportgroup/>.

A free App is available which may make donating easier:

<https://www.easyfundraising.org.uk/easyfundraising-app/>

Very best wishes to you all for 2018.

Jane Bennett

HSP Support groups on Facebook

1. Hereditary Spastic Paraplegia's Unite

A support group that is open to anyone in the world who is affected by HSP. To encourage, share information, offer advice, chat and support each other on good & bad days. A brilliant service to have. 1,788 members from all over the world. Members can and have made fb friends with worldwide members and have discussions on HSP and how it affects us. The biggest thing I have noticed is that symptoms/treatments (obviously) are the same wherever one is on this globe we call 'Earth'. Many have felt the benefit of being part of this group. It is growing all the time.

2. Hereditary Spastic Paraplegia Support For UK HSPR's

It is for all UK members to make this group work. Local & countrywide support & information, caring & sharing, all that would be of benefit to UK HSPR's. 149 members at this time. Hoping for more HSPR's to join. A fledgling support page, to encourage members in the UK to find support, empathy and generally post/chat to others in the UK. Maybe start a meeting in local area's, even a meeting of two members is a 'meeting'. Over coffee etc. Another choice for HSPR's who may find it easier to use a UK only version.

3. Take a look at the HSP Support Group UK Community page and see what the UK Support Group is doing and if you like what you see, please take the time to 'Like' the page.

<https://www.facebook.com/hspgroup.org/>

I do understand that many do not have internet access or are not computer savvy. That in my opinion is part of the reason that the HSP Support Group UK - 'Newslink' & 'Helpline' are essential for everybody in the support group to keep up to date with all that is happening in the HSP world and gain help with questions & support, as and when needed. All valuable options.

Della Brookman

VAT relief for HSPers

There are various VAT reliefs that as a disabled person you can qualify for. These are not means tested and are worth about £200 on every £1200 so that £2500 mobility scooter costs about £2000. It also applies to small things like RADAR keys where the saving is about £1.50.

Quite often the retailer has an easy form at point of sale, or if buying online it is just a tick in a box.

A lot of retailers don't tell you that things are VAT exempt as they don't want to mess about with doing the forms so we all need to ask.

Either way you must be eligible in your condition and the item being purchased. The retailer or online site will be able to advise as they are responsible for VAT but it might be worthwhile finding out if what you intend to purchase is VAT free.

Also, if you are importing something specific then you should claim exemption at time of import but HMRC may accept a late claim

The website <https://www.gov.uk/financial-help-disabled/vat-relief> gives details and regulations change so Google 'VAT relief for Disabled' and there will be a GOV.UK site.

If you're disabled or have a long-term illness, you won't be charged VAT on products designed or adapted for your own personal or domestic use. Also, you won't be charged VAT on:

- The installation and any extra work needed as part of this
- Repairs or maintenance
- Spare parts or accessories

The product and your disability have to qualify.

Your supplier can tell you, but usually products designed or adapted for a disability qualify. For example, certain types of:

- Adjustable beds
- Stair lifts
- Wheelchairs
- Medical appliances to help with severe injuries
- Alarms

- Riser recliner chairs
- Boats adapted for disabled
- Building materials
- Repairs and maintenance of VAT Free items
- Braille paper or low vision aids - but not spectacles or contact lenses
- Motor vehicles - or the leasing of a motability vehicle
- Building work like ramps, widening doors, installing a lift or toilet

There are some Helpsheets on the site.

There is also a telephone help line:

Telephone: 0300 123 1073

Opening times: 8.30am to 5pm, Monday to Friday. Closed weekends and bank holidays.

According to the site:-

- You have a physical or mental impairment that affects your ability to carry out everyday activities, for example blindness
- You have a condition that's treated as chronic sickness, like diabetes
- You're terminally ill

You don't qualify if you're elderly but able-bodied, or if you're temporarily disabled.

People with HSP may have a physical impairment and the condition is treated as chronic so the VAT relief is yours and saves one sixth of the price and as it extends to building work it could be several thousand pounds. This might be a lot of money if you don't qualify for assistance in adapting your house or buying a car or other vehicle. I suppose there is a case if the Motability vehicles on offer do not meet your needs and you want to buy an adapted vehicle.

You'll need to confirm in writing that you meet these conditions. Your supplier may give you a form for this.

This might be a simple tick and name. If in doubt, please ask.

As a patient with HSP you can qualify for VAT relief as you have a chronic illness and the things that you need are VAT free.

There are also some items that you can import tax free. The help line for this and general enquiries is:

0300 057 2100

Opening times: 8.30am to 5pm, Monday to Friday. Closed weekends and bank holidays.

The sort of things you can import are:

- Purpose-made items and equipment, specifically designed for the sole use of the disabled person, to assist them in everyday mobility, but not to be used for standard generic wheelchairs and mobility light vehicles, or for motor vehicles or other methods of transport that have not already been specifically adapted for the sole use of the disabled person
- Other specifically designed items and equipment for the sole use of the disabled person, to assist them in vocational pursuits
- Teaching aids and apparatus specifically designed for use by people who are disabled
- Table games and accessories specially adapted or designed for people who are disabled
- All other articles specially designed to be of educational, scientific or cultural help to people who are disabled
- Spare parts, components, tools and accessories specially or recognisably intended for any of the above goods

This seems to include adapted cars etc imported from abroad.

You need to claim at time of import though they may accept a late claim.

It might seem complicated but it is quite straight forward. I have used it twice and saved VAT of about £100 and realised I could have saved £1000 had I known when I had my bathroom adapted.

It seems a little known and used exemption that can save lots and make life easier in many ways.

Mike Cain

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 £750. 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 to 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 Milford meeting where Phil can pick them up.

Regional News

Attention Welsh Members

A member from Brecon in South Wales who isn't on Facebook would like to invite any other Wales based members to feel free to contact and maybe arrange some meetings. Contact details are kevinmills944@gmail.com or phone Kevin and Sue on 01874 622727

Colchester Branch Meeting

We met, as usual, at Feering Community Centre, between Colchester and Chelmsford. Once we were all settled with drinks, cakes and biscuits, we had a discussion on a number of topics.

First, we reviewed the conversations we had had at our last meeting to see how people had got on. One member has been referred to the 100,000 Genomes Project while others are still exploring the possibility of seeking a genetic diagnosis.

This lead on to the question of the degree of support members have from clinicians. About half experienced a considerable amount of

support from a variety of medical professionals and were happy with it, though most agreed that they find they have to chase things up sometimes. The remainder were either seeing no one at all or found that regular appointments failed to materialise. The consensus was that there is considerable variability in the provision of care from one area to another and with some clinicians being reluctant to refer to more specialist services. It was felt that there are advantages to being seen at one of the specialist HSP clinics, if transport is not too much of a problem. We discussed the availability of hospital transport to appointments.

We talked about the types of adaptations that people have made to their homes and the help that occupational therapists can provide.

We moved on to discuss Personal Independence Payments. Peter Gaskin described the steps he had taken to prepare for his application and also his experience of the assessment itself. This was very informative as well as being reassuring.

Stephanie Flower updated us on the spinal cord stimulator that she was fitted with a while ago. This was offered to her after the medical professionals had exhausted all other avenues for relieving the pain she was experiencing. It works on a similar principle to the Tens machine. She estimates that it has reduced her pain by half and finds that the equipment is very easy to use. However, it is extremely expensive and so is only available in exceptional circumstances and as a last resort.

We talked about the Facebook group that Ian Bennett set up called Hereditary Spastic Paraplegia's Unite. Della Brookman told us that there are nearly 1700 members now, from across the world. We spoke about the levels of support provided to one another by people in the Unite group and about the valuable information that Della, and others, provide for members. Some people at the meeting were unfamiliar with the group and some do not use Facebook so we discussed the various options. One member went straight home and applied to join.

We will be meeting again on Sunday, 18th March from **2.30** – 5 pm at Feering Community Centre, near Colchester, Essex, CO5 9QB. As always, everyone is very welcome to join us.

Hilary Croydon

Midlands Group (Birmingham)

We had a super meeting at our usual venue - The Kenrick Centre in Harborne, Birmingham, on 14th October. It was lovely to meet up again with our 8 regular members, and was super to be able to welcome a new member into the group.

We invited an Occupational Therapist – Fiona Shea – to our meeting, and shared a very interesting and informative afternoon hearing about her work, her role within the community, and the services the OT's offer people in supporting them to live more comfortably, and be more able to support and care for themselves with the added support. Fiona gave us lots of time after her talk to answer many questions from everyone – over cups of tea & coffee, and cake!

We will be holding our spring meeting on Saturday 21st April - 12:00 noon until 3:00pm, again at the Kenrick Centre, where we will be having a chat about the NAIDEX Exhibition at the NEC in Birmingham. This will be held on both 25th & 26th April, and we will be meeting up as a group on **Thursday 26th only, at 1pm** in the Refreshments area, should anyone want to come and say 'Hi'.

We will put an HSP sign up on the table, please do come to find us - it would be lovely to see you!

June Masding & Penny Cohen

The NAIDEX Exhibition

**The National Exhibition Centre
Birmingham B40 1NT**

**Wednesday 25th April & Thursday 26th April
10:00am until 5:00pm**

We just wanted to share with you that our Midlands group have decided to visit the exhibition this year, and we thought our whole Support Group would like to know about it.

The following tells you about the exhibition:

The Naidex National – will be at the NEC in Birmingham, and is Europe's biggest and most far-reaching trade, professional and consumer show, dedicated to the care, rehabilitation, and lifestyle of people with a disability or impairment. The exhibitors present the latest equipment for the disabled and elderly as well as services on the subject of care and rehabilitation. The exhibition is not only aimed at trade visitors like representatives of nursing and retirement homes, but also at individuals. The fair's goal is to present products and services that help people with disabilities and seniors to live independently. The fair is accompanied by numerous seminars, demonstrations and the Naidex CPD conference for health care professionals.

Products on show will be: access equipment, bathing aids, building alterations, building design, careers, castors, charities, children's equipment, clothing, communication aids, continence, daily living aids, drinking equipment, eating equipment, education aids, footwear, furniture, holidays, home care, household equipment, kitchen equipment, leisure activities, mobility equipment, mobility scooters, orthotics, personal hygiene, prosthetics, recruitment, safety equipment, showering aids, stair-lifts, therapies, transport equipment, vehicle conversions, walking aids, wheelchair accessible vehicles, wheelchairs.

Penny and I will be going on Thursday 26th, and have arranged to meet our Midlands Group members at 1:00pm for a coffee/lunch/natter in the Refreshment Area. We thought that it would be nice if any other Support Group members might like to come and say 'Hi' on that day (we will display an HSP poster).

Free tickets for the event are available through Naidex via the following link:

<https://www.eventdata.co.uk/Forms/Default.aspx?FormRef=Nai48Visitor&TrackingCode=>

Anyone who is unable to secure a Free Entrance Ticket by computer could ask a friend to register them.

There are **no** car parking costs for Blue-Badge holders, otherwise it is £12 for the day without a blue badge.

There are **no** allocated parking bays, but please use those by **Hall 16**, then overflow to Hall 17, which is located by Atrium 4.

Wheelchairs are available for hire – free to Blue Badge Holders. (see **NB** below)

Mobility Scooters can be hired - £15 for the day.

Assistance dogs are most welcome!

NB: It is **CRITICAL** to pre-book any equipment you need well before the event to avoid disappointment, **AND** there are only a limited number available on the day.

To book yours, please contact Bartram's who are the Booking Line, Tel: 01353 653752

With very best wishes,

June Masding & Penny Cohen

Forthcoming Events

HSP Support Group AGM

Saturday 9th June 10am – 4.30pm
Tally Ho Conference Centre
Persore Road
Birmingham
B5 7RN

Norwich Meeting

Saturday March 3rd 2pm
Meadow Way Chapel NR6 5NU
Call Barbara Jones on: 01603 423 267

Birmingham Meeting

Saturday 21st April, 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, March 18th 2.30 - 5pm
Feering Community Centre
Feering,
Essex,
CO5 9QB
Call Hilary Croydon: 01284 728 242
tohit@btinternet.com

Ashburton Devon Gathering

Saturday April 7th 2pm onwards
The Dartmoor Lodge Hotel, Ashburton
Call Ian Bennett on: 01202 849 391

Milford Afternoon tea South/South East

Saturday April 14th 3pm – 6pm
The Clockhouse Milford, GU8 5EZ
Call Jane Bennett on: 020 8853 4089

Malton Meeting

Old Lodge Hotel, Old Maltongate, Malton,
North Yorkshire, YO17 7EG
Saturday 17th February 2pm – 5pm
Call Irena Pritchard: 01524 261 076 or
Mike Cain: 01614 567 531
irena.pritchard@btinternet.com

Stockport Meeting

Quaker Meeting House
2 Cooper Street, Stockport, SK1 3DW
(For Sat Nav use: SK1 3QL)
Saturday 17th March 2pm – 5pm
Call Irena Pritchard: 01524 261 076 or
Mike Cain: 01614 567 531
irena.pritchard@btinternet.com

Potato Pants Music Festival

Saturday 2nd June 2018 from 2pm - 11pm
High Mead Farm, Ham Lane, Ferndown,
Dorset, BH22 9DR
Request disabled parking (much closer)

New Members

We welcome the following new members:

Maggie James
Dorset

Susan Woods
Ipswich

Mark Rice
Tenby

Ronald Ingleton
Essex

Peter Butler
Peacehaven

Tim Matthews
Lymington

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

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@jrmason.demon.co.uk	01225 761 788
Stephanie Flower - Help-Line 37 Alexandra Road, Great Wakering, Southend, SS3 0HN	FSPgroup@aol.com	01702 218 184
Ian Bennett – Membership Sec / Newsletter Editor 37 Wimborne Road West, Wimborne , Dorset BH21 2DQ	bravoechonovember@btinternet.com	01202 849 391
Simon Hubbard – Research committee	simonjameshubbard@gmail.com	01908 508 866
Jane Bennett – South / South East co-ordinator	luckyjane82@hotmail.com	020 8853 4089
Della Brookman – Trustee & Herts co-ordinator	della_brookman@msn.com	07710 637 941
Penny Cohen – Birmingham co-ordinator	pennycohen57@hotmail.com	07818 288 738
June Masding – Birmingham co-ordinator	june_masding@hotmail.co.uk	01214 445 095
Mike Cain - North West co-ordinator	michaelcain123456@yahoo.com	0161 456 7531
Irena Pritchard – North West co-ordinator	irena.pritchard@btinternet.com	01524 261 076
Hilary Croydon - Colchester co-ordinator	tohiti@btinternet.com	01284 728 242
Barbara Jones – Norwich co-ordinator	babs27833@gmail.com	01603 423 267
Liz Redmond Neurogenetics Nurse based at The National Hospital of Neurology & Neurosurgery	Redmond.liz@uclh.nhs.uk	02034 484 487