

SPF Summer 2020 Newsletter

in 16pt large print

Produced by Katie Robinson

Columbus, Ohio

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## Letter from the President

Dear Friend,

As you know, our Foundation's mission is to constantly support the best upper-motor neurological research on this planet so the day will soon come when all individuals with HSP or PLS can be quickly diagnosed, treated and cured. Believe it or not, that day is not the "someday by and by" wish it once was. Today, with the current state of genetic research, we should all be excited by the light at the end of the tunnel shining so brightly. This would not be possible without you. Thank you, so much!

I want you to know that when you donate to the Spastic Paraplegia Foundation, you are not actually donating to SPF, you are donating through SPF. You see, we have such a low overhead (only printing and postage) that over 90 cents of every dollar donated to the Spastic Paraplegia Foundation goes directly to the very best and most exciting research on this planet, as deemed by the expert voluntary advice of our world renowned Scientific Advisory Board.

I also must admit that, although donations to SPF were over 20% ahead of last year before the COVID-19 crisis, we are now falling behind. I know that so many of us are feeling very wounded, worried and weary during this COVID scare, but please remember that we need to maintain our social distancing, wear our masks in public and wash our hands often to maintain our health and safety. We have strong hope and expectation that a COVID-19 vaccine will be available early next year or sooner.

Even during this crisis, our Foundation is strongly doing its part to keep research moving forward. Thanks to you, we have been able to sustain the momentum we have formidably maintained for the last many years as more and more discoveries are opening new doors to finally conquering the miserably debilitating diseases, HSP and PLS. In the 2019 Annual Report you recently received, we tried to review the current research developments, but a few weeks ago, we decided what new research projects (totaling \$900,000) to sponsor for the next two years. I will touch on their highlights here.

Every year we designate half of our funding to PLS research and half to HSP research. Regarding PLS research, we are sponsoring Peter Bede, M.D., Ph.D., Associate Professor, Consultant Neurologist, Head of the

Computational Neuroimaging Group, Trinity College, Dublin Medical Patron,  
Irish Motor Neuron



*Frank Davis*

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## Volume 23, Issue 3-Summer 2020

The Spastic Paraplegia Foundation Inc. (SPF) is a national, not-for-profit, voluntary organization. It is the only organization in the Americas dedicated to Primary Lateral Sclerosis (PLS) and Hereditary Spastic Paraplegia (HSP).

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Published quarterly, Winter, Spring, Summer and Fall, for the HSP/PLS community. It is also available online at (<http://www.sp-foundation.org/>)

The SPF is a non-profit 501(c)3.

Tax ID # 04-3594491

Combined Federal Campaign CFC #12554

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President's Letter (continued)

Disease Association (IMNDA) A Fellow of the Biomedical Imaging Laboratory, Sorbonne University, in his study entitled "Using MRI techniques to Expedite Diagnosis in PLS and Monitor Disease Progression."

Also, in the PLS field, Hiroshi Mitsumoto, M.D., DSc, Wesley J. Howe Professor of Neurology at Columbia University Medical Center, MDA/ ALS



Clinical Research Center, The Neurological Institute of New York, New York, NY. is being sponsored by us in his study entitled. "Analyzing disease progress in patients with PLS to develop historical controls, which can be used for the first clinical trial in PLS in the near future".

A study that really encompasses both PLS research and HSP research is being conducted by Pembe Hande Ozdinler, Ph.D., Associate Professor, Director, Les Turner ALS Laboratory II, Department of Neurology, Northwestern University, Chicago, IL, and Nicholas Hatsopoulos, Ph.D., Professor; Department of Organismal Biology and Anatomy, University of Chicago, in their study entitled "Directed Gene Delivery to Upper Motor Neurons."

Now, regarding HSP research, Siddharth Manish Banka, Ph.D., Manchester Centre for Genomic Medicine, St. Mary's Hospital; and Martin Peter Lowe, Ph.D., Professor, Departments of Biology, Medicine and Health Sciences, University of Manchester, and Anna Nicolaou, Ph.D., Professor of Biological Chemistry, School of Health Sciences; Faculty of Biology, Medicine and Health, University of Manchester, Manchester, U.K., are being sponsored by SPF in their study entitled "Zebrafish models to study and treat hereditary spastic paraplegia."

Another HSP research that we are sponsoring, with your help, is Cahir O'Kane, Ph.D., University Lecturer, Senior Lecturer (2000), Reader (2001) in Genetics, Department of Genetics, University of Cambridge, U.K., in her study entitled "A neuron within a neuron: Is continuity of the axonal endoplasmic reticulum a factor in HSP susceptibility?"

The last new HSP research study we just started sponsoring is Carolyn Sue, Ph.D., MBBS, Director of Neurogenetics, Department of Neurology and the Kolling Institute, Royal North Shore Hospital, Director, National Centre for Adult Stem Cell Research, Kolling Institute, Royal North Shore Hospital, Professor, Sydney Medical School, University of Sydney, Gautam Wali, MSc, Ph.D.,

Post-doctoral scientist, University of Sydney, and Alan Mackay-Sim, Ph.D., Director, National Centre for Adult Stem Cell Research, Griffith University, Brisbane, Australia, in their study entitled, "Finding drugs to treat SPG7 HSP patients". These doctors have been remarkably successful in their work with drugs for SPG4 patients and now they are also working on the second most common HSP gene, SPG7.

Every year I seem to be more and more excited by the prospects of the research we are sponsoring. We insist that our researchers are open to working and sharing with other researchers so that collaboration and the synergy of group think is possible. Information silos are no longer acceptable. That has proven successful and some of our researchers insist on working this way, as well. I hope you join me in this excitement as our research charges ever closer to the day when HSP and PLS can be quickly diagnosed, treated and cured.

*Frank*

Frank Davis, President

**URGENT! URGENT!**

SPF Needs Your Assistance.



The Combined Federal Campaign or CFC is one of the largest fundraising campaigns in America. It is available for all Federal employees. Starting

September 1st, Federal employees can select which charities they would like to contribute to for the following year.

Do you know any Federal employees? They include postal workers, military personnel, police, and many others. If you do, please reach out to them. Let them know about your disease and the work SPF is doing to find a cure. Then ask them to choose Spastic Paraplegia Foundation during the selection process this Fall. Our CFC number is 12554.

Please help us with this great opportunity. We challenge each of you to recruit and get a commitment from at least one Federal employee.

## SPF 2020 GLOBAL VIRTUAL CONFERENCE SPF 2020 Global Virtual Conference By John Staehle, Senior Editor

This year the SPF Annual Conference was conducted in an environment not experienced by the Foundation during its 18 years of existence. The Annual Conference, scheduled for June 25th to June 28th in Nashville, was canceled due to the Covid-19 pandemic. Shortly thereafter, efforts began to organize a

virtual conference using current technology and the world-wide Internet. All the featured speakers from the canceled conference expressed a desire to make their presentations via Zoom and YouTube. SPF's conference coordinator, Norma Pruitt, and her small staff of "techies" worked out the details for scheduling and conducting three sessions, gaining experience and continually making improvements along the way to make our first virtual conference a global success.

The first session covered two days. Friday, June 26th featured Corey Braastad, PhD, who discussed "Basic Genetics and Cell and Gene Therapy Updates." Saturday, June 27th featured John Fink, MD, SPF's Medical Advisor, who discussed the research being done on HSP and PLS. This session was attended by 224 domestic and 77 international participants in 17 countries.

The second session held on Saturday, July 18th featured three presenters: Hiroshi Mitsumoto, MD, DSc; "We Have Made a Steady Progress in Clinical Front of PLS;" P. Hande Ozdinler, PhD; "Path to Improve Upper Motor Neuron Health;" and Stephan Zuchner, MD, PhD, FAAN; "Human Genetics and Neurology Update." This session was attended by 170 domestic and 40 international participants in 15 countries.

The third session held on August 22nd also featured three presenters: Darius Ebrahimi-Fakhari, MD, PhD, "A Multimodal Strategy To Finding Cure for An Ultrarare Disease;" Peter W. Baas, PhD, "HSP: Understanding what's wrong so that we can fix it;" and Craig Blackstone, MD, PhD, NIH/NINDS, "Research Advances in the HSPs." This session was attended by 124 domestic and 22 international participants from 8 countries.

To view SPF and related videos on YouTube, go to YouTube Videos and search spasticparaplegiafoundation. Visit the SPF website, (<http://www.sp-foundation.org/>) often. Look for announcements regarding future virtual visits perhaps with our doctors to discuss the questions submitted during each virtual conference. Norma continues to ask that questions be emailed to [SpasticConference@gmail.com](mailto:SpasticConference@gmail.com).

## Support the Printed Version of Synapse

Each printed issue of Synapse costs the SPF an average of \$4,900. Seventy percent of the cost is for printing and the balance is for postage and mailing an issue to subscribers of the printed version. On the other hand, each online issue costs \$0. The publisher donates its graphic services to create each issue from the text, graphic and photo files the editorial staff provides them.

Yearly, the SPF spends \$19,600 to print Synapse for approximately 1400 SPF members; money that could otherwise be used to serve our mission to fund research. That works out to \$14 per year for each recipient of printed copies of Synapse. You may say, "Well that's not very much." You're right, it isn't very much. In each mailed copy there is a remittance envelope for making a donation to the SPF. If you receive printed copies of Synapse, please consider making a very nominal \$14 donation each year to offset the cost of sending you four printed issues of Synapse. Afterall, that's not very much.

If you're saying to yourself, "I already make a donation to SPF, so I shouldn't need to donate any more for Synapse," you are actually reducing the amount of the donation you made for research by the amount used for Synapse. There may be some of you that do not have internet access to read our newsletter on the SPF website or that are financially unable to spend even \$14 on non-essential items.

If you are one of the many online readers of Synapse, please consider making a donation on behalf of those who are less fortunate to SPF to offset the production and mailing costs of printed copies.

Donations can be made on the website or mailed to the address listed on page 2 of this issue. Please specify your donation is for Synapse.

Every Donation of Any Size Helps!

John Staehle,

Senior Editor, Synapse

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## GENERAL INTEREST



*Celyna on Rare Disease Day, February 29, 2020*



# A Brief History of My HSP Journey

By Celyna Karitas Rackov, PhD Chemical Engineering, HSP SPG4, SPF Co-Ambassador-North Texas Region

I have experienced increasing HSP symptoms since I was a child. As misdiagnosis is the case with many rare diseases, mine was not initially diagnosed correctly. The incorrect diagnoses ranged from a psychological issue to Cerebral Palsy. Eventually I met a doctor who recognized the symptoms and gave a correct diagnosis. Thanks to the CReATe study at the University of Texas Southwestern Medical Center, I was precisely diagnosed in 2019 with HSP SPG4 using DNA testing.

Prior to the DNA testing, I received my first HSP diagnosis in 2009. Seeing the term “neurodegenerative disease” in the diagnosis was unsettling. I knew my symptoms were getting worse; but in the beginning, I could not embrace this reality.

One of the main reasons for my fear and uncertainty was a lack information about my disease. Being from Brazil, I first looked for information in Portuguese. Whatever information I was able to find was vague and not of much help. After some frustration, I tried to research in English and I found

the Spastic Paraplegia Foundation website, (<http://www.sp-foundation.org/>), where I would begin to read more accurate information about HSP.

The Spastic Paraplegia Foundation became an inspiration to create a group within Brazil where people with HSP and their relatives could go for information and emotional support. Naturally, I did not create this group alone; I was part of a team of several highly motivated people. The organization is called ASPEH-Brasil (Association of Hereditary Spastic Paraplegia from Brazil). [See "First Brazilian HSP Symposium" article on page 6 of the Winter 2020 issue of Synapse. Ed.] The first time I lived in the United States was from 2013 to 2014 for my doctoral degree fellowship at the University of Texas at Arlington. Since 2016 I have lived as a permanent resident in Texas with my husband and step-son (an Army soldier stationed in Kentucky). I currently work as a professor of Chemistry at Dallas College and in January 2020, I became SPF North Texas Ambassador, which I enjoy very much. It is an honor to be a volunteer at the Spastic Paraplegia Foundation.

## This Disease Doesn't Define Me

By Veronica LaPort, SP

Having a disability is hard, but having a phenomenal and loving family makes it all better. I would have never gotten this far without my family standing beside me. From finding shoes that best fit my needs or helping me get a first-floor dorm room, my family and friends have been my greatest supporters since the beginning, when I just thought that I was clumsy.

No one in my family suspected a thing until about second grade when the symptoms started to worsen. However, it wasn't until I was about 11 that my mother took me to Children's Hospital in Buffalo, New York, to find out what was wrong with my legs. At Children's, I received a diagnosis of Spastic Paraplegia, but they gave me no real explanation of what that was.

After the initial diagnosis, my family made an appointment at the Cleveland Clinic. The Cleveland Clinic was my savior; not only did they confirm my diagnosis, but they also told me what it was and what I could do to combat it. Their advice was to look into Botox treatments to relax my leg muscles and physical therapy to stretch the stiff muscles.

We then found that Strong Memorial Hospital would offer the treatments and I started when I was about 13. Now an essential part of my Spastic Paraplegia is that the back of my legs and the bottoms of my feet are

extremely sensitive, so sensitive that a light tickle feels like torture. Botox injections went into the back of my legs, and none of the cold sprays or the cooling gel ever worked. It was always painful.

Most days after the procedure, I couldn't walk and needed to be placed in a wheelchair. I would have to take an entire day off school to have this done and on the drive home, I could feel the muscles loosening up in my legs. When the Botox was working, I was walking better. I hardly needed to use my cane, but unfortunately, after a

few years, the Botox stopped working. It was no longer helping so I stopped doing the treatments about halfway through high school.

Even though the Botox eventually stopped working, I kept up with the physical therapy until I regrettably stopped. The workload of high school was too much and mixing that in with my general laziness, was enough for me to stop. I did carry on doing some of the stretches at home, but it wasn't until I did something utterly unexpected that I realized just how important it is with Spastic Paraplegia to stay active.

In my freshman year at St. Mary's High School, I joined a crew team. The girl with the awkward gait and ability to continually trip over nothing was now a part of a sports team. The best part of crew is that it is low-impact and doesn't require standing. Crew helps you build and tone all of your muscles, without the danger that being upright usually presents to people like me. I still work out today on the rowing machine.

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**“ALTHOUGH MY DISABILITY IS PART  
OF ME, IT DOESN'T DEFINE ME”**

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While I was on that crew team, I was in the best shape of my life since the disability started developing. Now I wasn't as good as the rest of the team, but that didn't matter to me. I found a sport that I could be part of and it made me feel normal. Joining that crew team is one of the moments in my life that I repeatedly reflect on; it was the moment that I did the impossible. The girl who couldn't even walk down the hallway without tripping was playing sports. It was then that I realized that all of the things I told myself I couldn't do because of my disability weren't as impossible as they seemed.

Although my disability is part of me, it doesn't define me nearly as much as I initially believed. It didn't define me when I hiked up a mountain, when I climbed up cliffs and waterfalls, or even when I hiked up and down for at least six hours at the Renaissance Fair in a dress. This disability didn't define me when I went away to college and walked through the snow-covered streets of Buffalo, New York to get to class. And it won't define me as I continue to live my life, as I continue to show the world just how strong and capable this young woman is.

## Do I Use My Condition as a Crutch?

By John Hayes, HSP SPG7

My first responses to that question are "NO" and "absolutely not!" I understand that this is controversial, but I sometimes wonder--is there more I can do to enjoy my life and be someone who my loved ones want to be around? Although I knew something was not right with me and it was getting progressively more difficult to do some things, like walking, no one else could really see what I knew was happening. I went undiagnosed for 14 years.

I remember feeling frustrated, helpless, demotivated and losing focus. In a “fight or flight” approach-well, I retreated. I hate that I did that! I did not share my circumstances for fear it just be seen as complaining. I should have somehow. They say hindsight is 20/20.

In retrospect, asking my physicians (even though I went through some misdiagnoses and, at that time, they did not know my specific condition) for support options would have helped me greatly. Talking about my situation with others in similar circumstances would have really helped, too. Instead, I felt and went on alone. I became a functional zombie, just going through my days without really thinking of others or my future. I wasted my time and the time of those around me. Finally, in 2017, my condition was identified. I became a member of the exclusive “Hereditary Spastic Paraplegia” group, SPG 7 to be specific. It was helpful to get a diagnosis-that it was real, even though very much uncertain. Though my HSP is not medically complicated and affects only my bladder and lower body, it still took a toll on my mind. I made some questionable decisions that affected my career future and my family. While they seemed rational at the time, they really were not; they were borne mainly out of uncertainty and frustration. I missed out too much on what was really important-life and relationships with my family.

Maybe I saw myself as a victim. Sure, I was upset and I had lost hope that things would get better, but I had to find something to move forward. Maybe it would be exercising, eating better, communicating more with old and/or current friends, spirituality, watching the classic movies you've always wanted to, reading, listening to audio books or music, and/or anything else that could give more meaning to daily life. For me, it is a combination of these things. The focus is often on our physical health, but our mental

health is vital. The power of the mind, body and spirit-and the systemic relationship of these elements-is so important to our overall health. While the symptoms of my HSP are not uncommon, by the process of elimination, I was able to find some physical activities I can do. Walking used to be one of my favorite leisure activities. That ended quite a few years ago. It's not relaxing or comfortable at all. I now have horrible balance, get fatigued quickly, can't lift my feet more than two inches off the ground and navigating stairs or bleachers is almost undoable. Funny thing, despite the challenges, I am probably in better physical condition than I've been in a long time. There are certain things I cannot do, but I am now working hard to combat my physical symptoms from HSP and improving others. I make myself do



stretching exercises. I dread starting them and they hurt, but I feel so much better afterwards and they prepare my body for further exercises.

I eventually found that I could ride a recumbent stationary bike (the ones with a low seat) to get some aerobic exercise. I invested in one that I keep at home since sharing equipment is not the best idea, especially at this time (Gold's Gym Cycle Trainer 400 Ri Recumbent Exercise Bike, available in limited quantity at Walmart. (<http://walmart.com/>) I also do daily balance exercises. The blue image in the pictures is a balance half ball trainer (No/Brand Yoga Ball Balance Hemisphere Fitness Trainer available at Amazon.com. I use it to practice my balance. I'm bad at it, but I want to keep what I have for as long as I can. It's very important to be able to hold onto something secure when standing on the ball.



*Recumbent Exercise Bike  
and Balance Half Ball*



Everyone is different. This works for me, but everyone needs to find their own activities (swimming, stretches and exercises, weightlifting, etc.). I have more energy now, but I also feel I think more clearly and I have more confidence. It's amazing to me how finding a way to be physically active impacted my outlook.

While I have regrets, I want to move forward positively instead of being stuck dwelling on the past. I guess I may have used my HSP as a crutch. I wish I didn't, but I had a right to. I guess my real message is, "Don't Let Yourself Use Your Condition as a Crutch." You can, of course, but look for something more and move forward. You owe it to yourself and those who care about you.

## "Automatic" Shoes

By Malin Dollinger, HSP SPG4

Are you tired of bending down to tie your shoes? Can't bend down? Can't tie the laces, like me? I bought shoes with Velcro fasteners instead of laces, so the two flaps close with Velcro-easy. I still need to bend down to fasten the Velcro. Reverse the procedure to unfasten the Velcro and take off the shoes.

But wait! Everything is different now! I just bought a new pair of shoes online from Zeba Shoes, [www.zebashoes.com](http://www.zebashoes.com). Once you adjust the laces the first time you wear them, you will never have to touch them again when putting on and taking off the shoes.

The ad for these shoes appeared in the middle of something I was reading. I wasn't looking for shoes, but I was intrigued by their cleverness. There are regular laces, but there are extra binders for the laces to hold them in place after you first adjust them.

They go on automatically! The neat feature is the heel, it's hinged with a spring. When the laces are adjusted for you, the first time you put them on (laces are loose), you tie the laces the way you need them so your shoes slip on and off like loafers. You never have to touch them again.

There's plenty of room to put your foot in the shoe. Remember T.G.I.F.: Toes Go in First.

Once your toes are in the shoe all the way, the heel of your foot is on top of the heel of the shoe, which is HINGED with a SPRING. You put your weight on your heel and the shoe heel drops down flat, and your foot is now flat inside the shoe. Then the heel of the shoe, on a hinge with

a spring, rises up by itself and covers the heel portion of your foot. It's automatic.

They sell for \$130 and shipping is free. Amazon also sells new Zeba shoes and eBay has a few used pairs. I took a gamble and bought a pair; I am so glad I did. I have 15 pairs of used shoes now for some homeless people.

They give you an extra pair of laces and a pair of short top sox. You tell them the size and width of the shoes you wear.

Due to customs and transoceanic shipping, it took about three weeks to get them from China where they are made.

At night I put my new shoes side by side on the floor. In the morning I simply insert my toes in both shoes, all the way forward, then let my heel drop down, pressing the shoe heel down, which then pops up by itself and covers the heel of my foot. I'm done. Never touched the shoes and they are all the way on.

To take them off, I put one toe at the top of the other heel, and push down and the shoe pops off. Or I use my stick with the metal prong on the end to push the heel of the shoe off my foot.



The photo at left is my Zeba shoes ready to put on. For me, it's easier if they are inclined, so I created a tilted stand. One responder with foot drop, drop, causing tripping on door sills, etc, asked me about this problem. The second photo shows the raised shoe tip which prevents tripping. Some of you have already told me how happy you are with the Zeba shoes.

Good luck; for me they are a godsend. I hope they would be for you, too. No, I don't walk, but I need to have shoes on all the time when I'm on my

scooter [a.k.a. powerchair] to avoid injuring my feet/toes if I bump into things. Also, it's important to have shoes on when I need to stand, like using the bathroom, reaching for things, transferring, etc.



## HSP Is Not Self-Correcting

By Russell Majors, HSP

During my 32 years of having HSP, I have seen doctors from the Mayo Clinic to the National Institutes of Health. I have purchased and used many pieces of exercise equipment with varying degrees of success.

What is needed is to recognize this illness is not self-correcting and much can be done by the patient to fight the loss of strength and slow the progression of the illness. You just have to look for it.

The Internet has a wide variety of treatments and exercise equipment listed and I recommend those SPF members looking to expand their treatment options spend the time needed to see if there is at least one piece of equipment or treatment they might feel comfortable working with. If their family doctor is unavailable, create a treatment plan that incorporates the new treatment(s) and review it with their therapist. This will give the patient a new feeling of chosen involvement and initiative and will break the mindset of helplessness brought on and strengthened by inactivity. Bodies at rest do stay at rest, sometimes forever.

Some of the devices I have tried that have been beneficial to me are:

- The Chi Machine (<http://chimachineshop.com/>) is an electric device that firmly moves the legs while you are lying on the floor or other horizontal surface.
- The Thumper Versa Pro Reflexology platform stimulates the nerves on the bottom of your feet with probes that shake powerfully.  
(<https://www.thumpermassager.com/massagers/versa-pro/>)
- I continue to receive Pulsed Electromagnetic Field (PEMF) treatments at my therapist's office in Greensboro, North Carolina. I lie on a padded cushion and another is placed on my knees. The operator turns on the

unit and I get a powerful vibration that is not painful. Each session lasts about an hour and costs around \$150 per session. My walking has improved by having sessions with this device.



I hope that all members of our group can find a machine or device that will reduce their stiffness and improve their mobility. It will take some time and persistence, but it is time well spent as it is an investment in yourself.



I wish all the best to each and welcome you to contact me at ([rmajors11@gmail.com](mailto:rmajors11@gmail.com)) about your exercise results. Be safe.

I am excited for what the future will bring us!

## My HSP Story

By Denise Ghobrial

In March 2019 I was diagnosed with HSP. My journey to this diagnosis began in 2017 when I went in for some physical therapy because I was having issues with my gait and was falling quite often. My mother and her father were both diagnosed with CMT (Charcot-Marie-Tooth) disease and so it seemed I had inherited it as well considering I had the exact same limp as they had. At one of my therapy sessions my PT was performing a certain procedure when my feet and legs started to spasm. She asked how long that had been going on and I informed her for as long as I can remember. She felt I had clonus and suggested that I inform my PCP and get a referral to see a neurologist.

This led to many tests including EMGs/Nerve Conduction Studies, MRIs, X-rays and a variety of other tests. I was diagnosed with PLS and stenosis of

cervical spine with myelopathy. I was scheduled for spinal stenosis bone graft surgery, but it was cancelled at the very last second. My surgeon noticed atrophy in my right hand. He was quite concerned that I had lost nearly 70% of muscle tone within a two-month period. Consequently, he felt proceeding with surgery would not be in my best interest.

I was sent to a neurologist specialist at Oregon Health & Science University in Portland Oregon. It was through this specialist and his testing that I was finally diagnosed with HSP related to REEP1 (SPG31) and (HMN5B) and ZFYVE26 (SPG15).

Since then I have made a few life style changes that have really helped me to cope with this disease and gain a more positive attitude. For one thing, I started on an anti-inflammatory eating program and have lost 57 pounds in 8 months. I also try to walk three times a week for 20-45 minutes and to use my stationary/elliptical bike.

I have also noticed that regular physical therapy (especially pool therapy), massage therapy and chiropractic therapy help keep my hips and muscles loosened up so I can enjoy moving around better.

I'm also taking 25 mg of baclofen three times a day which, so far, seems to help reduce some of the stiffness and spasms. I am in the process of getting new orthotic inserts for my shoes which I hope will help with some of my balance issues. My younger brother also has symptoms very similar to mine and I'm trying to keep him informed with the information I come across. Our mother and grandfather are both deceased so we have no other relatives to be tested to confirm which mutated gene we inherited. But we would both like to continue learning as much as we can about our HSP disease which, at this point, is through SPF's website and the Synapse newsletter.

*Don't Blame the Rain*

*don't blame the rain  
for turning on night,*

*because the beautiful  
sun is still there, cover*

*your eyes and ears if  
you can't stand sight*

*of the clouds becoming  
irate, just wait, light lives*

*james kenneth blaylock*

*6-23-20*

# Straight Toes

By Tina Croghan, HSP SPG7, Missouri SPF Ambassador, SPF Board Member, Chair Education Committee

On June 19, I underwent Flexor Tenotomy [a surgical procedure to release the tendon to straighten toes. Ed.] on the toes of my left foot. I have been dealing with my feet, especially the toes on that foot, for some time. I have been stretching them several times a day and still had my toes curling under my feet. They were curling so much that I would constantly walk on a “club” of knotted up toes and would “feel” the sole of my foot.

The surgery was performed with a local anesthetic only. My podiatrist, Dr. Michael J. Horwitz, stuck a scalpel in the side of each toe just nicking the tendon until it released enough for my toe to “pop out” straight. He didn't do anything to my big toe because he said I was still walking and I really needed my big toe for balance (such as it is!) After a dressing and a walking shoe (a moot point with my HSP!), I was sent home. I used no pain medication other than Advil. I was told to keep my foot elevated for two days. I used the occasional ice pack and there was no bleeding. I got into my AFOs and started riding my recumbent bike three days later.

Below are pictures of my feet before and after the procedure. You can really see the difference on my left foot. I'm waiting until the end of summer to do the right foot.



I will never be a foot model, but I am anxious to paint my toenails for pleasure rather than just to see if my toes are starting to curl.

## Vitamin D

By Malin Dollinger, M.D., HSP SPG4

From time to time, medical issues arise that suggest a note to you all. This is about vitamin D deficiency. As you likely know, vitamin D production is stimulated by exposure to sunlight, so people who are indoors a lot, like us, may become deficient. The best time for sunlight making vitamin D is between 7AM and 9AM. Later in the day, for example, mid-day, it's not as

effective in making vitamin D and is more effective in making sunburn (with the latter, the risk of skin cancers after severe sunburn increases).

in addition, one of us, me, has been "outside" only briefly for the past several months, due to my decision to isolate myself from coronavirus exposure. So, my recent comprehensive physical exam showed a very low vitamin D level. I am now taking a large dose of vitamin D (4000u daily) to replace what is missing.

Now I will discover if some of my symptoms are related to this vitamin D deficiency. The standard list of symptoms vitamin D deficiency can produce are: tiredness, frequent infections, bone loss, back pain, loss of bone structure, depression, slow wound healing, hair loss, muscle pain, and weight gain. Especially important now with the coronavirus, vitamin D is involved with the activation of T lymphocytes, a vital part of our immune response.

Ask your physician to check your blood level of vitamin D next time you are there. Normal level is 30 to 100; mine is 17 and I was already taking 1000u a day. Obviously, that was not enough. It seems that the HSP and PLS introductory "rule books" should mention checking vitamin D levels. Since publication of this message in the PLS and HSP chatrooms and on Facebook,

some of you responded with feedback, which I am thankfully able to summarize. Some people had low vitamin D levels despite early morning sunlight, so this reinforces checking your vitamin D level regardless of sun exposure. Then, there are toxic effects of too much vitamin D, so you should not simply start taking vitamin D without a blood test first. Your doctor will know how much to give you. My personal physician checked my vitamin D level three weeks after I had been taking 4000u a day. It rose somewhat, but it was still too low.

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My dosage again went up. Sounds like I don't absorb vitamin D very well. The overall message is your doctor should be involved in your vitamin D treatment; don't try to do this "on your own." You may end up taking too little or too much without knowing. Too much vitamin D is as harmful as too little.

## Mental Health

John Boucher, HSP SPG7



In the past, I've written articles for Synapse about the importance of having a good support network in place and the importance of a good exercise and stretching program for those with HSP.

There also is a psychological component to living with HSP, especially as the disease progresses. Let's face it, life has suddenly taken a 180-degree turn on you. You can no longer be the husband/ wife you'd like to be. For those with children it's extremely difficult not being able to be the father/mother you once were. Additionally, if you were the sole provider and can no longer care for your family the way you once did, it's extremely difficult and painful to deal with.

With that being said, it's not uncommon for depression and/or anxiety to impact those with HSP. Your neurologist and/or support network will be able to recognize depression. The signs to watch for are:

- Excessive worrying
- Feeling restless, on edge or hyperactivity
- Muscle tension
- Feelings of guilt or worthlessness
- Withdrawing from family and friends

- Reckless behavior
- Fatigue
- Difficulty sleeping
- Changes in appetite
- Anger and irritability
- Physical pain
- Persistent sadness
- Difficulty concentrating
- Suicidal ideation

If you experience any of these (or other issues) please get in touch with a mental health professional right away. If needed, you can reach the National Suicide Prevention Hotline on the internet at

(<https://suicidepreventionlifeline.org/>) or by phone at 1-800-273-8255

in People with PLS and HSP?" is the first to find that neuroinflammation (a type of inflammation that happens in the brain) is implicated in these diseases.



*Dr. Sabrina Paganoni*

## Supporting the Quest for Cures

By Pamela Jordan Handley, HSP SPG7, Associate Editor, Co-Ambassador-Ohio

The Spastic Paraplegia Foundation is committed to providing information about Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS), creating opportunities for mutual support and sharing, and discovering the cures for HSP and PLS by funding research. Since the Foundation's creation in 2002, we have raised and funded over \$7 million in research grants. Last year, SPF was able to pledge \$800,000 of research funding thanks to the support of members and friends of the SPF.

The 2019 Annual Report highlights researchers and studies sponsored by SPF and gives a glimpse into the exciting breakthroughs being made in the quest for treatments and cures to these two upper motor neuron disorders. The progress could extend way beyond HSP and PLS since researchers say

common threads link the many neurologic conditions that affect millions of people.

One highlight in the latest Annual Report is the work being done by Sabrina Paganoni, M.D., Ph.D. and her team of researchers at Harvard University, Massachusetts General Hospital (Boston, MA). Their study entitled: "What Causes Upper Motor Neuron Problems How does neuro-inflammation affect the upper motor neurons? Dr. Paganoni likens it to the telephone game where you whisper a message and it gets distorted by the time it reaches the last person. The more outside noise there is, the more the message gets distorted. In this case, the brain is trying to send messages to the spine and the Upper Motor Neurons are like telephone cables, passing the message along. If neuroinflammation causes a lot of outside "noise," that could reduce the ability of the Upper Motor Neurons to function properly and receive the "correct" message.

Dr. Paganoni's study team is using a special brain imaging technique called MRI-PET. They collected over 50 scans in people with PLS and

HSP and compared them to hundreds of scans from people who are either healthy or have different neurological diseases such as ALS (Lou Gehrig's disease, a different disease that can be initially confused with PLS). Results show that the pattern of neuro-inflammation is different in each disease.

**"LAST YEAR, SPF GRANTED OVER \$800,000 FOR RESEARCH."**

Results will provide important insights into the causes of PLS, ALS and HSP and will help identify ways to differentiate between these diseases. In addition, this novel imaging technique could be used to monitor response to experimental treatments. This is already happening in ALS trials and [they] hope to be able to include this imaging technique in clinical trials for PLS and HSP in the near future.

Other researchers and studies featured in the 2019 Annual Report are:

- Peter W. Baas, Ph.D., "Cause of Nerve Degeneration in People with Hereditary Spastic Paraplegia."
- Gerardo Andres Morfini, Ph.D., "Understanding How Mutant Spastin Affects the Intracellular Moment of Organelles."

- Xue-Jun Li, Ph.D., "Using Patient-Specific Neurons to Explore the Treatment of HSP and PLS through Regulating Mitochondria."
- John K. Fink, M.D., "Biomarker Discovery for Primary Lateral Sclerosis."
- Lara Marrone, Ph.D. & Professor Mimoun Azzouz, Ph.D., "Gene therapy for spastic paraplegia type 15 (SPG15)."
- Darius Ebrahimi-Fakhari, M.D., Ph.D. and Mustafa Sahin, M.D., Ph.D., "Generation of Human Nerve Cells from Children with AP-4 Associated Hereditary Spastic Paraplegia to Support a Search for New Therapies."
- Holger Sondermann, Ph.D., "Discovery of Novel Mechanisms Underlying HSP SPG3A."
- Typhaine Esteves, Liriope Toupenet, Julien Branchu, Ph.D., Khalid El-Hachimi, Frederic Darios, Ph.D., Daniel Stockholm and Giovanni Stevanin, Ph.D., "Identification of the neuronal transcriptomic signature associated with lysosomal defects in hereditary spastic paraplegia SPG11."
- Hiroshi Mitsumoto, M.D., D.Sc., Wesley J. Howe Professor of Neurology at Columbia University at The Neurological Institute of New York and New York-Presbyterian Hospital/ Columbia University Medical Center.

The complete report is available at (<http://www.sp-foundation.org/>). You'll find it in the "Who We Are" section; just select Corporate Documents and

then click on 2019 Annual Report (Latest). Information on how you can help the Spastic Paraplegia Foundation fund research studies such as these is also available at (<http://www.sp-foundation.org/>).



*Dr. Peter W. Baas*



*Dr. Gerardo A. Morfini*



*Dr. Xue-Jun Li*



*Dr. John K. Fink*



*Dr. Lara Marrone*



*Dr. Mimoun Azzouz*



*Dr. Darius Ebrahimi-Fakhari*



*Dr. Holger Sondermann*



*Dr. Giovanni Stevanin*



*Dr. Hiroshi Mitsumoto*

## LIVING WITH HSP/PLS TO CATCH A THIEF By S. A. Weinhold, HSP SPG4

In the twilight of a brisk November day when bold colors turn to evening shades, the 5 p.m. rush hour began. Waiting on the eighth floor of the One

Plaza office building were the documents to complete my client's investment portfolio changes. The documents were in hand and submerged into my oversized carry-all tote. I scurried back to my car while fitting the tote securely on the shoulder. There was a hurry in my steps, hoping not to arrive late for Grace's soccer game. I looked around before crossing at the light, noticing a number of chained doors and barred windows encouraging me to get back to the car ASAP.

The light messaged me to cross. I told my left foot to step up the curb, it rebelled halfway up. The message from my brain somehow got intercepted, landing me face flat on the cement. The carry-all tote flew off toward the pedestrians. A surreal slow motion took over. In need of a handout, I glimpsed at a man in a dark tattered jacket. For a few seconds our eyes met, both knowing what had crossed his mind. The tote flew past his reach into another woman's instinctive clutch, as a backpacked college student struggled to help me up.

I hastily straightened out my disheveled business suit and a bloodied exposed knee, thanked the bystanders and scurried my embarrassed-self off to my car holding tight to the now even more treasured carry-all tote.



Those mis-steps, among many in the early stages, were mis-steps right into HSP. Little did I know, I was stepping into an uneasy knowing and not knowing what or how life would change. As with others who go through this process, there's a thief in their story, too. The thief is HSP, and the thief steals.

First it steals away your "strut", the confidence and volition for the simple next step. Even if that step can be made, it has its own scraggly circular motion giving others to wonder if someone had too much of the "happy hour?"

Next it ransoms your confidence. It can slowly take you into a "shy" hiding not really wanting to move amongst people with the attention it brings. Not wanting to answer questions; "are you okay?", "do you have M.S.?". No longer moving in the circles you once smiled and danced your way through.

Thirdly, that HSP thief picks your pocket. At times, stealing your smile. That loss, going unnoticed by you, until denial turns into reality. The thief inside of HSP may not be able to be captured, but we can make the thief less powerful. We may not be able to regain our "strut;" however, our "strut" can take on a new confident form.

## "STEPS" TO CAPTURE THAT THIEF"

Endorphins are our crime fighting friends. Endorphins are neurotransmitters which are released in the brain to reduce pain, stress, anxiety and make us feel good. They are a natural analgesic, or painkiller. Endorphins work by gathering in the space between neurons, preventing negative impulses from traveling to the brain. Since endorphins act on the opiate receptors in our brains, they can reduce pain and boost pleasure, resulting in a feeling of wellbeing without the complication of addictions. Endorphins motivated in body movement have been proven to reduce the "sadness." They can be especially useful in boosting self-esteem.

Secondly, endorphins can regulate appetite along with reducing weight.

So just what do we HSPers do to acquire the promising effects of endorphins? Twenty to thirty minutes of upper body movement can release the positive consequences of endorphins into your system. It could be as simple as a seated boxing or a seated aerobic workout similar to the one produced by disabled Olympic skater, Lisa Ericson, found on YouTube: "Lisa Ericson's Seated Aerobic Workout." My routine started out with 5-10 minutes a day,

increasing every week by five more minutes daily until twenty to thirty minutes was doable.

Looking for other avenues, someone had placed an article at my desk about a local mayor whose two young daughters were disabled. That particular mayor had three-wheel hand pedaled bikes placed in local parks. My husband read it, googled the park and within minutes we were driving off to the park.

Quite unsure whether I wanted to showcase my inability to people in the park, I started reading and trying to access the app on my phone to rent the bike. We finally loosened the bike from the rack and I transferred from my wheelchair to the bike which was surprisingly easier than I expected. As coordination set in, my body immediately recalled

the bike rides from my "previous life." There was a moment of remembering "freedom," pure physical freedom. The fabulous feel of the wind through my hair was observed by my husband who later told me, "I will never forget the ear-to-ear smile on your face." Almost giving him more exhilaration than I got, cementing in his mind the intent to purchase an adult hand trike. And life has never been the same.

## FREEDOM FROM THE THIEF

We looked at two companies; Invacare Top-End Hand Cycle with three speeds. These bikes offer stability, transferring in and out is easier with its low to the ground frame design. The hand-braking is confident. And it has an easy take apart design for transporting and fitting into your vehicle.

The trike I chose was from Sun Bicycles and they distribute through retail bike shops which is great for any mechanical assistance you may need in the future (<http://www.sun.bike/trikes/adult-hand-trike/>). Seats and pedal levels are all adjustable for your ease and comfort. I like the front parking brake for easy transfers in and out of my wheelchair. Trikes are powered by the forward circling of your arms and hands, while your feet remain stationary. Due to the reliance on upper body strength, this has given me increased muscle power.

Our slogan now is, "this is how we roll." Many new avenues of travel have opened up. So many bike paths to discover. We may have to move to a year-round sunny state:). We went from a casual daily ride to a daily ride of 3 to 4 miles. If you take someone with you, they can easily bike or walk alongside you.

The hand-pedaled trikes are a great way to throw the HSP thief behind bars.

Doing all you can to send endorphins through your system clears the mind, strengthens the heart and frees the soul. And the exhilaration of moving yourself at a new sweet speed produces a new "strut." And you find yourself interacting boldly with other bikers and "trikers."

I am thankful for prayers answered and I encourage you to commit to giving yourself renewed energy and a windblown smile.



*Susan with trike*

## Gardening with PLS

By Alan "Skip" Jorgensen

In the fifth year with a diagnosis of PLS, as a 71-year old, my life has been enriched by activities that physically and emotionally give a boost to coping with a limiting condition.



*"4-Wheel Drive" Walker*

First is maintaining mobility. This is what works for me-today, meaning those with PLS know of the progressive but sporadic physical changes. Two walkers are used, one for indoors and the other referred to as the "four-wheel drive" for use in comment, "I like your sticks."

**"THERE IS ALWAYS SOMETHING TO LOOK FORWARD TO-AND YOU JUST KEEP GOING!"**

Next are the walking sticks, fashioned from limbs salvaged by a friend at the beach, cured, shaped and used for short distances such as going in a store, a brother's home or to church. Two sticks are necessary for balance and are

currently used for up to 30-40 yards. Having hand-crafted these aids they are unusual, finished with a shine, and often get the comment, "I like your sticks."

Then for longer distances, one-mile round trips to town, getting around a mall or viewing a football game from the sidelines, my "True" GRIT Freedom Chair (<https://try.gogrit.us/grit-freedom-chair>) is just that, offering the freedom to access public places most anywhere a wheelchair can travel. I enjoy park trails, paved or dirt, and can "hike" with friends. Similar to a wheelchair it is operated by two hand levers connected by a sprocket and chain to 26" wheels. A battery powered chair may be in the future but for now aerobic the yard and garden. It has larger tires, a basket under the seat and can carry outdoor garden equipment. It has to be tough as it gets dirty and roughly abused.



*Walking "Sticks"*

The yard, however, needed to be put in shape. Having done this in the past and being stubborn about it, why couldn't we do it again? We could, with help from nephew Cayden, and of course the "we" is my wife, Connie.





*"True" GRIT Freedom Chair*

A second coping mechanism is taking advantage of summer days to get outside for work in the yard. We were fortunate to have moved into a home with many conveniences for a person with PLS.

The "four-wheel drive" walker is the workhorse here. Soil has been moved, irrigation trenches dug, sprinklers installed, yard contoured, and grass planted. This work is possible from the seat of the walker with the help of sharp tools and timing to dig when the soil is moist. A basket carries seeds, fertilizer and small tools. Areas are designed so that the walker is on a path allowing an ability to reach garden beds. I do make many strenuous moves to the ground and back on my feet; it's just part of the deal though knee pads add comfort.

A garden? Yes, though reluctantly. While waiting to plant the back lawn this Fall, it was decided to plant potatoes in the Spring to help condition the soil. Not having a garden for several years, the bug bit and now there are onions, green beans, cabbage, cauliflower, carrots, lettuce, cucumbers, pumpkins, rhubarb, artichoke and an assortment of flowers. A few gophers enjoyed the bounty, until running into a trap! Excess harvest is given to family, friends and neighbors.

We get out each day and enjoy the constant changes of flourishing vegetables and blooming flowers as well as appreciating our work from the bedroom window or patio. Particularly in this period of COVID-19, our garden is an attractive distraction.



*Working from the  
"4-Wheel Drive" Walker*



*Crawling thru the garden*



*Garden Gift for a  
Neighbor*

Who knows what the next season will bring, let alone the next year, as the progression of PLS remains a mystery? For now, these mobility aids and yard activities keep me encouraged and engaged with a positive effect on physical health and emotional well-being. There is always something to look forward to-and you just keep going!

# Heels Are a Girl's Best Friend

By Veronica LaPort, SP

The most important thing I have learned in my 20 years is that heels are a girl's best friend.

With Spastic Paraplegia I have an awkward gait. I walk with my heels in the air and my toes dragging on the floor. This awkward gait makes it very hard to keep shoes in good condition as I wear out the toe-end of the soles. Shoes that have too much traction will prevent my feet from dragging and cause me to trip, causing me to scuff up my shoes further. I usually by-pass this by wearing flat shoes that have ankle straps or laces (with no bumps or any patterns on the soles) with a thick rubber or steel toe. However, I found that with steel-toed shoes, it is nearly impossible to wear the metal out, but you can wear out the rubber underneath, making a triphazard. I had to be careful with the steel-toed shoes, even though the ones I had were very stylish.

The strap around the ankle is also critical as my heel will pop out of any shoe I wear that doesn't have something tying down my feet. That leaves the flat, thick-toed shoes, although they are not the best economical choice as they can be expensive and don't last very long.

But there is another option, heels. I have found that heels work best for me in terms of stability, as even with the flat shoes described above, I still need a cane for balance. However, with heels (about 2 to 3 inches), I can have stability and,

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sometimes, I don't even need the cane. As the heels support my heel while I'm walking and I can walk down the sidewalk without depending on an aid (I still take the cane with me just in case). I have found that I can walk up and down stairs (my worst enemy, especially the carpeted ones) better in heels, even four-inch ones.

Although heels are my most ideal method of covering my feet, they aren't the easiest option to find. I have to have a particular design; they have to have a strap around my ankle and cover my toes. If there isn't a strap around my ankles, the shoe will come flying off my feet. If the shoes don't cover my toes, I will run the risk of injuring them while I drag my feet. Granted I don't drag my feet as much in heels as I do the rest of the time, there is still the risk of injuring unprotected toes. Although they can still wear out quickly and my specifications are hard to find, I find heels to be the best fit for my gait.

As with all things in life, no one solution is perfect. Heels bring with them all the issues they have for even people without spastic paraplegia. One problem is the stress put on your ankles. Another pitfall is that heels are best for city living and do not function nearly as well when walking in the woods. The ground you're walking on factors in as well, for heels would be ideal for long walks on the sidewalk, but not really in the more rural areas or for long walks between classes in the snow.

Given the right environment, I will always choose my heels. For more formal events and going out to dinner, heels are my go-to shoes. They provide me with a little bit of freedom as I don't have to hold on to someone's arm while walking, and I don't need to rely so heavily on the cane. And that little bit of freedom is everything to me, and why my heels are my best friend.

### **QR Code for Ease of Donations!**

Using your smart-phone, scan this quick response (QR) code as a convenient tool for submitting donations to the Spastic Paraplegia Foundation. Scan it with your smartphone and a QR reader app and it will go straight to our donate page. Your contribution allows for medical research of Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS), together we are #hspandpls.



# Your Scooter/Wheelchair As the Driver's Seat

By Malin Dollinger, M.D., HSP SPG4

With my new handicap van, I can drive my handicap scooter or wheelchair directly into the driving position since it has an empty space instead of a driver's seat. It also has the usual collapsible ramp to get in and out of the van. As with all side-entry handicap vans, the middle row of seats is removed to make room for scooter or wheelchair entry.

I drive my van from my scooter, which is locked in place by a device on the floor that matches a large metal pin under the scooter. This saves me from having to transfer in and out of the driver's seat from my scooter which would have been parked in the empty space behind the driver's seat. Those transfers were very difficult and painful for me, since I have HSP-related paraplegia and also torn cartilages in both shoulders.

After I bought the van, it took me six months to finally get everything working right, and it works perfectly. It seemed easy and logical at first, but then I discovered that no one, including the experienced dealer, knew "how to do it right." I've just completed a long trial and error period, to finally figure it out. If you have unlimited patience, some extra funds, an important

need to limit transfers, and a friend-me-to tell you how to adapt the van and the scooter, and want to give it a go, please notify me. New seatless vans are expensive, but used ones can be bought for about half the price, or less. The photos with this article show you the details.



*QLK-150 and front lock mounted on raised floor*

The van is sold without a driver's seat. Your scooter becomes the driver's seat. Only a very few scooters have the required floor clearance and the seat-raiser to be usable (so you can see out the front window to drive). I



know which scooters work and how to adapt them. Do not buy the scooter the dealer wants to sell you without first talking to me. Or ask me about the scooter you already have. I know how to install a seat lift for \$25, if the scooter does not already have one. You need to be sure this kind of van will work for you, before you buy it.

The locking device: is on the floor, requires two extra items on your scooter for the two interlocks on the floor. One is a bolt/rod underneath the scooter, pointing down, and the other is a metal fork in the front of the scooter, which meshes with an interlock on the car floor. Clearance is everything; both items must mesh perfectly in order to lock the scooter in place which then allows you to safely drive the car. I will tell you how to make this work. I will also explain how to modify the floor of the car, so it is smooth and doesn't disrupt the scooter wheels and mess up the locking maneuver.

What about servicing the van: dead battery, bad tires, someone else needs to drive the van? You also get the real driver's seat with the van, but the seat is on rollers and is portable. You keep it in the back of your garage, "just in case."

What about the "handicap emergency?" Someone has parked in the blue-striped no-parking handicap access lane next to your van. There's no way you can extend the ramp because that car is in the way. The old solution with a van that has a driver's seat is to have a regular driver back up your van about eight feet so the ramp can now be extended clear of the adjacent "blocking" car, long enough for you to extend the ramp, drive your scooter or wheelchair into the van, transfer to the driver's seat, retract the ramp and drive away.

Now with no driver's seat, except the scooter on which you are sitting outside the van, no one else can back up the van to allow ramp extension and entry. There is nowhere for the driver to sit, even briefly. A person standing in the driver area cannot work the pedals, and you dare not let them try using your hand controls. I keep a folding chair in the back of the van so a "back-up" driver can sit in a chair and reach the pedals to safely operate the van to back it up a short distance. The brake and gas pedals are now painted white, so the driver in the chair can easily see them, especially at night.

I know about several things that must be considered, such as getting a van with a ramp that can be extended part-way, in case you have limited total

room next to the van (between the ramp length and the turning radius, you need about eight feet). I have five feet where I park next to my home and I learned how to extend the in-floor ramp halfway out. In this "limited extension" ramp situation, you cannot use a folding ramp, which cannot be extended partway. You need a retractable in-floor ramp.

To place the van so you can see properly out the front window, you need either a scooter with a lift or a custom raised floor. There are tricks for how to "aim" the scooter so it meshes with the interlocking pins on the first try (not the third or seventh). I've made all the mistakes and trials and errors so you won't have to. If you'd like to pursue this project, email me at [malind@cox.net](mailto:malind@cox.net) or call at 310 378 4059.

## **We Flow**

**rolling in this wheelchair  
chugging down the street,  
wishing I could use my feet,  
trying to feel complete and  
capable of being independent  
without eyes and minds seeing  
discretely going with my children  
enjoying a Sunday stroll, we flow**

***james kenneth blaylock***

**3-16-20**

## **FLASHBACK**

Flashback is a new section of Synapse, The Newsletter of the Spastic Paraplegia Foundation, Inc. The following article is reprinted from the August

2001 issue of Synapse which at that time, had been "Serving the Primary Lateral Sclerosis Community since 1997."

## What is HSP and why am I writing about it?

By Mark Weber

In this issue you'll notice that I combined news about PLS and HSP (hereditary spastic paraplegia).

You may wonder why.

PLS and HSP share a number of similarities.

Some PLSers have symptoms only from the waist down. (Ok-they may have minor arm/ hand involvement, but nothing significant.) If they had a family history of similar symptoms they would be diagnosed with HSP. But without a family history, some neurologists would diagnose them with PLS. Others would still call it HSP or "apparently sporadic HSP".

Some PLSers experience those symptoms and also have speech problems, or symptoms in all four limbs, or both. If they have no family history of similar symptoms, they have PLS. But if they have a family history, they have HSP.

So far, no one knows whether any version of HSP shares the same cause as a corresponding form of PLS. But if you attend a meeting with HSPers, they appear indistinguishable from PLSers. We share the same gait problems. Some HSPers also have the same speech problems as some PLSers. The difference appears when you ask an HSPer about his/her family. That's when you'll hear about the symptoms experienced by their children, parents and grandparents.

Serious scientific progress has been made on HSP. At least five separate genes have been discovered that are responsible for various forms of HSP. (See the previous article about the "atlastin" gene discovered recently by John Fink, M.D., of the University of Michigan.) And at least ten HSP gene loci have also been discovered.

Further, the ALS2 gene discovered by Dr. Teepu Siddique (Northwestern University) that causes juvenile-onset PLS is theorized to encode for the same class of protein as the protein encoded by the "atlastin" HSP gene discovered by Dr. Fink.

Why does this matter?

A group of PLSers and HSPers are currently creating a foundation to fund medical research and education on PLS and HSP. Dr. Fink is very active in helping to create the foundation and is committed to including PLSers along with HSPers in the group.

Also, some meetings known only to PLSers or HSPers will now be known and open to both groups.

I have great hopes for this new collaboration between HSPers and PLSers. Anyone interested in volunteering to work for the new foundation is urged to contact Mark Weber or Kathi Geisler.

Together, we will find the cure.

[2001 contact information for Mark and Kathi has been deleted. The entire Autumn 2001 issue of Synapse is available on the SPF website, (<http://sp-foundation.org/news-resources/newsletter.html>)



## Have Something to Write About?

Synapse began as a PLS newsletter in June 1997 for people living mainly in New England and the mid-Atlantic states who had been diagnosed with PLS. The newsletter added the Spastic Paraplegia Foundation in 2003 after the SPF was incorporated in 2002. Synapse, became the SPF's official quarterly publication in January 2008.

Issues of Synapse contain articles on medical and research topics; articles about how people cope with or have overcome a symptom of their HSP or PLS that had affected their quality of life; human interest stories; stories about



children who excel in spite of having HSP; fundraisers; new mobility aids, daily living aids, and homemade gadgets that make life easier.

My goal is to prepare four 20-page issues each year, Winter, Spring, Summer and Fall. The Spring issue was just 16 pages because I did not have enough content for 20-page issues.

Nearly all of the content in Synapse is written by members of the Foundation, just like you. If you have something related to HSP or PLS that you would like to share with the SPF community, send it, with pictures if you have them, to John Staehle, Senior Editor, at ([jstaehle@swbell.net](mailto:jstaehle@swbell.net)).

August 23-29, 2020 was the #HSPandPLS Awareness Week SPF Challenge. To celebrate Awareness week, each of us was challenged to post, tag and share a photo in the #HSPandPLS, #SPFAwarenessWeek or #SpasticAwareness Facebook group of what you did each day to spread awareness of our diseases. The editorial staff will select a variety of the postings for the Fall Synapse.

Back issues of Synapse, from the Fall 2000 issue to the most recent issue, are posted on the SPF website, (<http://www.sp-foundation.org/>). Click on

Resources from the left menu and then Synapse Newsletter from the sub-menu.

## HOW TO HELP

We operate out of the strength of our community, caring friends and sponsors. Your help makes a difference!

Please contact us at ([volunteer@sp-foundation.org](mailto:volunteer@sp-foundation.org)) to help in one of the areas below or to suggest another way you can get involved.

## SUPPORT RESEARCH TO SPEED OUR CURES BY VOLUNTEERING

Below you'll find information on some of the ways you can help SP Foundation in their search for a cure to PLS and HSP.

Raise Funds: The primary focus of SPF is to raise funds to support research to find the causes, treatments and cures for Hereditary Spastic Paraplegia and Primary Lateral Sclerosis. Our major fundraising activity consists of a Team Walk. Individuals can help organize local fundraisers. People are also needed to secure corporate sponsorships and help with grant applications.

**Patient Connection Programs:** Organizing a Connections gathering for people to meet, share stories and help one another is a great service. Events can be as simple as meeting for coffee! In areas with large patient populations, SPF seeks to establish Chapters.

**Conference Organizers:** SPF's conference coordinator gladly welcomes planning and organizing assistance from SPF members living in or near the metropolitan areas selected for annual conferences. These events feature speakers and programs on special topics of interest to our community as well as provide the opportunities for individuals to meet others. Conferences can be half-day or full-day events.

**Communications:** Individuals with writing, research, website or graphic design skills are needed to assist with various communication initiatives.

**Ambassadors:** Ambassadors raise awareness about our disorders as well as enhance community building and industry relationships. You can assist with media relations, share your story, speak at local groups or help with grassroots advocacy.

**Business and Administrative Support:** Volunteers with business and administrative skills can play a valuable role in administering the work

of the SPF. Most of the help is coordinated through email correspondence and uses popular Office applications.



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Awareness Week: Virtual 5K Run, Walk, or Roll