

SYNAPSE

The Newsletter of The Spastic Paraplegia Foundation Inc.

Volume 23, Issue 4

WINTER 2021

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Letter from the President



Frank Davis

Dear Friend,

I hope you agree that the Holiday Season is a favorite time of the year. I think it is for me because of the joyous holiday spirit that seems to be a part

of so many traditions and events. Frankly, I don't know why it is called the "Holiday" Season because it is usually the busiest time of the year for most businesses. With your help, it hopefully will be a very busy time for our Spastic Paraplegia Foundation, as well.

We are very fortunate that, again this year, our anonymous donor is matching every donation up to \$200,000 received by The Spastic Paraplegia Foundation between November 14, 2020 and January 15, 2021. That's right, you will enjoy double the satisfaction from your thoughtful generosity, knowing that you are bringing new hope to twice as many people with HSP and PLS. If you would like to get in early, he or she is matching all donations that are made on a monthly or quarterly basis, so every monthly or quarterly donation anytime will be doubled. Many people are discovering the convenience of a monthly giving plan so please don't hesitate to be a part of our increasing numbers of monthly donors. Just click on the "Donate Now" button on our website

to find out more about monthly and quarterly giving. Additionally, you can write "match" on the lower left front corner of your check and we will make sure it is matched.

For those of you who donated on Giving Tuesday, THANK YOU! Because of you, The Spastic Paraplegia Foundation raised over \$45,000 to get us even closer to the day when a cure is discovered to end the pain and suffering of people with HSP and PLS. Giving Tuesday is the first Tuesday after Thanksgiving. It comes right after the shopping spree of Cyber Monday and reminds us that giving and unselfishness are a huge part of the true holiday spirit. It is a time when we realize that we have so much to be grateful for; a time when we can assess our year-end financial situation and let giving and altruism be a big part of our holiday spirit.

For all of you who donate during the "match season" of November 14, 2020 through January 15, 2021, your tax-deductible gift will be multiplied in other ways, too. First, The Spastic Paraplegia Foundation is an 18-year old, well respected, patient advocacy organization that carefully scrutinizes how we spend your research dollars. Our Scientific Advisory Board of world renowned neurological experts compassionately donate their time and expertise to rank the many

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SYNAPSE

Volume 23, Issue 4 – Winter 2021

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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outstanding research proposals we receive. Only the top ranked "Excellent and Very Promising" (EVP) proposals are funded, seeking to get the most bang for your dollars.

Second, when the US National Institutes of Health (NIH) sees that we have sponsored a researcher, it is like they have been given a five-star recommendation from an Ultra Expert Medical Rating Agency with a huge personal stake in the game. The NIH is then much more likely to sponsor them in ways that often more than quadruples what we have contributed.

Third, all of the people that put in countless hours working for The Spastic Paraplegia Foundation are volunteers. That's right, they don't cost you a dime. We have a first-rate attorney and a CPA working pro-bono. We also have a professional writer, a PhD in genetics, a retired judge plus many more well educated, experienced volunteers - all donating their time and talents so your donation can work even harder for what you believe in - finding a cure or treatment for HSP and PLS.

In the Annual Report you received last July, I listed thirteen pages of just some of the many scientific breakthroughs your past generous donations have achieved. The progress is so fruitful, it should make you proud - because none of this would be possible without you and your generous support. Thank you! During the last year, scientific discoveries concerning PLS and HSP were being announced every three days. That's right - twice weekly! The pace is very exciting, keeps us on the edge of our seats and it demands to be paid for. We are getting ever closer to the day when the focus will change from finding the cause of these disorders to having real life ways that your friends and loved ones with HSP and PLS can be free of pain and stiffness and actually WALK NORMALLY!

Every year, as the science gets ever stronger and the pieces are falling even further into place, we receive more and more research proposals that our expert Scientific Advisory Board objectively rate as "Excellent and Very Promising" (EVP). I know, like me, you must feel disheartened that we can't afford to support all of the EVP ranked research. Scientists we cannot afford to support are forced to find another disease to work on and cure.

Think of what could happen if we could fund

more of these premier EVP research projects? What doors could we open? How much suffering could we stop?

Every gift counts. Your donation of just the cost of ordering a pizza dinner - \$25 - will be doubled to \$50. \$250 will be doubled to \$500, \$500 to \$1,000 and \$10,000 to \$20,000. I challenge you to use every nickel of this match! Our anonymous donor is asking you to stretch your gift this year. What power for good this gives you! You truly will make a difference!

There has never been a better time, but time is of the essence. Our anonymous donor has understandably set a deadline of January 15, 2021.

I can't thank you enough for your generosity. We can't do it without you!

Please send your tax-deductible gift today!

Sincerely,

Frank

Frank Davis,

President, Spastic Paraplegia Foundation

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.



Print Too Small to Read?

By John Staehle, HSP, Senior Editor Synapse

Is the print size in this issue too small for you to easily read? Do you need a magnifying glass to read your printed issue of *Synapse*?

Since the Winter 2020 issue, there has been a large print issue of *Synapse* available online that can be read online or downloaded to your PC, laptop or tablet as a PDF file. SPF member Katie Robinson volunteered to use her skills to create large-print versions of a variety of publications to create the large-print version of *Synapse*. Read more about Katie by reading her article on page 9 of the Winter 2020 issue, "Party of More Than One."

Links to the large-print versions of 2020 Winter, Spring and Summer issues of *Synapse* appear directly below the descriptions of the issues' contents (see Winter 2020 text graphic below).

Winter 2020

President's Letter, Thanks for the Privilege, A New Look for Synapse, Annual Conference 2020: Registration Form, Conference Graphic, General Interest: Resilience Matters Part Two, First Brazilian Symposium, Party for More Than One, Staying Active with HSP, Importance of a Strong Support Network, This is Not All About Me, My Long Search for a Diagnosis, Still Searching for a Diagnosis, Becoming an SPF Ambassador, The Lab Rat Chase, Problems with your Bladder, Bridge to Sleep, Winter Walking Aids, Shirts with Magnetic Buttons, Fundraisers: Annual SPF Fundraiser in Mount Kisco, NY, The Rosella Vigliotta Golf Tournament, Connections Around the Country, Dropping by Hugh Fenlon, Time by Kathleen Klenlen, QR Code for Ease of Donations.

[Click Here for New Synapse Winter 2020 Large Print](#)

If you use the large-print version and like it, or not, send Katie an email at klr16333@gmail.com and tell her what you like or dislike about the large-print version of *Synapse*.

My advice to you is download a copy and do not print out the large-print version. The regular printed copy of the Winter 2020 issue is 20 pages long. The large print version is 80 pages long!

GENERAL INTEREST

A Chance Encounter...

By Mark Patinkin, Journal Columnist

Posted Jun 11, 2020 at 4:27 PM

Updated Jun 11, 2020 at 8:58 PM

It was an unusual sight – an older man in an exercise wheelchair pumping forward with two hand-cranks along Providence's [RI] Blackstone Boulevard.

He was working his way up a slight hill on a hot day. He wore a T-shirt, shorts and cap. Because of passing cars, he'd put an orange flag on a rod above the back of his chair.

I pulled over to ask if we might chat, explaining I write for the newspaper.

He gestured toward his mouth in a way that made it clear he was unable to talk. Then he lifted a phone hanging from his neck by a strap and began to type a message.



Kenny in the shade in his freedom chair

A few seconds later, he showed me the screen.

"My name is Kenneth Hersch," the note said. "I have a speech deficit but can hear you just fine."

To get away from the traffic, he pumped the chair onto nearby grass.

I thanked him for giving me a few minutes, calling him "Kenneth."

He typed an answer: "I go by Kenny."

That's how our conversations went – me talking, and Kenny typing.

He said he is 66.

Using the index finger of his left hand, he typed some more.

"Ask anything you like," he said. "I'm not shy."

So I did – wondering about his condition.

"A very rare neurological disease called Primary Lateral Sclerosis," he typed.

How long had he had it?

He flashed his left fingers three times: 15 years.

He lives nearby on the East Side and used to run three or more miles along the boulevard. Now he covers the same ground in the chair.

He typed that he can use a walker, but the chair allows exercise. It bore the name "Freedom

Chair” on a steel pole leading to a front tracking tire.

Kenny nodded toward a blinker behind him.

“The lights,” he typed, “are so I don’t become roadkill.”

I told him he was a funny guy. It brought a laugh, and Kenny typed again:

“My mantra is accommodation without surrender.”

I asked him what his job used to be.

“I still work,” he typed, “and drive, and cause as much trouble as I can.”

I apologized for assuming he couldn’t have a career.

It got a smile as he typed his response: “I’m pretty hard to offend.”

He added: “I see the best in people. Just my nature.”

We were on Blackstone Boulevard’s central greenbelt. Joggers and walkers went by. The sun lit up the running path.

He typed that he and his wife own a shop called the American Wallpaper and Design Center in Fall River.

So he has a wife?

He nodded.

“The best,” he typed. “We have three adult kids and 10 grandkids.”

I might have been impatient if a stranger flagged me down while exercising but Kenny was happy to keep talking.

I asked how the illness started.

He typed that it began with mild neuro problems and took two years to diagnose. At first, doctors thought it was ALS.

“That sent us into a tailspin,” Kenny typed.

It turned out to be Primary Lateral Sclerosis, which is in the same family but not fatal.

“It affects mobility and speech,” typed Kenny.

He spent the next minute composing a message, then held it up.

“I went from clumsy walking to a cane to trekking poles to my walker over 15 years,” he said. “The speech went from slightly slurred to barely intelligible to the present.”

Using that index finger, he added one more thought: “Cognitive function is normal despite what my kids say.”

I asked how he had such a good attitude.

“I’m still the same me,” he typed, “and I choose not to hide under the covers. I just enjoy every day.”

His wife, he said, has taken on more household work, but Kenny does what he can.

“I’m in charge of laundry and kitchen cleaning,” he typed.

He can still do that?

A smile and nod.

I asked about the prognosis.

“The symptoms progress at a glacial pace,” typed Kenny. “But death can come as a result of food aspiration or falls. I have had some nasty falls.”

But he feels there’s a good chance he’ll live until elderly years.

It was warm out, with a pleasant breeze. The two of us were under a large oak that cast dappled

**“I’M STILL THE SAME ME, AND I
CHOOSE NOT TO HIDE UNDER THE
COVERS.”**

shade on the grass. Runners occasionally glanced our way.

I asked Kenny if he ever felt pangs for what he’s lost.

He nodded.

“I do,” he typed. “The hardest part is the speech difficulties as I am a big talker, if you haven’t figured that out yet.”

He also wishes he could do more with his grandkids. Then again, they’ve always known him “in this incantation of me.”

His family, he said, is a blessing.

“I really don’t dwell on what I can’t do,” he typed, “but what I can.”

Looking up from his Freedom Chair, he said he mostly feels lucky.

Then it was time for him to get going.

I watched as he took off down the boulevard, thinking to myself how much there is to learn from those we usually just drive past.

[Reprinted with Mark Patinkin’s permission.]

PLS and My Travel Bug

By David Buseck, PLS

Exploring new places has always been one of my favorite leisure activities, but my travel is looking different since I was diagnosed with PLS in April 2019.

My travel bug started with family camping trips around the Western United States. It grew while traveling around Europe with my parents when we lived in England during second grade. Since then I've traveled for business and pleasure across the U.S. and around the world. I have often traveled alone but love it when my wife Linda is exploring with me.

When I'm in a new place, I've always enjoyed walking freely to experience it more intimately than I can from a vehicle. I love to wander in ever-widening circles from where I am staying, or to set a goal—like finding a vegetarian restaurant or an offbeat attraction—and to find my way there on foot as part of the adventure. I also love walking in nature, from climbing Mt. Snowdon in Wales when I was eight to traipsing through the Panamanian jungle on a business trip in my 30s, to hiking up to a guest hut in the New Hampshire mountains in my 50s.

At this point the pandemic has slowed down my travel far more than PLS. But my experiences at home show me that my travel will have to change when I can be on the road again. My walking range has shrunk so much I will have to plan ahead instead of taking off to explore a city or hitting the trail without thinking about it. I'm now down to a maximum of 4 miles—on my best day—with two walking sticks, a slower pace and a rest stop every 30 minutes. This forces me to think, more than I want to, about how to use my walking time more pleurably.

I want to keep walking in new places for as long as possible, so I pay attention to how my leg tires and how that affects other parts of my body. I use walking sticks or a cane when I know I'll be walking for more than a mile, walking fast, dealing with rough terrain or doing lots of standing. As a side benefit, the cane is a signal for kind people to give me a seat so I can get the rest I need between activities. I will also have to plan my downtime creatively after an active day so I don't just spend the time sitting in a hotel room.

My wife will be a good partner in this, as she has been during my PLS journey so far. She challenges me to do things when I'm hesitating,

and helps me figure out adaptations to make them possible. She also tempers my sometimes-misplaced enthusiasm and gently helps me think about slowing down. She will need to adapt her own expectations and behaviors as well. Fortunately, she is comfortable exploring on her own, so she can still have fun on days when I need to rest.

My range will steadily diminish as the disease progresses, so managing our travels will be an evolving project for both of us. But my situation also brings a certain sweetness to visiting new places since I know that there may be a time when I choose to stay home instead of dealing with mobility issues on the road. In any case, I look forward to many more years of explorations in new parts of the U.S. and the world, but with evolving knowledge of emerging limitations and creative adaptations as I go.



A Crushing Moment of Fear

By Linda Levine, with growing awareness of the implications of David's diagnosis

David lifts his leg with his hand as he enters the passenger seat of my car.
I wince.

Yet another sign of this sickening reality.

Every day there are new, or new to me, surprises like this.

Evidence that the disease is winning.

I feel punched in the stomach.

I hear wolves howling in my head and clawing at the door.

I am ambushed in a dark alley but wait... it's a sunny day in the suburbs!

I am crushed as the scaffolding of the future collapses around us.

Breathe in. Breathe out. Repeat.

Trying to breathe my fears away.

I roll my shoulders, begging the tension to release.

Stretching my neck, I look to the left.

I look to my right...

Startled!

Sweet David is smiling my way,

Patiently waiting for me to start the car.

His eyes catch mine and twinkle.

"Where shall we go for dinner?" he asks.

Blessed Beyond Measure

By Laura Stephenson, Caregiver for Robin Grossbier, HSP

Being a caregiver is rewarding. Now I know that some of you will agree with that statement and others will have found themselves thrown into that position and at this moment don't find it rewarding. Some of you found yourself gradually assuming this role and for others it arrived with little notice.

There is no doubt that the life of a caregiver can be challenging and many times it borders on exhaustion. You may have never expected to find yourself taking care of the lawn and making sure the car was in running order or perhaps you are the one now doing the laundry, grocery shopping and cooking. You didn't know you would need a medical degree to understand all the words now in your vocabulary such as motor neurons and the difference between SPG 4 and all the other gene mutations. Also, you have a new role as advocate for someone with a disability. The list of new challenges continues to grow with each passing year, but none of these are really at the heart of being a caregiver.

I would like to challenge you to think about what being a caregiver really means. Some of you may be thinking I didn't sign up for this job. All I can say is that the person for whom you are providing care didn't sign up for this either. They dislike having to depend on others for assistance and grieve their loss of freedom with each level of loss.

For the past 30 years God has given me the privilege of walking (she now wheels) with my friend Robin on this journey called HSP. I have seen her go from cane to walker to wheelchair and with each step give up more of her freedom. I have learned that there is a grieving process that takes place with each loss and that I need to be there to comfort and encourage at the same time.

Over the years I have learned that caregiving is much more than just meeting a person's needs. Here are some of the important things I have learned about the subject:

- Think ahead of what the person you are caring for might not be able to do as the disease progresses and try to do it now. When Robin realized she was losing her mobility she mentioned how she had wanted to go to Disneyland. Well, we went to Disneyland while she was still walking and made a lifetime

of memories for when she couldn't walk.

- Anticipate a need before someone has to ask for assistance. Try putting yourself in their place and ask "what would help me?"
- Find ways to assist while leaving the person's self-esteem and independence intact.
- Whenever possible, let them be independent. Look for things they can do, not what they can't do.
- Understand that life for the HSP person continues to change and so does yours. Your attitude can make this easier or more difficult for that person.
- Find things to laugh about each day. There is a wonderful world waiting, help them see and enjoy it. Help them to learn to laugh at themselves but also learn to laugh at yourself. You can always try driving their power chair! I took out a door once in Robin's chair.
- Did you know you can travel to anywhere in the world from your own living room? Travel there via your cable channel or DVD. Cook or order in a meal from that culture. Now sit back and let your travels begin.
- Bring joy into their lives and yours will be full of joy as well.

The Amish believe that it is a blessing from God to be able to take care of someone with special needs. After all these years, I can assure you that the caregiver is the one who is blessed beyond measure.

My Journey with Hereditary Spastic Paraparesis/Paraplegia

By Mike Cain, HSP SPG7

Currently age 73, I first became inconvenienced at age 58, though others had seen changes but said nothing. I have no signs except a funny walk, which people thought was because I was drunk! The taxi driver's face changed as I walked from the pub and spoke to him!

In order to get my diagnosis, I experienced the usual odyssey. We knew something was wrong but didn't know what. I went to several different consultants and eventually got to a neurologist and had several tests. When I got confirmation of HSP, I cried for all of ten minutes - until the doctor said I might as well find my own cure.

I live in the United Kingdom (UK) and our health system locally gives me access to a gym and,

Continued on next page

about once a month, to neurophysiotherapy. I learned remedial massage, and have a friend who is a physio [physical therapist] who volunteers to give me a massage of my feet and legs every week.

The route of massage and neurophysiotherapy has worked well for me. I read about several ancient “meridians” [(in acupuncture and Chinese medicine) a set of pathways in the body along which vital energy is said to flow. Source: Oxford Languages] and nerves, and learned how some muscles take over the work of others.

I was speaking with another neurologist who specialised in HSP and I got myself referred to him. I now have two neurologists, one at an HSP specialist centre and the other locally. I see them both six months apart. I am glad to say that the Queen of England visited the specialist lab and awarded it her prize.

Research and knowledge regarding HSP has grown, yet there is a lot we don't know - which is why we need to share knowledge across the world. As people have spoken together about HSP it has become obvious to me that:

1. Nobody is the sole person living with HSP. Joining with others and sharing our experiences is important.
2. Finding an appropriate HSP group can be challenging since “HSP” has different meanings in different contexts (e.g., HSP can stand for “Henoch-Schonlein purpura” which is an inflammatory disease). Spelling out “SPASTIC” or “Hereditary Spastic Paraparesis/ Paraplegia” when searching online is a great aid to finding a suitable group.
3. Any group/research cohort needs to be representative of the HSP population. The HSP population in any area might have a prevalence of a particular gene/variation and any resulting research might only apply to them or similar groups.
4. Patients need to be closely involved with research and research design priorities.
5. There are many views on the way to find a cure; even the most “off the wall” idea deserves to be heard.
6. We need to be aware of scammers. If someone offers a miracle cure for HSP (if you pay them loads of money!), that's a clue to be suspicious or sceptical. It is unusual to have a “cure” that no other person has tried.

I've learned that what is most different is the

way different communities treat HSP symptoms, or come forward with questions. However, we all have similar general living issues. A stick (cane) helps to show others that something is wrong (we're not walking drunk!) But then pride stops some from using the aids that make life easier - walkers, shoppers, wheelchairs. Sometimes it is easier for us and others if we use these aids. It might prompt people at work to think of the future when they might no longer be able to do their job. It might remind some partners that we are “pulling our weight.” There are parents who see those with HSP and imagine their own children having this disease. Being a parent is hard, more so if your child needs extra help.

I have been fortunate to get about the UK to the Houses of Parliament, a Royal College in Edinburgh, a concert hall in Manchester and other places, and I am glad that some ears there listened. HSP needs to be better known among the medical professions and they need to know where they can obtain help and information for their patients. For people with HSP, it is important that they don't feel isolated and know where to link for help and information. The Spastic Paraplegia Foundation is a welcomed resource.



A Long Walk to Non-Freedom

By Keith Gurney, PLS

I used to be a marathon runner.

In South Africa there's everything from half-marathons to the bucket-list Comrades Marathon of 90km, Durban to Pietermaritzburg.

In 2008, while training for the next one, my right foot started dragging.

After consulting a neurologist, I was submitted to a major hospital for tests to establish the cause. The test team, headed by my neurologist, carried out a battery of tests over three days. It could have been a very frightening experience. But I placed my mind in neutral, as differential diagnoses were done to test for a very scary list of things like a tumour on the brain or spine and the big daddy ALS.

Nothing was found, except a small upper vertebra bone spur pressing on my spinal cord. In the apparent absence of any other cause of my foot dragging, it was concluded that this had to be the reason.

Neurosurgery removed the bone spur, and for

six weeks I went around with a neck collar. I was told not to drive. I had to ignore this advice, as the only other driver in my small business was a learner-driver, a danger to all in my van and other road-users. At the first post-surgery consultation, the neurosurgeon had no problem with my driving. Said he was merely covering his back.

Post-surgery I spent one night in intensive care. In the adjoining bed was a young man of about 30 with a heavily bandaged head. Said he was in for the third attempt to remove a brain tumour. He hoped to live to 50. Often the advice I have been given about my PLS situation is that there is always someone worse off than you.

Whilst that is true, in my recent stage of PLS, I have not been able to draw much comfort from this.

After six weeks with the bone spur removed, I returned to running, successfully, albeit slowly and awkwardly. This reprise was short-lived. My ability to run deteriorated. And I started slurring my speech. Never a sign of anything good.

I returned to the hospital for further tests. My treating neurologist was away. So these tests were carried out by a different, younger neurologist. Did things by the book. Another three days of very extensive differential diagnostic tests. Conclusion: SCA – Spinocerebellar Ataxia.

Not one to take anything at face value, I researched the topic extensively. I found that SCA was specific to certain families and age groups. Neither this nor the symptoms I was experiencing were a fit. So, I sought external advice from a specialist group, the Ataxia Unit at the University of Chicago. The Head contacted me and confirmed my conclusion. He said that there were gene tests for SCA and enquired whether blood samples had been sent for testing.

I subsequently learned that this had indeed been done, but that I had not been informed of the results. It was not SCA.

I returned to my treating neurologist for further advice. He carried out a number of additional tests at his rooms. He gave me a clinical diagnosis of PLS; said it was so rare that it not been previously considered. And indeed, I have since discovered that it is usual for a diagnosis of PLS to take up to five years. A sort of last resort diagnosis with no tests currently available to confirm or refute. Not cool!

My neurologist said that because it was such a rare, and clinical, diagnosis he wanted a second

opinion from another experienced neurologist. This was done and the clinical diagnosis of PLS was confirmed. Only person in Cape Town. About 40 in all the UK.

As the disease has progressed, I have continually adapted to the new normal.

At first, I was limping badly. Then I had to use



My Sons Kyle and Liam, now 24 and 20, with me and my staff.

a staff or surfaces such as table edges to get around. I erected railings from my front door to get to my vehicle. Then I needed two staffs to get around outside the vehicle. Never crutches, two staffs of about 1.8m with rubber

stoppers looked odd but were much safer and more versatile than crutches. Remarkable to some was that I was always able to drive without any problem. Finally, I got around client properties in a wheelchair. This phase did not last long.

I finally had a collapse that I do not recall very clearly. Except that I found myself in the hospital and then moved to an assisted-living facility by my family. Which I came to hate intensely once I became more clear-headed and stronger.

With the assistance of my fine sons who adapted my home to make it wheelchair-friendly and accommodate a hospital bed, I returned to assisted-living at home.

So, at 65, this is where I am.

What gets me the most is my total dependence now on others to get in and out of bed, into my wheelchair, and so much more.

It has been a long walk to non-freedom...PLS sucks!!



SPIllinois Connection Zoom

*By Sid Clark and Hank Chiuppi
Illinois Co-Ambassadors*

SPIllinois normally has two or three Connections a year. It is a time for us to get together, meet old friends, and join with those new to HSP/PLS. We shared ideas on what works and what does not, tricks and traps

Continued on next page

of living with our disorder, promising discoveries and the hope the future may bring. Then came the pandemic and every thing stopped, no meetings. Now the country has become a Zoom nation. SPillinois has joined this trend and we have had a number of Zoom Connections.



I have been around computers since the 80s. Until this year, I had never heard of Zoom. The book club, the church, the Home Owners Association, and even the local government and voter participation efforts are now on Zoom or teleconferencing. I think there are many of the “regulars” and members of SPFoundation that have not yet joined in and are unsure about Zoom. Let me talk about a basic how you go about attending a Zoom Connection.

From the host, the person holding the meeting, you will receive an email invite giving you the information on the Connection. You can join on your phone and listen in. Of course, you cannot see, nor can you be seen, for the Connection. You will not see any presentations. The invite email will have the teleconferencing number provided you will need to call. In addition, you will need the Meeting ID number to join the Connection.

For the Connection to be a visual event, you need a computer. A fully-charged, or connected to a charger, Apple device (iPhone, iPad), or a smart phone, tablet also work. The email you receive will have a link that will take you to the meeting site. If this is your first time on Zoom, you will be asked to download the Zoom app. That is not a big deal and may take 5 to 10 minutes. You then will be in the waiting room until the host opens the Connection. You can then join in.

Once in, you should check a few basic controls. On the bottom left side of the screen check the microphone icon to make sure your microphone is on and the audio volume is where you want it. Likewise, make sure the camera icon is on and focused on you. By the way, check your background and do not forget to smile. Remember others can see you when the camera is on so watch what you do and be courteous. Do not leave it on when you leave the room or eat. On the upper right of the screen, you can toggle between the speaker view and a gallery view that shows thumbnail size views of all in the Connection. On the bottom of the screen is a Chat icon that lets you make a comment or ask a question without interrupting. Zoom Chat is a great way to share links, clarify something said on the video call or post lists or large blocks

of text. One last thing to mention is when the connection is over, select Leave the Meeting to sign off.

First, the few personal notes and the procedure given above are only one way to get into a Zoom Connection. There are several ways to join a Zoom conference; this is not meant to be all-encompassing. Launching Zoom from Firefox, Google, or Internet Explorer is the same. For other computer platforms, check the Zoom website. Once in Zoom there are many other functions available.

Secondly, my computer was a good grade PC half a dozen years ago. By today's standard, it is a Fred Flintstone out-of-date boat anchor. I needed to buy a camera to be visual and that turned out to be a problem. Many of the computer cameras are manufactured in China and not stocked in the USA! Your order, as was mine, may be put on a slow boat coming across the Pacific! If so, you need to allow a lot of time. If you need an equipment upgrade, read the fine print.

Lastly remember to always treat the mic as “hot.” I was in a Zoom meeting recently with the county clerk on voting. She talked to someone off camera that I am sure was not meant to be broadcast to others.

Please remember Connections, a get-together, even by Zoom are great for us to avoid self-isolation, maintain community, and share. We are not alone.



The Fifteen-Year Odyssey to Diagnosis: An All Too Familiar Story

By Tina King, PLS

My 15+ year journey to definitively obtain a diagnosis and finally be able to put a name with my increasingly problematic symptoms began in 2004. My primary care physician (PCP) had ordered a sleep study because I was constantly fatigued, despite sleeping eight hours every night. Results showed Restless Leg Syndrome (RLS). No wonder I was tired; my legs moved 30 seconds of every minute. A prescription for Requip, which I still take, provided some relief. I have often wondered if RLS precipitated, contributed to or masked Primary Lateral Sclerosis (PLS) symptoms, making a PLS diagnosis that much more difficult.

I also experienced symptoms that seemed to

overlap with other neurological disorders like Parkinson's, Sarcoidosis, Multiple Sclerosis (MS) and neuro conditions such as migraines, TIAs (mini-strokes) and seizures. I have been checked for all of them, sometimes thoroughly and other times with barely a glance at my medical history.

The neurologist who tested me for MS watched me walk and get up from sitting in a chair, then promptly announced I didn't have MS. Another neurologist ordered an MRI and then stated that the images were normal for a woman of my age. His summary notes indicated I was an elderly white female in no apparent distress. My distress was dealing with doctors who never looked beyond the limited testing they ordered! It became apparent that they either didn't care, didn't want to take the time, or had no medical curiosity about what was happening to me. I began to lose strength in my right side and experienced numbness, tingling, drooling, excessive saliva, choking, weight loss and overall fatigue.

My odyssey continued with more tests, more specialists, more incomplete or inaccurate diagnoses (including a stroke diagnosis) and further decline in my health. Eventually I received a diagnosis of conversion disorder, rather than stroke, when yet another MRI and scan were ordered and showed no brain bleed.

In 2018, life began to change when I attended a stroke workshop. The neurologist who gave the presentation believed strokes were not always caused by bleeds. She seemed to care about her patients and her specialty, so I decided to make an appointment with her. It took three months to get in, but it was worth it. She spent two hours with me at my first appointment and ordered neurological tests which never had been ordered by previous doctors. By January 2019 I'd had multiple blood tests for Lyme and autoimmune diseases, Dak scan, referrals to ophthalmology and infectious disease specialists, lumbar puncture, genetic testing, speech and physical therapy assessments, and cognitive evaluation.

When all results came back within normal ranges, she did not tell me I was crazy. Rather, she felt Parkinson's disease (PD) was a possibility since my mother had PD. She started me on a low dose of Cardopovia, to which I responded, along with speech and physical therapy and cycling at the Y. She was never convinced of PD, though, because of speech and EMG tests which began to show upper motor problems and lack of tremor. (I sometimes shake when fatigued, but never

exhibit true tremor.) Ultimately, it was concluded that my upper motor neuron issues were specific to PLS. Finally, what was happening to me had a name!

It's been over six months since I was diagnosed and, despite having to navigate around COVID-19, I successfully continue on my quest for care. I was able to keep my neurology appointment on July 2 and received confirmation of PLS. I also received a referral to an ALS clinic of the St. Louis University School of Medicine. Once I receive another necessary evaluation in December, I'll begin the ALS clinic in 2021.

I'm eager to move to this next phase of care and documentation for PLS, but remain concerned since conversion disorder still appears on my medical records. Joining the Spastic Paraplegia Foundation (SPF) and SPF of Illinois, plus Primary Lateral Sclerosis (MND) has given me wonderful resources and some peace of mind. Sharing our experiences with this illness helps me understand the disease and how to deal with it.

Also, watching a documentary on Dr. Deborah Warden, a neurologist and psychiatrist with PLS, was like giving voice to my own journey for diagnosis. Even though she is a well-respected doctor in the field of neurology, she had to seek a doctor who would believe her symptoms and experiences and follow through to diagnosis and treatment. I have started yoga, which Dr. Warden finds helpful, and focus on moving some part of my body every day -- finding most days "fabulous," relatively speaking!



What's in a Name?

Two Short Stories

By George and Tracy Sprowls

Hello, my name is George Sprowls and I have HSP, I think.

In the 1960s I went to the Naval Academy. We would call the plebes who were clumsy or awkward "spastic." I guess you can say what goes around comes around, right? I have a whole new understanding of that word now.

As early as 1979, my legs started to jerk a bit. This brought with it challenges. I finally was concerned enough to get a CT scan but it was inconclusive.

In the mid-1980s, I was serving as the Naval

Continued on next page

Attaché in Saudi Arabia. In some adventure there, I jumped off of a wall and collapsed on the ground. My legs would not support the jump. My legs were weaker. My legs were spastic, meaning they were rigid and hard like the stones of that wall, and they were jerking (spasms) even more.

I went for more tests at a hospital in Germany. These were painful, terrible tests and I wouldn't wish them on my worst enemy. For example, they put a cattle prod behind my knee and then measured how long the electric impulse took to get to my brain. Still, no understanding of what was going on.

After my tour in Saudi Arabia, I came home and went to Bethesda Naval Hospital and again I was disappointed with the inconclusive test results. However, the doctors could see a distinct weakness in my right leg.

My next tour was in Egypt where, again, I served as the Naval Attaché. I was also assigned in a flying billet. The weakness in my legs progressed so that my co-pilot had to back me up for takeoff and landings.

When I left Egypt in the early 1990s, I went to the VA Hospital as well as the Pittsburgh Medical Center and the Cleveland Clinic with unsatisfactory results, and so found a neurologist near where I live in Fairmont, WV. That doctor treated the symptoms by putting me on various drugs including gabapentin, baclofen, and mirapex. The neurologist suggested I might one day end up in a wheelchair given the progression of the disease. He was right. He called what I have Spinal Paraplegia, a clinically descriptive diagnosis. But what's in a name?

Hello, my name is Tracy and I have HSP, I think, maybe. As you can see from my father's story and countless others, this disease seems very hard to diagnose. Part of this is the rarity of the disease and part of it is the inconsistent manner in which it shows up, except for the dragging-of-the-toe gait. I do not have that.

Since my thirties, I am now fifty-five, I have had trouble with my legs, particularly my right one. It started with a feeling of weakness but the pain continued to increase. The pain is around my knees and more in the muscles. I have had x-rays and MRIs and all we know for sure is that I do not have arthritis. I have balance issues and the fronts of my shoes are worn out. One neurologist said I did have Dad's disease based on the symptoms but the next neurologist said I did not. Again, I do not have the gait that was

so prominent a part of my dad's diagnosis.

For a long time, I searched for Spinal Paraplegia online and never found anything. And then one day there it was! A whole website devoted to this condition I was starting to think didn't exist. And then there was this foundation, the Spastic Paraplegia Foundation. From the website I learned about the conference in Pittsburgh in 2018. At the conference, we began to understand the disease and were very enthusiastic at the research and the supportive community.

In 2019, Dad had a genetic test done on 65 genes but they did not find HSP. We know there are other HSP genes with variants not identified by current genetic tests, but we have decided to not move forward with further genetic testing at this time for Dad. Dad has been clinically diagnosed with HSP by two separate doctors. However, I will continue to try to get a conclusive diagnosis supported by genetic testing. Why? In the family there are six grandchildren. We want to know for them and for their children. And perhaps with our experiences and the continued research supported by the foundation, more definitive answers will be available to them.

What's in a name? A certain sense of security that there is a real diagnosis and all of this isn't just in our minds. What's in a name? Research on the disease with a possible cure. What is in a name? An understanding of the disease and suggestions on mitigating the symptoms. What's in a name? A community of knowledge and support. What's in a name? A tremendous amount when the name is the Spastic Paraplegia Foundation.



My Children's HSP Journeys

Rejane Mota, Mother, VP of Association of Hereditary Spastic Paraplegia in Brazil (ASPEH Brasil)



Camilla & Rejane

Ilive in Brazil with my husband and three children (a daughter and two sons). In 2001 my daughter Camila, who is 34 now, began to show HSP symptoms, and it took more than one year to know that Camila has HSP-SPG11.

Due to complications of this subtype, it was very difficult to see my daughter, who was studying to be an actress, losing her dreams.

Years later we found out that my youngest son, Filipe who is now 28 year old, also has the same disease. Both developed symptoms at the age



Filipe

of 15. It was not easy to see everything happening again, and in 2018 both were also diagnosed with ALS-juvenile (ALS-5). Both are using a wheelchair, Camila since she was 22 and Filipe since 27.

In spite of all the difficult times for our family, we decided to turn the pain into something positive. In 2009, Camila started painting so she could do something that would make her happy and she showed to have a beautiful gift with brushes. She converts what she lives to flowers, which are her favorite pictures. Filipe enjoys doing realistic paintings,

“IN SPITE OF ALL THE DIFFICULT TIMES FOR OUR FAMILY, WE DECIDED TO TURN THE PAIN INTO SOMETHING POSITIVE.”

designing mugs, traveling and exercising.

Feeling lost and alone in the beginning was unsettling for our family. I did not want this same feeling to affect other families, so I decided to join a group of friends with HSP that I met on social media. In 2017, we founded the ASPEH Brasil (Association of Hereditary Spastic Paraplegia in Brazil), with the main goal of giving emotional support and information in Portuguese to people with HSP and their families.

We do not let this disease defeat us. We continue doing physiotherapy, eating healthy, and getting out in the sun. I have hope that one day the science will advance to find a cure for HSP and my children and other people with neurodegenerative diseases will be healthy again. This is the dream of a Mom who loves her children.

MEDICAL & RESEARCH

Making Diamonds

By Tina Croghan, SPF Ambassador and Board Member, SPG7

My left foot and ankle have collapsed in with HSP. In order to counter this and to increase my balance, I roll it out. This stretches the outside of my lower leg (Anterior Tibialis) and strengthens the inside of my lower leg (Interior Tibialis).

Here’s how I do it.



Position 1



Position 2

Sit in a comfortable chair with feet flat and ankles touching (Position 1). Roll your ankles out keeping your knees together. You will be making a “diamond shape” with your feet (Position 2).

Repeat this for a count of 10 and do this at least twice a day.

Brain Tissue Donation to Help HSP and PLS Research

By Jackie Wellman, Iowa State Ambassador, SPF Board Member

This is sort of a morbid article. It is not meant to be that way but I wanted to share my experience with you.

My aunt, who had HSP, was in the hospital for ulcer repair. She had just been transferred to a rehabilitation facility. She was checked on at 10 pm and was sleeping. On a 12:30 am check, she was gone. She had completed the paperwork to donate her body to a medical school in town. They would not take the body due to COVID. I called Dr. Züchner at the University of Miami because I knew the doctors there do research on brain and spinal cord tissue for HSP.

From there he got the ball rolling for the tissue donations that must be completed within 20 hours. The tissues begin to change after death so the sooner the better. After 20 hours the tissues are useless. We could not find anyone who would do the autopsy. My aunt’s wishes were not accommodated.

I write this to tell you if you wish to donate your tissues after your death for research, you need to make arrangements now.

HSP:

Call 1-800-UMBRAIN (1-800-862-7246)

The University of Miami Brain Endowment Bank

PLS:

Northwestern in Chicago

Naliah Siddique

312-503-4737

Yoga Changed My Life

By Veronica LaPort, SP

When I was about 12, I was introduced to physical therapy. I was told that this was the only way I could walk normally and combat my Spastic Paraplegia. The therapy worked for a while, but as I got older (my late teen years), I found myself with less time to spare for my therapy between school and homework. During this time, I really let my legs go. I didn't work on them as much as I should have except for one year of rowing and I began to lose a lot of mobility. I should have been doing all of my exercises, but it was easier not to do them after a while. I was falling a lot and it was getting harder to get back up. Most of the time, I needed help. I could no longer go on long walks without acute muscle pain the next day. I was severely out of shape.

When I started college, it got better as I was walking all over campus all the time. However, it wasn't as much an improvement as I needed. My mobility was still low and I was still falling almost twice a day.

It wasn't until a late-night yoga class that I realized just how out of shape I was. My Residential Advisor (RA) invited me to join her in the de-stress yoga class. It was terrific, and I was honestly surprised by how many of the poses I could actually do! I thought for sure that my lack of balance and flexibility would be an issue, but I was wrong.

While my routine is different from the first class two years ago, I have found that with yoga, I can do so many things that I had lost the ability to do. These were ordinary things such as bending over to pick something up off the floor or carrying my dirty clothes to the laundromat. I still have trouble with carpets and stairs.

No question, yoga has vastly improved my life. I have some balance now! It's not as good as most people's, but I can use my muscles to keep myself upright when I stumble. A year ago, I would have had significant trouble doing that. If I stumbled, I was going down, but now I have a real chance to regain my balance. I have also had terrible leg cramps; cramps so bad they would keep me up at night tossing and turning in pain. But a little bit of yoga before bed to stretch out those muscles has significantly helped. Yoga is an exercise that I can do almost anywhere and anytime. This flexibility allows me to find a

way to fit it into my daily routine. Thanks to daily yoga, I was able to go on a walking tour in Amsterdam, which was no easy feat. Yoga and sticking to a routine have brought a vast amount of mobility and balance back into my life.

En Pointe: Ballet as Therapy

By Liz Ferry



Everyone always looks at me incredulously when I tell them I dance ballet (sometimes en pointe). Those who have known me all my life knew me as a gymnast, a vault specialist, good at the most aggressive apparatus. Those who have met me in recent years couldn't possibly

see how this girl who walks funny, has muscle atrophy, and has nerve issues can dance. Yet somehow it's true.

I had to give up gymnastics nine years ago, when I moved from Michigan to an area of northern Spain that doesn't have a gymnastics facility. About three years ago, I decided to give ballet a try, knowing that I wasn't built for it and had hated learning it in gymnastics training. But it was the only dance class I could find in my city that fit my work schedule.

It turns out that I didn't really hate ballet, I had just hated my first ballet teacher. My teacher now is an incredible technician, who looks for whatever explanation of a step or technique works to get through to each student. She has been very responsive to my neurological issues, at first offering suggestions of how to adapt the exercises when I couldn't do something, and now giving me free rein to adapt them as I see fit within the limits of the music.

I danced in my first recital after just a few months en pointe. Unfortunately after that, my symptoms progressed. Now I'm not only dealing with spasticity, but also atrophy, especially in my left calf, which has led me to tear the junction of my Achilles tendon and my soleus twice in less than a year. Yet I keep going back for more. Some would call me a masochist, but I call it passion.

How do I possibly dance ballet with spasticity and atrophy, you may ask? Honestly, not very



well, but it serves as an additional type of physical therapy. It helps to build muscle strength, increase flexibility and improve balance. Although my new atrophy issues mean I am less able to build muscle, ballet helps me maintain what I have until disease progression hits again.

Ballet for me is also a type of mental therapy. It's the most technical style of dance – really it's the base for all other styles. As a gymnast, I appreciate technique. I have always strived for

technical perfection. Dancing ballet is a way for me to continue pursuing that goal, though it's a goal that I continually adjust as I pile on injuries and more neuron damage.

I also enjoy the challenge of finding ways to compensate – something I learned from being my gym's "injury queen" and having to compensate for something in gymnastics. Now I do the same in ballet. These challenges provide me the mental and physical stimulation that I strongly believe have helped my disease progress more slowly.

Finally, it's a way for me to have a mental escape from the frustration of still being undiagnosed, after four and a half years with symptoms. While my private neurologists have been leaning towards some upper motor neuron syndrome, my public neurologist, assigned by the public health system, has only recently grudgingly moved past her diagnosis of "it's all in your head." While I do see a psychiatrist to deal with the mental frustration of this situation (who firmly believes that my neuro issues are just neurological, and are not in the least psychological), ballet offers me a therapy beyond what I could receive by trying to talk it out.

One thing's for sure – whenever I have wanted something in life, I have always done whatever it took to achieve it, disregarding the opinions of those who didn't think I could



or should go after it. I want to keep dancing ballet as long as physically possible, so I will. Or as goes the motto from my alma mater, Michigan State University, "Spartans will."

It's ironic – the thing I'm losing in my physical battle is the very thing that keeps me going. Maybe, just maybe, by fighting to keep what I need most in my life at the moment, I'll be able to keep going far longer than could have been imagined.



When You Are Ready to SCOOT...

By Cherine Berg, HSP

Unfortunately, for most people with HSP, there will come a time when you will need more than a WalkAide, cane, rollator or a walker. But you aren't ready for a wheelchair.

A mobility scooter is often the next choice. A scooter will give the user the feeling of independence. Being dependent on others is tough. Everyone likes being independent, with the ability of doing tasks, chores, or fun activities as before.



The scooter I would like to recommend is the TravelScoot. I have had my Standard/Deluxe model TravelScoot for about 15 years. It is one of the first produced and it continues to give me the independence that I yearn for. Yes, I would LOVE to be able to

walk again! Since I can't, this little scooter has become 'my legs', it is how 'I roll.' I often refer to my scooter as 'My Angel.' I am so glad that I can still go shopping by myself, just me and my scooter.

Why is this scooter a favorite of mine? I can walk a little, but every step is becoming more difficult. As my condition has progressed, I am still able to use this scooter independently, with no help. It is lightweight, weighing about 35 lbs. It folds up easily, taking me about a minute to set it up or break it down. My TravelScoot has only three parts: the battery, the chair and the scooter base. It fits easily in the car trunk. I now use it inside my home as well as continuing to use it for shopping and travel. The lithium battery is lightweight. A number of accessories are now available for the scooter, including shopping baskets. I have taken the scooter and battery on different airlines with no issues.

Continued on next page

For more information, pricing and contact information, go to the TravelScoot website, www.travelscoot.com.

Making Strides with the WalkAide

By Kim White, HSP

In 2003, when I was diagnosed with HSP, I was looking through my emails and ran across a couple that said "RareConnect." I found that



The ACP WalkAide®

several people with HSP were talking about the WalkAide® [a medical device that uses functional electrical stimulation to activate the muscles that lift the foot. Ed.]. I decided to find out more by visiting <https://acplus.com/walkaide> and going to YouTube.

On the WalkAide site I saw a video of a girl about six years old who had cerebral palsy and could not walk. They tried the WalkAide on her right and left legs and it worked for her. She walked very well with them and she even learned to run with them on her legs. When I saw that, I started crying because I was so happy for her. After that, I asked my neurologist about the WalkAide. He had never heard about it, so he gave me a prescription to go to the Hanger Clinic to try it out.

I tried one on my left leg and it worked for me, but my insurance, which at the time was Bravo, would not pay any part of it. I appealed and won. Hanger ordered the WalkAide and I paid a 20% copay. I still wear the WalkAide and just purchased a new one. It was a lot less expensive than it originally was in 2003; my copay was only \$295 in 2020. Coverage and copay depend on your insurance, though. Some people say they had to pay for the device themselves and some successfully appealed to their insurance to get it.

The technician at the Hanger Clinic set it up for me using a computer program that analyzed my walking and then programmed the WalkAide with that information. I have to go back soon to have

my devices reset because I recently got Botox injections in both of my legs and the technician wants to make sure my WalkAide program is properly adjusted.

The WalkAide uses an electrical impulse, just as a TENS unit does. The impulse can be set at different levels so you get the level of impulse that is right for you.

The device has a cuff that goes around the upper calf area just below the knee and can be worn under jeans, a dress or anything else worn on the leg. The cuff is plastic with a cloth-like material on the inside. It also has a battery-operated box, like a TENS unit, and is connected by two wires from the box to two electrodes that are inside the cuff. The electrodes have a sticky base that goes towards your leg and sends an electrical impulse as you step. The impulse signals your foot to pick up and not drag your toes. The electrodes need to be changed out in one to two weeks.

It is really wonderful! With a prescription from your neurologist, you can try it out at a prosthetics and orthotics clinic. If it works for you, get it; if it does not, at least you tried.

The WalkAide also has an exercise mode. While you are sitting down you can exercise the foot pick up motion. The technician can program the exercise mode time. The Hanger Clinic set my exercise mode so I can practice lifting up my foot for five seconds and going down for two seconds, repeating the foot pick up for about ten minutes. When it stops, you can press the exercise mode button and do it once again. It is really hard/tiring to walk having HSP and wearing this device does take some of the tiredness away.

A word of caution: Be sure to turn off your WalkAide when getting an x-ray, ultrasound or other imaging procedure since it will mess up the device if left on. Also, you cannot wear this device in water.

Best of luck to all of you who successfully try the WalkAide. I am thankful that it works for me!

Life After Diagnosis: Learning to Thrive with PLS

By Ron Schwing, PLS

In 2014, I was 43 and an active-duty Air Force officer serving as a Flight Test Engineer in a promising career, having recently been selected for promotion to Colonel. For the previous two to three years, I had been experiencing reduced athleticism and weakening in my lower

body. I chalked my symptoms up to being in my forties until 2014, when I could no longer pass the military fitness test. I was referred to a neurologist and after six months of diagnostic screenings was given a diagnosis of PLS/HSP (later genetic testing would come back negative for known HSP genes).

I did not take the news well and immediately began to experience severe anxiety, depression and insomnia which required professional mental health support. I was concerned about my life, my family and my career. At that time, my anxiety symptoms were far worse than any of my PLS symptoms. It took a good eight to twelve months, with strong family and professional support, to recover my mental health. While my military career would be truncated, I was not immediately discharged. Instead, I was given a non-combat deployable job to finish my career.

After a difficult transition, I have settled down to what is my new normal. My most severe symptoms are poor balance/weak legs, slowed and slurred speech and reduced lung capacity. My poor speech is the most frustrating symptom for me since I was always an excellent verbal communicator. What once was my best attribute as an Air Force officer is now my biggest limitation. Currently, COVID is also a big concern for me with the potential attack to my already compromised respiratory system.

Despite the adjustments and limitations, I feel I live a full and meaningful life. I am still able to work in a meaningful and satisfying job that supports the Air Force and our country. My previous hobbies of ice hockey, running, hiking and volleyball are long behind me and my current two primary outlets are golf and bicycling. I can still golf with a cart. My swing is slow and the ball doesn't go far, but my miss hits are not nearly as bad. I haven't hit a house since PLS! I bought a recumbent trike (Catrike Villager) which I ride for an hour, four to five times per week. The gearing is low and doesn't require significant leg strength.



Ron on his Catrike

No one can predict how my PLS will progress but, for as long as possible, I want to be able to do tomorrow whatever I can do today. It's a use-it or lose-it mentality. I do a lot of stretching to aid in flexibility and mobility. I have

a 30-minute stretching routine that I do every

morning and evening. My walking gait tends to be better after stretching.

Muscle stiffness is a significant challenge for me and I find massage therapy works best for me. Pre-COVID I was getting a deep tissue massage weekly from a licensed therapist but when that stopped I purchased a handheld massage gun (Theragun Prime, information at https://smile.amazon.com/Theragun-Prime-Generation-Percussive-Treatment/dp/B086Z6V3S6/ref=sr_1_5?dchild=1&keywords=Theragun+prime&qid=1602198610&sr=8-5). I use the massage gun for about 20 minutes, typically after a magnesium Epsom salt bath in the evenings. The results have been very good for me; less stiffness and better sleep with fewer leg spasms. I find the results as good as the in-person licensed therapy without the \$60-per-hour cost.

"I FIND MASSAGE THERAPY WORKS BEST FOR ME."

If you are a military veteran, please contact your local Veteran Administration (VA) facility and determine what assistance your disability may qualify for. The VA has been and continues to be a huge source of support. In addition to medical care, I qualified for and received significant financial assistance to modify my home to accommodate my disability. Additionally, when needed I can receive financial assistance to modify my automobile.

Finally, if you have the opportunity and means to participate in a PLS/HSP clinical study, please consider it. I have participated in two: Dr. Floeter's National Institutes of Health (NIH) PLS Study (now closed) and Dr. Paganoni's Mass General PLS study. It provides much-needed information to the medical community searching for causes, treatments and a cure. While it's unlikely your participation will improve your condition in the near-term, it will give you access to the leading medical experts in our disorder. My local neurologist is very good but I am his only PLS/HSP patient. After every clinical study visit, I have come away with more knowledge about the disease, more knowledge about my own manifestation of PLS and excellent recommendations on specific drugs, exercises and physical aids to improve my quality of life.

FLASHBACK

This issue's flashback is from the Winter 2003 edition of Synapse, "Serving the Primary Lateral Sclerosis Community since 1997." You can view the entire Winter 2003 issue on the SPF website, <https://sp-foundation.org/news-resources/newsletter.html> [J. Staehle, Sr. Editor]

Meet Synapse Founder

Joe began publishing Synapse in 1997. He actually sent it out on a monthly basis! Often he featured a different PLSer each month. We are all indebted to Joe for his inspiration to create Synapse and for his dedication to the task he set for himself.

Thank you, Joe Alberstadt

Contributed by Ronnie Grove



My first contacts with other PLSers came as newsletters from Frank Levy and Joe Alberstadt. Those first newsletters were just that: letters with PLS news. Were they ever welcome! For me, this was pre-computer and the greatest thing happening in my world. Joe reported meeting other PLSers in Florida.

Several of us asked Joe to consider a meeting a little farther north. I attended that first gathering Joe hosted in Vienna, VA in 1998. That's where I met Ed Ames who encouraged me to get a computer.

By this time the newsletter was becoming quite savvy and had gotten itself named Synapse. Through Synapse, I was aware there was a lot happening that I was missing out on. Ed kept after me and I finally got on line in April 1999. Hallelujah!!! What a day!

Thanks to Joe, who brought me to Ed, who brought me to the computer, I now had all of you.

Then we had the great Connecticut Connection and I put so many faces with names from the PLS Friends group and I can't begin to tell you how wonderful that was. Thus came the first thoughts of a West Virginia Connection, a.k.a., Spring Fling. I wanted to share my PLS knowledge and maybe reach someone who was out there struggling all alone. Since that Connecticut meeting in October of 1999, there have been many regional connections, lunches, gatherings, meetings, dinners, creation of SP

Foundation, and finally, this past September there was TeamWalk.

Above all, call them IMPORTANT. This is NETWORKING! Networking is something we can all do to be a part of the big picture. From Joe to Ed to computer to PLS-Friends to TeamWalk. We are making a difference! Thank you, Joe for starting the ball rolling.

CONNECTIONS

North Texas Virtual Connection

By Celyna Rackov (SPG4) and Tina Curfman (HSP), SPF Co-Ambassadors North Texas Region

Virtual North Texas Connection happened on August 15th at 1:00 pm. Carol Real (HSP), Tina Curfman (HSP), John Staehle (HSP), Wade Pierce (PLS), Jeana Fraser (SPG4), Celyna Rackov (SPG4), Cherine Berg (SPG3A) from North Texas and Kim White (SPG4) from the Houston area participated in the meeting. The meeting was held over Zoom and lasted two hours.

The meeting started with introductions and social conversation to break the ice. Each one shared their brief HSP or PLS journey. Age of on-set, medications, therapies, and devices were the main topics of the discussion. John Staehle shared his experience as North Texas ambassador and as Synapse editor; it was a great moment to hear and to learn so much great information from him.

Some of us complained about pain (mainly low-back pain). Low-back pain is not a symptom of HSP or PLS, but it can be caused by gait abnormalities. John S explained how baclofen pump works from implantation all the way through maintenance and people's experience with it. Kim White shared her journey using WalkAide. After listening to how much it helped her, our interest in testing this device was greatly elevated.

Tina Curfman spoke about the "Awareness Week 5K Run, Walk or Roll" that would happen in the coming week. She gave details about the event and the daily challenges. John Staehle encouraged everyone to write an article for Synapse and include pictures and personal experiences.

The North Texas HSP and PLS Facebook group was created for North Texas members to enable communication of upcoming events and to provide a reliable conduit for members to stay connected.

The next North Texas Connection event is scheduled for November 14th, using Zoom again.

Iowa Virtual Connection

By Jackie Wellman, Iowa State Ambassador and SPF Board Member

On the evening of September 30th we had an Iowa Virtual Connection using Zoom. Dina Landphair, Jackie Wellman, Colette Ergenbright, Dave Statezni, Dana Sadler and Caty Juhlin attended for some HSP conversation. We each shared our diagnosis and testing stories. We talked about testing and various medications for spasticity. We decided to meet like this every other month.

FUND RAISERS

Adli Does It Again!

By Ami Hagan

At 22 months of age, Adli was diagnosed with Cerebral Palsy even though doctors continued to determine her situation as a "mystery." After many appointments and many tests, it was finally confirmed at age five, she had a rare neurological disease called Hereditary Spastic Paraplegia (HSP) SPG3A. Currently at age eight, she is an active girl involved in softball and Ninja U and enjoys shooting hoops, riding her bike, and playing with her brother and sister. Although her legs are "different" she has never backed



down from a challenge. She may not be able to perfect everything she does, but she gives it her all when she tries!

To kick off HSP Awareness week in August we held a Hot Dog/Burger Fundraiser outside of our local Fire Station, population 1,593. We served 80 burgers and

160 hot dogs. On two separate occasions we had to go and get more food! We did this for two hours on a VERY HOT & HUMID day, but still had an incredible turnout and raised \$4,400.00 for

the Spastic Paraplegia Foundation!

To help spread awareness about HSP and celebrate Rare Disease Day on February 29th, we sold over 100 "#hopeforadli Warrior" t-shirts during February and raised \$600 for the SP Foundation.

We hope to improve and continue it each year; it is something Adli looks forward to! She is a true warrior for the cause.

Editor's Note: Then seven-year old Adli kicked off 2019's HSP Awareness Week with a Hot Dog Fundraiser that, in two hours, raised \$1,336 for the SPF.

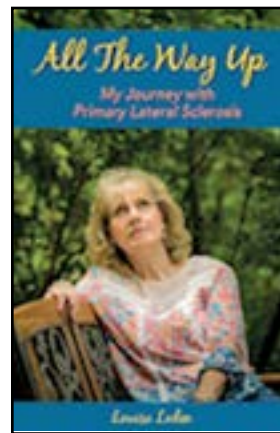
OTHER

All The Way Up - My PLS Journey

By Louise Ledin

I was diagnosed with PLS in June 2011. Nine years later I am still walking with a walker and still driving. My speech has declined over this time but is still intelligible. In 2013, I had my first Baclofen pump implanted and last November had it replaced with a new one. I am still independent with my self-care like dressing and showering. Overall, I've had a slow progression of PLS. It has not been easy, but has been slow.

In 2019, I was motivated to write a story about my journey with PLS after a woman on the Primary Lateral Sclerosis Facebook group announced she had just published her book. I wasn't sure where to begin as I have never written a book before, but once I created an outline of my chapters, it flowed quite well. I reviewed many of my medical files to put things in a chronologic order and was happy that I kept so many notes.



My book, All The Way Up, tells my story from the beginning of when I knew something was off, my diagnosis, working, the Baclofen pump, faith and finding strength, my support group, NIH studies I participated in, and helpful advice to newly diagnosed patients. My hope is that my book will be beneficial to others to get a better understanding of what living with PLS is all about.

All The Way Up, a 72-page soft cover publication, is now available to order at <https://silver-rhombus-trsw.squarespace.com/>.

