

# HSP Newslink

The Newsletter of the Hereditary Spastic Paraplegia Support Group

Issue 50 – October 2020

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

## Covid 19! or Foot and Mouth?



Great Spotted Woodpecker in John's garden

Leading up to lock down I was taking one of my granddaughters to school on certain days even though she had a reducing cough/cold, and of course I caught it as well. To me it was just an ordinary cough/cold lasting in total about 10 days. Whether there was an element of covid only a test will show if I had it or not.

All the news was covid, rightly so, and of course Facebook was just the same. I began to find Facebook too gloomy so I needed to do something to give a bit of cheer. Our garden is predominately a spring garden and all the bulbs and early flowering plants were making an appearance as they should and I enjoy taking pictures, particularly close ups, of the flowers as well as the birds. There

have been so many more young birds in the garden this year than before, including woodpeckers. As an idea of the bird life in our garden I do the annual RSPB bird watch, which takes place in late January, and I usually see between 10 – 15 different types. So from lock down, which I seem to remember as 23 March - through to 28 May, I posted daily photos of flowers and in total put on about 190 from over 500 that I had taken (that's the beauty of using digital cameras). Since then I have taken almost 200 pictures plus of summer flowers, and still taking, and am posting some about every 10 days as an update. As I am able to potter around outside gardening, taking the pictures plus the bird watching, it has made being at home in lockdown easier.



A lovely Bleeding Heart photographed by John

So what about foot and mouth? Well. Friday 27 March I was standing colouring my wife's hair when I lost my balance and fell backwards twisting at the same time. As I began to get up, I could feel something odd with my foot only to find that my middle toe was crossed over the next toe at a strange angle, and a small amount of blood on the floor. This was about 8.30 in the morning and I am still in bed clothes and dressing gown, not yet having had a shower or a shave. I just couldn't believe that this had happened and I would have to go to A & E just a few days into lockdown. My wife was also in her night clothes so between us we were in a bit of a panic. Anyway, the ambulance arrived in about 20 minutes, by which time I was able to have a quick shave and wash while sitting in the conservatory where the accident took place. Still in bed clothes I reached Colchester Hospital very quickly, as hardly any traffic, and straight into a cubical as there was no one else waiting. Strange how the virus suddenly stopped people from attending A & E! I must have been seen by about 10 doctors including the orthopaedic surgeon, as it was planned to take me to surgery with a possibility of losing

the toe. In the end it was decided, because the threat of covid, to put the dislocated toe back and patch me up rather than keep me in over night. A week or so later I got a toothache, mainly after meals, but it was getting worse as the days went on. Again the timing wasn't good! The up shot was that the dentist prescribed an antibiotic and after a week the ache had disappeared. Not content with that some days later while eating I felt something hard in my mouth and this was part of a tooth. Great! The following week the same happened again to the adjoining tooth. Fantastic! Could anything else happen? Another 2 weeks on and a filling fell out on the other side of the mouth. Another fantastic! Fortunately these episodes are not causing me any pain and I will get an appointment sometime when convenient (toilets not in use at dentist).

So to the title of this piece. No I do not believe I had covid but yes I had foot and mouth, but not the viral type. As for lockdown, no problem.

**John Patching**



## Chairman's Column

Happy Autumn Everyone! – I love those crisp clear still mornings, and I love to see how the plants change on a daily basis as I go about life.

This is another column from me with several different things in it, so I'm using sub-headings so that you can easily see where things are.

### Potential Group Name Change

At a recent trustee meeting we were considering changing the group's name. We are hoping to make our group appeal to a wider audience, and there is a view that some may get stuck on the word "support" in our name. Also the name "support group" may not adequately reflect the research that we fund. After some brain-storming of ideas, we whittled 15 options down to a short-list of three:

- **HSP UK** – this ties in with equivalent charities like Ataxia UK, MD UK, CMT UK, it identifies where we are in the world, and we may be easier to find.
- **HSP Foundation** – this is similar to the USA group SP Foundation and The Maddy Foundation, and the word foundation in our name might appeal more to organisations we may seek funds from.
- **HSP Group** – this simply shortens HSP down to its acronym and drops the word support, and perhaps ties in mostly with our current name.

There are advantages and disadvantages to each, but we could also keep the name as it is. For such an important decision we would take a members vote on this. So, start forming your views and I will update you on how we intend to ask you!

## Meetings Update

Those of you who read this electronically will know that I recently wrote about our decision to postpone re-starting face-to-face meetings until at least after the flu season. (<https://hspgroup.org/coronavirus-and-meetings/>) Since then the rate of infections has increased, and I write this column just at the start of England's three tier system. I know many will be disappointed, but we have to balance the wellbeing positives of meeting against the increased coronavirus risks from meeting, and I hope you understand our decision. We are carrying on the Zoom path we started at the AGM, and are holding digital meetings (some of which are being set up in November). So, you can get your Zoom apps ready and chat with members in another part of the country without leaving your home!

I would welcome hearing from anyone who is bold enough to try hosting a short digital coffee meeting for members, so that we can get more regular contact made. You can either drop me a line or get in touch with anyone on our Meetings committee, for example Hilary Croydon!

Hilary Croydon and Jane Bennett have also been busy drafting out an excellent welcome pack for anyone thinking of helping the group and becoming a meeting organiser. There are well thought out details about planning, and of course the meetings committee is there for support and advice as well.

## Annual General Meeting and YouTube

As you know we had our AGM virtually in the summer, and I have had various positive feedback from you about this. It was good that so many of you were able to join in. I like the way that we're able to talk to so many of you at once without having the trouble of travelling. Following from the AGM the three presentations we held were also really successful. You can read about them elsewhere in this newsletter, and if you are able you can watch them all again (and the AGM itself) on our YouTube channel. <https://www.youtube.com/channel/UCkxTfcl4tKYNMYsgzVumpWA>

Talking of YouTube, I am trying to include links to other relevant HSP videos, and to subscribe to other relevant channels. If you happen to find any HSP information (or indeed make your own!) on YouTube, please drop me a line so I can add it to our channel.

## Trustee Update

Just after the AGM I was contacted by Neil Cuthbertson, who has been a member for a few years. He said he was interested in helping the group and was considering being a trustee. We were pleased to welcome him to one of our trustee meetings, and we all agreed that he would be a great help with the group. We have made Neil a trustee, and he will be up for election at the 2021 AGM.

Also, over the autumn, Mitesh Patel has taken over from Ian Bennett as Membership Secretary. Mitesh is happy to help you with membership things, and Ian doesn't get away completely, he still chairs our membership committee.

## Want to Help The Group?

We added a page to our website recently which describes different ways that people could help the group. I'm very pleased to report that I've now had a couple of people begin to ask how they can help, who work with Mitesh. This is great, as it shows that people are finding our site, and are offering their help to us.

You may like to know that I have been talking with Maryam Borumand, who is a 2nd year medical student who is keen to help with fundraising. When we get back to being able to do sponsored events and that kind of thing, she may be able to help people maximise their sponsorship, direct people to the easiest way of getting their sponsorship to us, and that kind of thing. Do let us know if you need help with your fundraising!

Whilst I think about it, if you happen to be talking to someone who you think might be keen to help the group, then drop me a line or point them at our website and we can easily start having conversations.

## Christmas Shopping (and Utilities)

Please remember that you can easily raise money for the group when doing your shopping on-line, at no additional cost. There are two ways of doing this. You can use Easyfundraising.co.uk which we have had set up for a while (if you sign up via this link it will raise us another £5:

<https://www.easyfundraising.org.uk/causes/hspsupportgroup1/?invite=SBBB4F&referral-campaign=s2s>) – The app or toolbar will automatically prompt you if you wish to raise money.

Rachel Mortimer Holdsworth has just set up a Group account with Amazon Smile, so you can also raise money with any shopping through 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.

Remember us when you're doing your Christmas shopping, and remember that many insurance and utility companies are also on EasyFundRaising, so you can even raise money for the group whilst cutting your household bills at the same time.

## Going Digital

If you're reading a paper copy of this newsletter and you also have a computer or tablet at home, then please consider opting to receive your communications electronically. Not only will it save money for the group (because our costs are lower) but I think that the environmental cost of producing and posting a hard copy are much smaller than the environmental cost of us e-mailing you the PDF. I am also trying to get relevant news stories up on our website as they occur, so you can always check there for information and updates.

We are in the process of updating some of our policies at the moment. The website always holds the most up to date versions, as well as our constitution. <https://hspgroup.org/privacy-policy/>

## List of Centres

We are trying to get a list of all the different consultants and neurologists who members see, so that we can get a list on our website. The list should help those who are just starting their HSP journeys (or those who haven't seen a specialist in a while) identify potential places to get relevant advice.

## My Annual Survey

It's that time of year again, and I'm using my column to let you all know about my HSP survey for 2020. This year I am mainly looking at; participation and activities, identifying the needs of those with HSP, and access to healthcare. I would really appreciate if you were able to spare some time to answer these questions, and I'll report my findings on Rare Disease Day 2021. Here is a link to the page on my blog: <http://hspjourney.blogspot.com/2020/10/2020-survey-open.html>

**Adam Lawrence**

## Editor's Column

Welcome to the 50<sup>th</sup> edition of our newsletter that I have now edited. The first one I did was November 2004, I can't believe I've been doing this for 16 years, where does the time go? It's impossible to put an interesting edition together without your help, so many thanks to everyone who's contributed material over the years. Please continue to send in anything that you think may be of interest to other readers.

I'm enjoying some rare, early October sunshine in my back garden as I write this. I've really made the most of my garden this year and used it as a positive distraction to the current awful covid situation. My garden's actually looking tidier this year than ever, weather permitting I try to do at least 30 minutes work in it every day. I have two bird tables and a feeding station which is always full of goldfinches and greenfinches, which I can happily sit and watch for hours. We've probably had more BBQ's this year than ever before and of course these are nearly always accompanied by a nice bottle of something or other.

The reason I'm waffling on about my garden and the great outdoors is because I feel it's very important to have a hobby or something to focus on during these strange times. I notice that John Patching also makes this point in his headline article. Unfortunately, I've come across one or two of our members who've admitted to me that they're struggling mentally with the restrictions and isolation caused by the pandemic. If this applies to you, please try to find something new to focus on, maybe even write me an article about it for the next edition. Any distraction is a good distraction if your feeling a bit low and I'm always available for a chat.

For me, there have actually been many positives this year. The biggest one of course is the fact that I'm now a grandad and my grandson is now over 9 months old. Again, how time flies! He lives only five houses along the road so we've managed to see plenty of

him and it's been lovely watching him grow up so fast.

In addition to that, my youngest daughter Cara, announced her engagement recently which means both of my daughters plan to marry next summer. Jade, my eldest daughter had intended to get married this year but unfortunately the strict covid regulations forced her to delay her plans. It means I'll have to deliver two speeches in two months. Maybe I can get away with just writing one speech and simply changing the names. I wonder if anyone would notice.

Another positive was that I was very surprised how much money I saved during the lockdown. It made me realise how much money I spend each month just going to pubs and restaurants, I'm sure I'm not the only one. I also lost half a stone in weight which is further evidence that perhaps I spend a little too much time in pubs and restaurants. I'm sure my old habits will return when things get back to normal, because as many of you know, I do love a beer or two and a good curry from time to time.

I used some of the the money I'd saved to purchase an automatic garage door and what a difference this had made to my life! I can now simply wheel into my garage on my wheelchair, transfer to my scooter and away I go, closing the door behind me with the push of a button on my key fob. This is so much easier than before when I had to use the rear entrance to my garage and walking was necessary.

I'm continuing to record my radio show every week and I now do this from home. I absolutely love my local music scene and I really enjoy compiling the show. I know a few of you listen to it, but if you've never heard it before and it's of interest, just ask Alexa to play Forest FM at 8pm on a Friday evening. If you let me know you're listening, I might even say hi.

Unfortunately, I've lost too many friends this year and three of them have been fellow HSP Support Group members. Since the last



edition, Maggie Gilson, Michael Jarvis and David Jeffery have all very sadly passed away. None of these deaths were related to Coronavirus but all three of them will be dearly missed. Over the years I got to know David Jeffery really well as he never missed an Ashburton meeting and I considered him a close friend. My condolences and best wishes go out to all their families and friends and if they'd like to remain in contact with the HSP Group, they are of course very welcome.

I was delighted that at our most recent committee meeting, trustees agreed that we would delay any regional meetings until early next year at the earliest. I personally always felt it was risky to organize gatherings with coronavirus in circulation and as a charity, I felt it would be highly irresponsible of us to do so. With the recent rapid escalation in cases we obviously made the correct decision. With this in mind, I'm holding a virtual Ashburton meeting on Zoom on Sunday November 15<sup>th</sup> at 2-30pm. If you are interested in taking part, everyone's welcome, so please get in touch. I'm intending to hold a short quiz and I may do a presentation on Flying Scholarships for Disabled People.

You will notice that Mitesh Patel has taken over my role as Membership Secretary. The changeover passed without any problems and Mitesh is already making a great job of this role and I'd like to thank him for all his hard work and commitment.

Please look after yourselves during these strange, testing times. Make use of the Facebook Groups to communicate with others in similar situations and to share any advice or concerns. Use any lockdowns as an excuse to do some exercise or stretching every day and try to take up a new hobby or continue with an existing one. Try to eat sensibly because many people put on weight during the recent lockdown and of course it isn't in our interest to put on any extra pounds. As I said earlier, I'm always on the end of the telephone. Finally, and apologies for this, but there won't be another newsletter before January, have a very Happy Christmas.

***Ian Bennett***

## Meet our new Trustees

### Mitesh Patel



**Hello everyone,**

I am one of the new trustees of the group, having started work in February 2020 and formally elected at the AGM in July. My main role is being the membership secretary, a role that Ian has done a sterling job with over the years, so big shoes to fill! I also sit on the research committee.

As membership secretary, I also want to try and get more members from far to reach groups. This includes health care professionals and students, who can help in various ways such as keeping us up to date with current research and clinical practice.

I am a GP and also now working in a hospital in Birmingham. I became involved in the group as my partner has HSP and I feel the group has a lot to offer for everyone. In my spare time I like to travel (although that will be on hold for the time being!) and play sports.

Over the last 8 months, I do feel that we have made huge strides with the group, setting up zoom meetings locally and nationally, hosting our first online AGM and getting more members to the group. Long may this continue!

***Mitesh Patel***

## Neil Cuthbertson



Hi all,

I am very much looking forward to helping the Group grow and achieve its aims. My background is in Human Resources (although for my sins I also qualified in tax). Hopefully this will complement the skills and experience of the other trustees. Until 2017 I lived in South East Asia (Singapore and Bangkok): it is a wonderful part of the world and I have missed not being able to visit this year. Due to work I relocated back to the UK and I now live in Hertfordshire, close to family. I recently started to learn to play golf (again) after stopping ten years ago when I was diagnosed with HSP. However, through the patience of a local coach over nearly a year, I have just managed to play nine holes without falling over when I hit the ball. I won't be challenging for any trophies...but that was never my aim: it is important for each of us to set our own goals however modest they may be.

**Neil Cuthbertson**

## Increasing Awareness

Since the Stockport meeting in March we have been in lockdown and so the planned meeting for May in Scotland was postponed and was eventually postponed to September before being postponed again probably till spring next year, depending on Covid.

So everything has moved online, which in some ways makes it easier to gather the information we need and also to 'attend' distant 'meetings' with influential people.

There has been an opportunity to meet the Scottish and Welsh 'Cross Party Groups' of MSPs and MSs on Rare Disease and make known the existence of HSP. As members with right to speak, we are invited. I think individuals can also, but they cannot speak. Your MSP or MS will have details – and at least they will know your wishes. Also in Wales there is a regular 'coffee morning' at which people with Rare Diseases (HSP included) have a chance to 'meet' other parents – These things happen at very short notice. Someone in Scotland has started a MESSENGER group, maybe someone in Wales can do likewise

Our reach in Scotland has increased and we have made contact with the lead of the Scottish Genomic service Prof Zosia Miedzybrodzka from Aberdeen university who was talking yesterday (24<sup>th</sup> Sep) about the differences in the areas of Scotland and the distances she covers from Shetland to the Borders

Yesterday (24 Sep), our Genetic Alliance partners held a webinar about the UK genome service, which has been going for a year, but Covid has slowed its development.

It was by Alex Rickard from NHS England who gave an outline of the service available in England while Zosia and Vinod gave outlines of the services in their countries.

Wales is in the very early stages of taking back control of their genetic services from Bath. The first step covers only Neonatal and Paediatric Intensive care children and will grow, first children, then adults.

Alex outlined the seven regions that will cover the whole of England and I'm still a bit puzzled as how Oxford is seen as West Midlands!!

It is not yet decided how/if they will all share data.

Information is at web site:-

<https://www.england.nhs.uk/genomics/genomic-laboratory-hubs/>

We have also been learning from other groups and companies how best to communicate with them. Included in those we have spoken with are people and companies in UK and USA. We are also

pleased that an American sort of Newslink has accepted an article as they have sent it back being 'Americanised' for publication. (What we call 'neuropsychiatrist' they call 'PT' (much quicker), and 'Travelator' becomes 'Slide walk'. So, we'll see what happens!! - I'll let you know WHEN it has been accepted.

Genetic Alliance held a webinar so that a charity could show the effort and results of their work.

Basically they wanted to find the numbers, age range, and spread around the UK.

They had the free help of some people from University of Keele and contacted most of the places they thought would help.

They got little response, but a significant result showed the incidence of their disease was twice that originally thought.

Another group, in another country, for a different rare disease got some free interns and set about finding lots of info about their patient group. Even restricted to numbers they managed to double the number expected. Someone in USA has done likewise and doubled the expected size.

What was also shown is the benefit of awareness. As we have found with our Facebook groups, people diagnosed with a rare disease, including HSP, can find it quite devastating and often feel they're alone. It is one way of linking up quickly.

Genetic Alliance and another charity 'Findacure' are to investigate the advantages of a group approach, to avoid 7000 rare disease charities all asking for similar things from the same people at the same time!!

GA are to host a webinar on Tuesday (13<sup>th</sup> Oct) where a range of companies will see how they can help.

It's also been said that companies like to see large groups of patients and researchers are influenced by large groups and money. As Adam reported at the AGM, we have started supporting long term goals at some establishments, and we are continuing to raise awareness of HSP as well as listening to experiences of people.

What is most common with a rare disease is that people feel isolated. Some feel that they are the only one, which is never the case. Even if ultra rare, the Facebook groups usually find someone else in a couple of days – not always in this country. And one benefit of 'Zoom' meetings is that people who find it difficult to get to physical meetings will be able to 'attend' and connect with others who recognise many of the issues.

Another thing that I have found is that we have a lot of youngsters who star at their sport. We know of Amber and Lily, but there also basketball, golf, tennis and swimming stars that I know of. One is 3<sup>rd</sup> in the Scottish Open Golf, another is high up in his basketball league. These are all under 16 and found by chance that they could take part fairly locally – but beware, if your child excels, then you may be required to be a taxi service over UK!!

As we get more used to the changing environments you will be updated in Newslinks.

Meanwhile, if you have any suggestions for raising awareness of HSP to clinicians and patients, or companies, please email us.

**Mike Cain**

## Fundraising News

### Please read this!

Since I publicised

[Easyfundraising.org.uk](https://www.easyfundraising.org.uk) at our 2019 AGM, we now have 53 individuals raising funds for us using this facility and we have raised £563.58 to date including £32.06 so far this month.

We have nearly 400 members, and no end of friends, so we should easily be able to attract many more than 53 supporters and raise significant funds for HSP with Easyfundraising. If you ever shop online and are interested in supporting the HSP charity, please register for this or get in touch. It's so easy to do. There is no catch: it really is a no brainer. For example, every time we do our supermarket shopping online with Sainsbury's, 50p goes to HSP. This alone raises £25 a year for HSP and



there are thousands of retailers who support this including Amazon, Groupon and eBay, not to mention most high street stores. Use the following link and follow instructions:

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

As I said, any problems, give me a call but it's proving to be a great way of raising funds, we simply need to get more members and friends involved, and it really is simple.

Many thanks to the 53 people who have already signed up to this great facility.

**We are now 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. Please bear this in mind when doing your Christmas shopping.

**Ian Bennett**

## HSP Group Grants

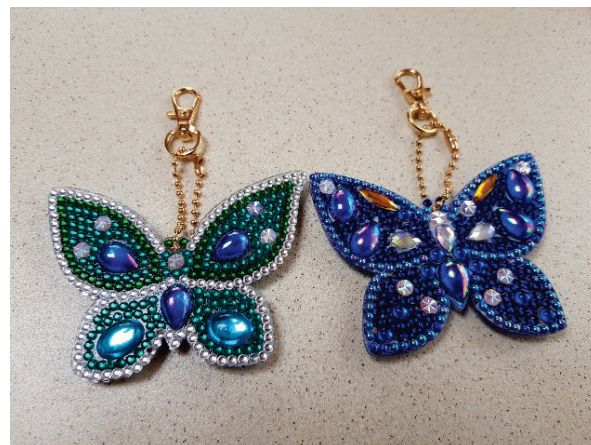
**Funds are available for members to apply for financial assistance with the purchase of mobility aids or equipment that may improve quality of life or simply make life easier.** The maximum grant available is currently £750. Completion of one year's membership is a requirement for applicants. If interested, 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

Hi all my name is Kelly, I am 40 years old but sometimes I feel 90 haha! I have obviously been living with HSP all my life but started my diagnosis journey 7 years ago but found out on 7.7.20.

Previously I enjoyed running, walking, gardening, but as the years went on my legs and back got worse. Thankfully still active and work for how long only the illness knows.

Bored, bored, bored became my evenings, no energy to go and my legs didn't want to walk. So, as most people do, we turn to social media and all the unwanted adverts appeared until diamond art did and become regular as well. At first glance it was someone doing pretty sticking with beads to pictures. Well nothing to lose but have a look. What do most of us turn to find out how to do something? YouTube! I tapped in diamond art and painting by numbers appeared, but yes, it is really painting by numbers but using diamonds, very small and pretty diamonds. Ok let's have a go, so amazon came up with 5 keyrings and all you need to complete for £9.99, yeah I can do that, ordered, result. parcel arrives let's give it a go. Addicted, addicted, addicted, but what does this do for my HSP?



Mentally, it's so relaxing. I can zone out, tv on or tv off, music on or off. It helps for short periods of time.

How difficult and unpredictable my future will be? Pain: well it never goes away but a comfy chair and correct support is just as good as watching tv.

The future: for me my lower limbs are affected, for diamond art that's all I need is my arms and eye sight and for a small part of my life is predictable. I have attached some of my work and can absolutely encourage people to try diamond art.

**Kelly Elt – Swansea**

## Petula's accessible break in Cromer

After realising that our two holidays booked this year, one to the Lake District in May, and a week's cruise to the Norwegian Fjords in July were not going ahead because of all the restrictions due to COVID 19. I decided that perhaps by September things would be much better and booked a self-catering property on the outskirts of Cromer through a holiday property letting company called:- CRABPOT COTTAGES. The property I chose was called the The Anchorage. This was after reading an article by Martin Sibley in the magazine Disability Horizons, he had been invited to visit to do a review for the magazine. It did the trick as it aroused my interest.

The Anchorage is a fully refurbished accessible holiday property in [Cromer](#). Situated in a peaceful position just a few minutes from the town centre and famous pier.



The property is bright and light with large windows. There is contemporary hard flooring throughout. There are two bedrooms, both with en-suite shower rooms. The master suite having the advantage of a large contemporary wet room.



The house is designed to be of ease for anyone using a wheelchair, but without

compromise on style and luxury. The wrap around deck really does bring the outside in and is perfect for al fresco dining or a gin and tonic in the evenings. There is parking outside with a sloped driveway for accessibility.



Award winning disabled travel blogger Carrie Anne Lightly stayed at The Anchorage and you can read her review on her website [The Anchorage, Accessible holiday cottage in Cromer](#)

Also as stated before recently reviewed by Martyn Sibley, read his review on his website, Disability Horizons.

On Crabpot Cottages website there is a very good short video showing you the entrance and taking you through to all the rooms and outside, giving you a very good idea what is manageable for you.

The kitchen has a hob and sink that could be raised or dropped down for all users if you are cooking or washing up!

What I found relaxing was a recliner chair which is a first for me in a holiday home. Usually I am in my wheelchair the whole time so it was nice to actually be able to transfer in the evening to watch the television or read.

We travelled around the coast and inland during our week, visiting Sheringham, first time we had visited the seafront as before on our visits we had taken the train to Holt which is also a pretty town to visit or just looked around the shops.

Had to go to Wells to have our yearly taste of fish and chips sitting on or by the harbour wall, very nice too.

We travelled to near Stalham to see a garden (East Ruston Old Vicarage Gardens) run by two gentlemen noted for its views of the Happisburgh lighthouse and church. We

arrived just after 12.00 p.m. and did not have long to wait. It said it was 95% accessible for wheelchair users but I would challenge that as it seemed that when I looked from one part of the garden to another there was a step or two linking them and the map was not very good in showing how to explore the garden in a chair. That said we enjoyed our visit but I would not probably venture there again.

Mundesley is a favourite of ours as my friend owns a chalet holiday home and when I was more mobile and not reliant on a wheelchair fulltime, we used to stay there sometimes. The beach is accessible down a very steep ramp where there is toilet facilities and shop for your bucket and spade, deckchair hire etc., and up some steps a café selling beverages and sandwiches.



Petula with her brother and sister in law, Terry and Betty

We love Norfolk for ease of travelling, about 3 hours at most and getting to know the area which helps when planning days out.

Hope this prompts you to look at this area and property as it had been designed for someone with Multiple Sclerosis and I would say it takes out some of the concern and worry when planning a trip away when you know a property has been designed for someone with a disability in mind.

**Petula Baker**

## Forthcoming Events

### Virtual Ashburton Meeting

Sunday November 15th 2.30pm

In the comfort of your own home

Online using the Zoom platform

You can join by clicking on the meeting link:

<https://us02web.zoom.us/j/87697606014?pwd=WG9od05DNDIZVUtLaGludE0wVTEydz09>

Or by loading Zoom and then entering :

Meeting ID: 876 9760 6014

Passcode: 952825

Contact Ian Bennett on: 01202 849 391 for further details

## New Members

We welcome the following new members:

Dorothy Stuart  
Glasgow

Emma Wares  
Mauchline (Scotland)

Mark Palmer  
Chester

Beth Penn  
Halesowen

Julie Stroud  
Chester

Michael Willis  
Cambridge

Kathy Hargreaves  
Brighton

Cath Ward  
Sheffield

Ian Green  
Bradford

Victoria Garratt  
Monmouth

Pauline McKenzie  
Cullompton

Robert Stokes  
Birmingham

Alan Thomas  
Carmarthenshire

Juan Vazquez Ruiz  
Chiswick

Marian Jones  
Sheffield

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



# Useful Contacts

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**At our AGM the technical presentations were held digitally via the Zoom platform, and each one was held on a different day. This article reports what was said, and you can watch the AGM and all of the presentations on our YouTube channel: <https://www.youtube.com/channel/UCkxTfcl4tKYNMYSgzVumpWA/>**

## **A Eureka Moment, presented by Professor Andrew Crosby and Dr Emma Baple from Exeter University**

Andrew and Emma presented together, alternating between sections of the presentation. Andrew began by explaining that his interest in HSP stems from his belief that its later onset and slower progression make it the kind of condition where it is possible to slow or prevent progression.

### **HSP**

Emma gave an overview of HSP, noting that the differences between the types of HSP is very large. The common feature is progressive lower limb stiffness and weakness, but beyond that it is difficult to draw conclusions about how a person is affected. HSP is a condition which affects the upper motor neurons, which sit in the spine and provide the connection between the brain and the lower motor neurons which then connect to muscles. The symptoms of HSP are progressive because of the gradual deterioration of the upper motor neurons over time.



Over 80 different genes have been identified for HSP. Overall we have some 22,000 genes in our DNA, each making a protein which is responsible for the development or function of an aspect of us. A spelling mistake in a gene can cause it not to function, and HSP is often associated with spelling mistakes in the genes which are part of the operation of the upper motor neurons.

The team at Exeter have been responsible for identifying 15 different HSP genes to date. They are also looking into commonalities between types of HSP.

When they see someone in clinic with HSP that person often wants to know if they will develop HSP or not. Particularly people want to know when they will develop symptoms, how HSP and symptoms will develop over time, and what will the effect of HSP be on their lives. A genetic test can answer if someone will get HSP, but it is only the first step.

## **Fat Processing**

The function of most of the genes which are affected in HSP are not known. However, the function of the gene which is responsible for SPG5 is well known. SPG5 was discovered by the Exeter team. The function of the gene is known to process fats within a cell in a specific particular way. From this, we can be sure that this fat processing pathway is important in the way that upper motor neurons work, and that disruptions in the pathway can cause HSP.

The next step was then to see if the other HSP genes were also involved with the same or similar fat processing pathways. It was found that many of the other HSP genes are responsible for the same or similar pathways as SPG5, and this hypothesis has been published in Brain: <https://academic.oup.com/brain/article/143/4/1073/5679762>

Additionally, there are similarities and overlaps with HSP and other degenerative motor neuron conditions - which means that if a treatment can be developed for HSP it may also benefit those with other similar conditions.

Various work is being undertaken which is showing that the hypothesis is most likely correct. The work has involved cellular models and new methods to analyse fat processing pathways so that the effects of each HSP gene in the fat processing pathway can be investigated.

## **Future Plans**

Their future plans are to allow a completely different approach to testing. At the moment tests are looking for the specific known HSP genes, whereas the new understanding allows the test to look at the fat processing pathways instead, which avoids the uncertainties with interpreting genetic test results. They are hoping to be able to do this from a standard 10ml blood sample.

The approach to potential treatments also varies. The aim is to look for treatments which have potential to alter the affected fat processing pathway. Any that are found can be tested in a clinical trial. The crux of these two things is that they would expect to see an improvement in the fat processing pathway with a treatment, and that improvement should be detectable from the blood test. The detection of the improvement from the blood test should be more certain than seeing a change in how HSP affects a person with their day-to-day symptom variation. Essentially the fat processing pathway is a biomarker for HSP.

You can watch the whole presentation on

YouTube: <https://www.youtube.com/watch?v=c54r3h-Zans>

## **Q&A**

From the Q&A at the end there were some interesting questions:

- A question was asked around gene editing - this is a lab-based technique for editing one cell. These techniques cannot be used in the bodies, so it is a tool for studying rather than a tool for altering someones DNA in the body.
- Although this presentation talks about fat processing, this is not the same as the levels of fat in your diet. The management of fat/cholesterol in the blood is not the same as the processing

of fats/cholesterols in the cells. There is no evidence which links levels of fat/cholesterol's in the body with HSP, although there are several with HSP who also have issues with digestion. This is an area where further investigation is needed.

### **Insights from a large regional HSP cohort. Presented by Dr Channa Hewamadduma from Royal Hallamshire Hospital in Sheffield**

Channa began with a brief introduction to HSP, acknowledging that it is very variable between patients. He described that the SPG genes are numbered in the order of their discovery, and it took a long time to identify the gene for SPG3 and as a consequence this is called At-Last-In or Atlastin!

## **HSP**

The spasticity in HSP is due to the degeneration of the motor axons in the spinal cord. He described that, as a parallel, if the diameter of the motor axon were the diameter of a football, then the length of the axon would be 7 football stadia!

Understanding the potential effects of HSP on an individual requires knowing about which type of HSP the person has. In a cohort of HSP patients some will have a family history, but many will not, they are the first person to be affected. The Sheffield cohort has 420 patients, with a clinical dataset for 371 and a gene identified in 211. Of those with a gene identified about 60% are Spast/SPG4 and around a quarter are Paraplegin/SPG7. SPG7 was thought to be rare, but may not be. SPG7 has a later onset. Cerebral palsy has been a common misdiagnosis for younger HSP patients.

## **Inheritance and Optic Atrophy**

More than 40% of patients have bladder involvement and around 40% have pain or spasms. More than half of people with complex HSP have optic atrophy. With optic atrophy problems are spotted when the vision is challenged.

SPG7 is one of the genes which shows the spectra of the different overlaps with other conditions and effects. 10% of those in the Sheffield ataxia clinic have SPG7. SPG7 was discovered in 1998. Sheffield has 55 SPG7 patients, and there is a spread between those with HSP, those with ataxia and those with both. The mean age of onset is 42 years.

Further detail was given on optic atrophy. If people are less able to move their eyes, they may have been told they have had a stroke rather than have HSP. Optic atrophy in HSP may mean that people are not able to move their eyes equally in every direction. They are hoping to be able to use this as a biomarker for HSP.

An analysis of published data shows that the age of onset of HSP varies with where the mutation occurs within the gene. If the patient has inherited the same mutation from both parents then their onset may be later than if the patient has inherited different mutations from each parent. If the mutation is sufficient to prevent the protein from working (loss of function), the patient would have greater spasticity.

## **The Sheffield Clinic**

Channa described the in-clinic process for patients, getting an assessment of spasticity, coordination, visual, mood, gait and more. They have a range of interventions available. They are planning to identify the potential for a gait biomarker, to look at the natural progression of HSP and look at the differences between types of HSP.

They have been experimenting with a single sensor gait monitoring, worn on the lower back, which can be used to see how the gait has been affected. Some data was presented looking at a 10m walk test, where a person stands, walks 10m, turns, returns and then sits. Those with SPG4 tend to have more problems standing up, whereas those with SPG7 have more problems sitting down. The gait analysis can also spot effects in mildly affected, which gives them a "trial ready" group of patients.

## Future Plans

They are hoping to be able to analyse differences in neuro-imaging to help predict how HSP could progress in an individual.

They are also working on a drug screening programme, looking at the effects of different drugs on cells, from SPG7, using drugs identified through re-purposing programmes. A high content imaging screen is used to differentiate between cells and controls.

You can watch the whole presentation on

YouTube: <https://www.youtube.com/watch?v=s3qZqLnNpBY>

## Q&A

In the Q&A there were a few interesting points.

- There is no difference between the terms paraplegia and paraparesis.
- There are differences in the mutations in specific types of HSP around the world.
- Some people get benefits from co-enzyme Q10, some from CBD oils and some from gluten free diets. A study is planned around the gluten free diet.
- For each type of HSP there can be many different mutations. Some of the mutations are more common than others, and there is some variation in the mutation type/location in particular parts of the world.

## **Rehabilitation and Physical Activity in HSP, Presented by Dr Gita Ramdharry from the Queens Square Centre for Neuromuscular Diseases in London.**

### Physiotherapy

Gita began by outlining some of the aims of physiotherapy for HSP. A key part of this is understanding walking patterns, and how HSP varies peoples walking pattern. They monitor gait by looking at the amount of movement in muscles and joints, and compare those with HSP against those without. There are two types of muscle stiffness - active stiffness, where there is spasticity and spasms in the muscle, which is caused by issues in the nerve pathway - and passive stiffness, where the muscle tissues become stiff or stuck-down, with stiffer muscles becoming shorter.

They found, as an example, that during walking the knee does not bend as much for those with HSP. One of the factors leading to this was passive stiffness in the calf muscles. Passive stiffness can be relieved by stretches and splinting, whereas medication (e.g. Baclofen) can relieve active stiffness. Another factor affecting the knee movement was weakness of the calf muscle - if you don't get as much of a push up from the calf muscle, the knee doesn't bend as much. Weakness was also found in other muscles as well.

Strengthening exercises can be used to regain some strength in muscles, for example using a resistance band (Gita mentioned Theraband: <https://www.theraband.com/>), weights, other exercises or functional electrical stimulation (FES). Physiotherapy for those with HSP is a combination of managing stiffness with either stretches or medication (depending on the type) and undertaking exercises to keep muscles strong.

### Fitness and Activity

Next Gita talked about general fitness and activity, and aerobic exercise, noting that physical inactivity is responsible for 1 in 6 deaths in the UK

(<https://www.gov.uk/government/publications/physical-activity-applying-all-our-health/physical-activity-applying-all-our-health>). Gita also found a study into Charcot Marie

Tooth (CMT - a related condition to HSP) showing that there is a relationship between peoples body mass index (BMI) and the amount of time they do nothing (i.e. are sedentary) irrespective of if they had CMT or not. She has found that there hasn't been much research done into the benefits of aerobic exercise in those with HSP. She reported a study undertaken in Norway (<https://ojrd.biomedcentral.com/articles/10.1186/s13023-016-0469-0>)

which showed that people with HSP spent more of their day sitting than those without HSP, and the next element is to look at the impact of this inactivity.

A recent study looked at the impact of impact of inactivity on symptoms of those with HSP from Covid-19 lockdowns in the Netherlands

(<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7339095/>). The study showed that where people carried on with physical activity as before lockdown there wasn't much change in their symptoms. However, people who said that they were less active during lockdown reported worse symptoms. This provides a backdrop to discussions around why people need to keep themselves active.

### **Physical Activities in Rare Conditions Collaboration**

The next part of Gita's talk covered the Physical Activities in Rare Conditions Collaboration (PARCC) project. Gita began by defining that physical activity is an all-encompassing term for any physical activity which you might do - sports, household activities, gardening, general movement (etc.) whereas exercise is a sub-set of this, which is planned and structured with an aim to improve an aspect of health.

The PARCC programme began by identifying what was important from those with HSP and other related conditions - Ataxia, Muscular Dystrophy, PSP, Huntingtons, MSA and Motor Neuron Disease. There were a lot of common issues between these conditions, both in symptoms and in accessing facilities and difficulties in finding information. The first step was to identify barriers to undertaking physical activity. Common themes were around how healthcare and community facilities are organised, communication with healthcare/fitness professionals, carers and others. There were also common themes for individuals around motivation, worries and knowing what they should be doing.

A scoping review of published works showed no papers around exercise in HSP. So, there is a need to assess this. It was found that from a patient perspective the important aspects to measure for a physical activity scheme are physical wellbeing, psychological wellbeing, and being able to participate in activities. The next stage is to then develop the on-line tool for the project, which will have a range of tools, materials and stories. The project will also offer some one-to-one coaching in how to choose what to do to help with making lifestyle changes to become more active. A grant application has been made for this project, and if the grant is made then work will start!

You can watch the whole presentation on

YouTube: <https://www.youtube.com/watch?v=VVEi0VZdtS0&t>

### **Q&A**

There were a few interesting things in the Q&A.

- In a discussion around muscles, Gita explained that muscles work most effectively in certain range of the joint movement, and that you are more likely to notice stiffness at the extreme ends of the joint movement.
- A question was asked about Revitive power plates. Gita explained that these work in a similar way to functional electrical stimulation, and that needs an intact nerve to work well, so can work well for those with pure HSP or where their nerve degradation is only in the spine, but are less likely to work well when you have nerve damage in/near the muscles.
- A few questions were asked about PARC, and Gita explained that should the grant be successful the initial work would cover the four conditions: HSP, Ataxia, Muscular Dystrophy and Inherited Neuropathies. It was also asked how PARC would be certain to get a representative spread of the HSP population. This is partly to do with the numbers of participants, but Gita also emphasised that the program will give every person their own intervention, agreed in discussion with the skilled therapists, so all plans may look different to each other.
- It was asked if there might be anything useful for HSP patients in the Bridges Self Management site mentioned (<https://www.bridgesselfmanagement.org.uk/>) - There might be - go and look!!