Synapse

Volume 22, Issue 1 Winter 2019

Newsletter of the Spastic Paraplegia Foundation

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Spastic Paraplegia Foundation
Annual Conference

June 21-22, 2019

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Synapse

Volume 22, Issue 1 - Winter 2019

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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or www.sp-foundation.org

Letter from the President

Dear Friends,

Many of you know that I am a fan of good quotes. Well, I have a few for you today regarding my gratitude for your giving in 2018. As a matter of fact, I am overjoyed by your generosity because I know what wonderful progress the scientists we support are making toward curing HSP and PLS. The researchers we are supporting are creating gigantic leaps forward in the knowledge of and possible treatments for HSP and PLS and it is very exciting.

I hope you will share in my gratitude for the generosity of our entire community because as Naomi Williams said, "It is impossible to feel grateful and depressed in the same moment." Epictetus said, "He is a wise man who does not grieve for the things which he has not, but rejoices for those which he has."

I am very grateful that we have each other to depend on. Alone, we are weak but working together makes us powerful. The synergy created by your thoughtful giving is the reason our hopes are high that HSP and PLS will be cured in the foreseeable future.

The goal for our year-end fundraising campaign, that began in mid-November and ended in mid-January, was to reach $150,000.00. This amount, if we could reach it, would be matched by our anonymous donor. Well, we did much better than that. We raised over $235,000. Therefore, in two months, including the anonymous match, we raised over $385,000.00. The total amount raised in 2018 that will be used for vital research to find a cure for HSP and PLS was over $600,000.00.

One of the goals many people have in life is to leave a legacy. Well, your generosity makes you immortal. As Albert Pine said, "What we do for ourselves dies with us. What we do for others and the world remains and is immortal."

William Shakespeare has a succinct quote that will be a good one for me to close with: "I can no other answer make, but, thanks, and thanks."

Thank you so much,

Frank Davis

Frank Davis, President

How to Help

We operate out of the strength of our community, caring friends and sponsors. All of the hard workers in our Foundation, including the Board of Directors, are volunteers. Your help can make a difference!

Please contact us at volunteer@sp-foundation.org to help in one of the areas below or to suggest other ways you would like to get involved.

Support Research to Speed Our Cures by Volunteering

Below you'll find information about some of the ways you can help the SP Foundation in their search for cures for 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 fundraising activities include: SPF Team*W*alks (actual and "virtual"); Golf Tournaments; national and international fundraising events like Rare Disease Day (the last day of February each year) and Giving Tuesday; and local special fundraisers. Individuals like you can help organize local fundraisers. Volunteers are also needed to secure corporate sponsorships and help with grant applications.

Patient Connections: Organizing a Connection, a social 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 many states, the SPF State Ambassador organizes and hosts their respective Connections (see below).

Conference Organizers: The SPF seeks event coordinators in or near metropolitan areas who can work with us to organize Conferences for our SPF community. 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 with similar conditions. 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, including SPF's closed Facebook group and this newsletter, *Synapse*.

Ambassadors: Ambassadors welcome new members of the SPF community who reside in their respective states or regions and invite them to participate in local events. Visit the SPF website, www.sp-foundation.org, click on Get Involved, then Join the State Ambassadors to see a complete description of the State Ambassador job.

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 MS Office applications.

New Board Member, Hank Chiuppi

Hank has been part of the Spastic Paraplegia Foundation team since 2011. He is currently Co-Ambassador for Illinois where he and Sid Clark hold support "connections" three times a year. Recently, he volunteered for the role of Social Media Coordinator to enhance conversation with members on Facebook, Twitter and Instagram. A graduate of DeVry University with a BS in Electrical Engineering, he has worked in various positions with Northrop Grumman, Chicago Telecom and Illinois Bell Communications. Hank is retired and looking forward to promoting the Foundation's goals. He has PLS.

SYNAPSE APPEAL

Synapse costs lots of money to print and mail, and we need your help to keep it going. If you or a loved one enjoyed this issue and would like to support it, please use the enclosed response envelope to make a donation.

Every little bit helps.

Please consider making a gift to the Spastic Paraplegia Foundation in your Will and Financial Plan.

"Bush 41" and the ADA

George H. W. Bush, the 41st President of the United States, died on November 30, 2018. Though his life was full of personal and political accomplishments, it was during his administration that he was instrumental in the passing of the Americans with Disabilities Act of 1990. The idea of federal legislation enhancing and extending civil rights legislation to millions of Americans with disabilities gained bipartisan support in late 1988 and early 1989. In early 1989 both Congress and the newly-inaugurated Bush White House worked separately, then jointly, to write legislation capable of expanding civil rights without imposing undue harm or costs on those already in compliance with existing rules and laws.

The Americans with Disabilities Act of 1990 (42 U.S.C. § 12101) is a civil rights law that prohibits discrimination based on disability. It affords similar protections against discrimination to Americans with disabilities as the Civil Rights Act of 1964, which made discrimination based on race, religion, sex, national origin, and other characteristics illegal. In addition, unlike the Civil Rights Act, the ADA also requires covered employers to provide reasonable accommodations to employees with disabilities, and imposes accessibility requirements on public accommodations.

Senator Tom Harkin (D-IA) authored what became the final bill and was its chief sponsor in the Senate. Harkin delivered part of his introduction speech in sign language, saying it was so his deaf brother could understand.

On signing the measure into law on July 26, 1990, George H. W. Bush said:

> *"I know there may have been concerns that the ADA may be too vague or too costly, or may lead endlessly to litigation. But I want to reassure you right now that my administration and the United States Congress have carefully crafted this Act. We've all been determined to ensure that it gives flexibility, particularly in terms of the timetable of implementation; and we've been committed to containing the costs that may be incurred.... Let the shameful wall of exclusion finally come tumbling down."*

Source: Wikipedia

New York Fundraiser

By Ann Marie Lakin

On the evening of October 26, 2018, I held my annual fundraiser for SPF. The location was the same as last year, the United Methodist Church of Mt. Kisco, New York. This year I changed the time to 7:00 pm - 9:00 pm which seemed to work well because I had a great turnout, about 75. As in the past, the evening was dedicated to my sister, Helen, who passed away a little over three years ago. She was the Pennsylvania State Ambassador for SPF at the time of her death.

To entertain us, we had two fantastic singing groups, Bedside Manor and the Forget-Me-Nots. Both groups had us dancing and singing. I asked people to bring a dish to share and we had some wonderful dishes - like chili, mac-and-cheese and homemade lasagna just to name a few.

There was a silent auction for gift cards, jewelry and other items donated by local vendors. I was pleased to see that a lot of people were willing to pay an auction price that was more than the value of the gift card. I also asked for a $15 suggested donation to SPF at the door. The event raised over $3,000 dollars that night and I received another two thousand dollars in donations sent to me by those who did not attend. Overall the evening was fantastic and everyone who attended had a great time.

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Golfing for Rare Disease

By Greg Pruitt, SPF Board Member

Spastic Paraplegia Foundation in Kentucky raised approximately $20,000 with a Golfing for Rare Disease fundraiser on September 8, 2018 at Drake Creek to help fund scientific medical research for the rare diseases HSP and PLS. Despite the rain, many thanks go to the fifteen golfing teams and more than fifty-six sponsors that raised funds to help find cures and treatments. These diseases, hereditary spastic paraplegia and primary lateral sclerosis, result in weakness and spasticity in the lower body and arms, slurred speech and difficulty swallowing. We invite everyone to participate in next year's fundraiser on September 14, 2019. Anyone interested in learning more or matching donations, please contact us at SPFKentucky@gmail.com or visit SP-Foundation.org. Follow us on social media at #HSPandPLS.

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California Team*Walk* 'n' Roll

by Linda Gentner, SPF Ambassador Northern California, SPF Vice President and

Jean Chambers, RN, SPF Ambassador Western Canada, SPF Secretary

On warm sunny day, October 6, 2018 at St. James' Episcopal Church in Fremont, CA, an enthusiastic group got together for the 17th California Team*Walk*, hosted by Craig and Linda Gentner. In fact, for many of us, after 17 years, we appreciate very much that we no longer do a vigorous walk. Things have settled down to a shared lunch (very tasty), a raffle with many intriguing items and, probably the part that is most beneficial for those attending, the 'share and compare' discussion group.

Every year we are able to host people who likely have been recently diagnosed with HSP or PLS. This is probably the very first time that they have been in a group that truly understands a life of dealing with one

Continued on next page

of these disorders. It is an eye opener for both those who have the disorder and for their caregivers who have been able to attend with them. We share "things that work and things that don't work!"

Many have been attending for many of the 17 years and remember the huge events that involved the trek to the Farmers Market in Pleasanton. We have a gentler gathering now. Several people travel a fair distance to attend this event - John and Jane Mitchell drive up from Southern California and Jean Chambers (and Annie!) come down from Vancouver - the Canadian one - not the one across the river from Portland, OR. This year we enjoyed the company of 32 people and raised $21,500.

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North Carolina Fundraiser

By Marcia Elliott

On Saturday November 3, 2018 the Bethesda Ruritan Club of Durham, NC presented the "Bethesda Spotlight Talent Show." This community event brought together talent of all ages and walks of life to raise awareness of a rare motor neuron disorder, Spastic Paraplegia 11 (SPG11). *[SPG11 is an autosomal recessive variant of Hereditary Spastic Paraplegia (HSP). Ed.]* The club designated all monies raised through sponsorship, ticket sales, raffles, canteen sales and donations to be given to the Spastic Paraplegia Foundation (SPF). The club collected over $5,600 during the show and is still collecting donations to be forwarded to the SPF.

The Ruritan Club is a national organization dedicated to improving communities and building a better America through Fellowship, Goodwill and Community Service. There are no national programs, rather the local community clubs across America look for ways to improve their communities and impact the lives of the individuals in them.

Supporting the SPF is personal to the Bethesda Ruritan Club because one of our young members is battling a rare form of HSP. 20-year old Spencer Elliott was diagnosed with a complex form of HSP when he was 14 years old after he began having difficulty walking. A battery of tests including MRI's of the brain and spine, EMGs on his arms and legs and genetic testing, revealed that Spencer was battling SPG11. This complex form of HSP not only causes progressive mobility issues it very often has cognitive decline and other brain function problems. Finding a cure for this progressive disorder is very important to Spencer's family and to the Bethesda Ruritan Club. The Ruritan Club has decided to make the talent show an annual event to help find a cure for HSP. We are already planning for a bigger and better show for next year and hope to double the money we raise.

Generous donations by local merchants enabled us to raffle off 30 prizes and 19 program sponsors donated money for advertising space in our program. A lot of money was raised by selling delicious desserts donated to our canteen by the Prime Time Ministry at Bethesda Baptist Church. This event truly was the community coming together with their talents and gifts to show support to Spencer and his family in helping to find a cure for HSP & PLS!

Pictured left to right: Marcia Elliott (mom); Spencer Elliott; Norman Stallings, Bethesda Ruritan Club President

2019 SPF Annual Conference

The Spastic Paraplegia Foundation invites you to be part of its 2019 Annual Conference to learn, share, network, and have fun! The conference will be held in the Hilton San Antonio Airport Hotel in San Antonio, Texas. Mark your calendars to join us beginning at 9:00 am Friday, June 21st and ending 3:00 pm Saturday, June 22nd, 2019.

Every year, Spastic Paraplegia Foundation sponsors a conference to bring together the leading SPF researchers, clinicians, and families living with #HSPandPLS. SPF has hosted the Annual SPF Conference since 2003. We look forward to reuniting as a community at this year's conference in order to lend each other support and strength, and to learn about the latest advances in research and care.

The two-day event is filled with a variety of workshops, keynote sessions with leading researchers and more—plus fun events like our meet & greet/family fun fest, as well as teen and adult social activities. There are also many opportunities to connect and interact with other SPF families and to receive first hand updates from the researchers.

Registration for the 2019 Annual Spastic Paraplegia Foundation Conference is now open until June 21st. Early discounted rates must be paid by April 15th. See the inside of the back cover for the official registration form and the discounted rates available.

Contact hotel reservations at 1-210-340-6060 and be sure to mention Spastic Paraplegia Foundation to receive the $109 per night room rate. You may also make your reservations online by going to the SPF home page at www.sp-foundation.org and click on the Register Now link at the end of the Early-Bird Discounted Rates column.

Moving Past Denial

by Mary Ann Inman

An old friend signed-up for my annual week-long summer mixed media workshop. Karen had taken my art retreat about 7 years ago. She was excited. My classes had always been high-energy and I introduced new techniques daily.

On Monday, we made collage papers outdoors using a household cleaner and magazines. The liquid detergent caused inks to ooze, bubble, and create patterns. We pressed out the extra inks, tore out beautiful collage pages …one by one… and hung them to dry on a clothes line with fasteners. The papers were interesting and colorful.

When we were finished, I felt good about how smoothly things went. But Karen noticed that things were different for me. My movements had slowed. It was difficult for me to walk on the grass.

The same day, the retreat coordinator told me that Karen had tears in her eyes when she asked about my health. The coordinator told her that I had been recently diagnosed with a rare disease called Primary Lateral Sclerosis (PLS). The next morning Karen and I had a heart to heart talk.

This incident happened in 2011 but I remember it like it was yesterday. I was in denial. I knew but had hoped that others would not notice. In hindsight, I should have told other workshop artists. But it was easier for me to move on than to face the sobering truth.

Before I was diagnosed, I had fallen many times. During sixteen weeks of physical therapy, the specialist had moved from balance exercises to how to avoid injuries during a fall. He said that he couldn't help me…there was something cerebral going on. He recommended that I see a neurologist.

Later, I was diagnosed with "probable PLS" at Mayo Clinic in Rochester, MN after a triage of neurologists eliminated other possibilities. Knowing what was going on helped tremendously. I made up my mind early to just keep on going…like the Energizer Bunny.

Over time, I have learned to stay focused during every move, especially when I change direction. I have developed a heightened sense of awareness. I believe other parts of my brain have become stronger.

My advice to those newly diagnosed is to talk about your limitations openly and publicly…not to garner sympathy but to educate. This will help you move past denial and onward to acceptance. Most people will respect you for "not giving up."

Join social media groups and share. You will find parallels and surprising differences. This will help you understand problems doctors face as they try to sort out why each of us present unique symptoms.

Visit http://sp-foundation-org. The vision of the Spastic Paraplegic Foundation is, "The day where all individuals with HSP or PLS are diagnosed, treated and cured." On the website, you can search archives for specific topics. I encourage you to learn as much as you can. Become your own advocate. You will find printable information about HSP and PLS that you can read and share with family and friends.

And remember, humor is helpful. Practice lighthearted phrases for situations. Now, when I am offered a drink, I say, "No thank you. I can't drink and walk." Really good friends offer to seat me in a comfy chair, pour me half of a beer, and bring it to me.

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Sprint IP Relay

By Hank Chiuppi, PLS, Illinois State Co-Ambassador, SPF Board Member

Okay! You are having trouble speaking. People don't understand what you are saying. So how the heck do you make a phone call?

In the past, before the Internet, the phone company had a relay service where you could rent or buy a Teletypewriter. The Teletypewriter was basically a keyboard with an acoustical modem. With it you could connect to an operator at the phone company, type a message, he or she would talk to the called party for you and then type their reply back to you.

Now, using the internet, your computer or mobile device and a Sprint relay operator, you can accomplish the same thing today. AT&T was at one time the supplier of relay services. Now Sprint is the only relay services supplier.

To use the service you need a computer, tablet or phone with an Internet connection (DSL, Cable, Wi-Fi, 3G/4G, etc.). Also, you must use a major Internet browser: Internet Explorer, Firefox, Google Chrome, or Safari.

Here is a diagram that depicts the operation.

If you use a mobile device you need an Android device running on OS 4.0.3 or higher or an Apple device running iOS 9 or higher. Also, you need any of the following networks: 3G, 4G or Wi-Fi (Data charges may apply if using 3G or 4G wireless networks.) Plus, you need the Sprint IP Relay Mobile App.

One attractive feature of using a relay service is the ability to save your conversation for later reference. Spanish is also supported. All calls are strictly confidential and no records of any conversations are maintained by Sprint. And did I mention, the calls are FREE!

To get started go to www.mysprintrelay.com. Click "Create New Profile/Call Now Number Registration" and follow the instructions.

Sprint offers other services for the hard of hearing and those that are blind. Visit the above website for more information.

Giving My Trike A Boost

By Thomas J. Poulton, M.D.

Like many with upper motor neuron dysfunction, I have benefited greatly from my recumbent trike (a TerraTrike). I agree with Mary B. Schultz in the Fall 2018 *Synapse* about the amazing benefits of pedaling oneself about town.

Copenhagen Wheel on Rear of Trike

As my weakness progressed, I was less able to cover meaningful distances and feared my pedaling days were behind me. A visit to the local bike shop where I purchased my TerraTrike solved the problem. The mechanic said, "I know exactly what you need---we just started selling them!" He proceeded to show me the "Copenhagen Wheel", a fully self-contained replacement hub for the drive wheel on a bicycle or trike. This amazing device incorporates an electric motor and batteries along with clever sensors to boost the rider's mechanical input via pedaling.

Closeup of Installed Copenhagen Wheel

The harder you pedal, the more of a boost (assist) you obtain. It is controlled via a smart phone app that lets you track your ride(s), check remaining battery life and the charging status when at home.

There are other brands of roughly similar devices, but I chose this for its flexibility and the ability to require myself to continue pedaling and maintaining fitness at the highest level possible. A full charge is good for up to about 30 miles of assisted pedaling. For those who can do so, there is even a "charge while pedaling" mode that removes the assistive feature and charges the battery when you are pedaling.

It has turned my trike into a true mobility aid and has put a smile back on my face. It is usually purchased as a new wheel with the device built into it. The Wheel is mounted on your existing bicycle or tricycle.

Search online to find a local dealer who can sell you The Wheel and install it on your bike or trike. The price on the website, https://www.superpedestrian.com/en/tech, is $1749. Your local dealer may be able to offer you better pricing. Regardless, it is worth every penny!

Disclaimer: I have no financial interest in this product… just a happy end-user.

Stepping into the Future with Mark Dvorak

by John Dvorak

Mark and John Dvorak

I used to take walking for granted and thought nothing of standing up and strolling across a room. Walking is actually a controlled fall with each successful step forward, in effect, preventing you from falling flat of your face. It is a very complicated process that involves numerous biological components including the brain, muscles, and the ever-important communication pathway between the two. If all of the components aren't working in flawless synchronicity, the results can be devastating. Just ask my "little" brother, Mark Dvorak, a transplanted Texan now living in Norman, Oklahoma. We grew up in a fairly typical household, doing the usual things: playing sports, going to church and trying not to get into too much trouble. Mark was by all accounts a pretty normal kid and an above average athlete. He was a good Little League pitcher, a decent basketball player and a member of his high school's golf team. In his 20's, he worked in the Oklahoma oil fields, very physical and demanding work.

Then, almost 30 years ago, when he was in his late 20's, Mark began having more and more trouble walking. For no apparent reason, he started tripping over his feet, oftentimes falling down. Once, while playing softball, Mark was running out a base hit and he inexplicably veered out of the base path and ran right into the fence along the first base line. Another time he was trying to backpedal while playing basketball and ended up flat on his back. It was then that he knew something was wrong, but what? Several years of tests ensued resulting in a diagnosis of Hereditary Spastic Paraplegia, or HSP. HSP involves a progressive degeneration of the upper motor neurons, causing many problems including, but not limited to balance and gait disturbances, leg weakness, severe pain as well as bowel and bladder problems. Losing the ability to walk also understandably results in anxiety and depression as one loses their independence associated with the lack of mobility. As Mark's symptoms worsened over the years, he needed more and more help. At first, he just needed a cane, but now his legs are virtually lifeless and he needs a wheelchair or motorized scooter to get around. It takes every ounce of his concentration and effort to pick one leg up and slowly take a small step that so many take for granted. Routine chores, like taking out the garbage, now take over a half an hour, but he doggedly insists on doing as much as he can by himself to lessen the burden imposed on his family by his condition.

Not only was Mark trapped in his body, he was also trapped in Oklahoma, the state with the highest incarceration rate in the country and a fervent "just say no" attitude when it comes to cannabis. Because of this, medical marijuana was completely out of the question. His doctors, however, had no qualms whatsoever loading him up on all sorts of legal painkillers and psychoactive drugs. For his severe back pain, Mark was given Lortab (a combination of the opioid hydrocodone and liver destroying acetaminophen), Roxicodone (oxycodone hydrochloride), a very strong opioid analgesic and even Fentanyl, a substance several times more powerful than morphine. For anxiety and to help him sleep, doctors switched Mark between different benzodiazepines including Lorazepam (Ativan) and Clorazepate which cause dizziness and decrease one's ability to concentrate. To help Mark deal with his depression Citalopram (brand name Celexa), an antidepressant in the selective serotonin reuptake inhibitor class, was prescribed. These were so strong that they made him feel like he was going to die, so he didn't take them very long. This mélange of medications caused Mark to live in a fog. They also made him more claustrophobic and caused panic attacks, the latter of which landed him in the Emergency Room one night where a shot of Valium in his keister did little to help. His debilitating illness was being treated with incapacitating drugs.

Despite this, Mark didn't let his depression show, but rather stoically accepted the hand that fate dealt him. This started to change when Mark became more involved with the

Spastic Paraplegia Foundation (SPF), a not-for-profit, all-volunteer run organization that is dedicated to finding a cure for Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS). He attended his first SPF annual conference in Nashville in 2005 and met several inspiring individuals. While serving as SPF's Oklahoma State Ambassador, Mark organized SPF Team*W*alks to raise funds and awareness and Connection events to establish a fellowship of Oklahomans with HSP and PLS. As Mark's mobility declined even more, he began channeling his energy into his art, repurposing common items and used materials into eclectic 3D collage conglomerations. Other works of his utilize his unique drawing/drafting skills inherited from our father and painting ability passed down from Grandpa. Mark also crafts custom-made frames using paper strips or colorful cut up cardboard containers.

Several of his pieces focus on the "differently abled" as he likes to call himself. "Disabled" carries too many negative connotations. His "speedy wheelchair" logo was an instant classic in that it illustrates the positivity of swiftly moving forward within the confines of a wheelchair. Mark also created several pieces that relate to the SPF and the National Organization of Rare Disorders (NORD).

Art provided an excellent outlet for Mark, but he needed more. Living in ultra-conservative Oklahoma, he was justifiably afraid to use marijuana even though he knew that it was safe and effective for several of his ailments, including pain, anxiety and depression. As a cannabis activist, I've learned a lot over the years from Mark about the draconian nature of the War on (some) Drugs and the actual, incredibly negative effect it has on typical Americans like Mark. Then, in September 2014, I was speaking on a hemp panel at the Boston Freedom Rally with Chris Boucher, a long time hempster and senior executive at CV Sciences, a maker of high-quality CBD products. Chris spoke about the many benefits of CBD and how his company was shipping to all states including Oklahoma, so I thought that Mark should give it a try. Soon after Mark began taking CBD, he noticed positive effects. He experienced much less pain and anxiety, he had more patience, better acceptance of his overall situation and he was happier.

Mark knew that the laws must change, so he took a more active role in the legislative process, lobbying and educating his local representatives and attending sessions like an Oklahoma Senate interim hearing on medical marijuana where he was stirred by the testimonials of patients and family members extolling the therapeutic virtues of cannabis.


Cold Turkey

Thanks to CBD, Mark was able to slowly reduce some of his prescriptions for pain and his mental health. He decided to take the last step in kicking his addiction by going "cold turkey" in October 2016. This resulted in several of the hardest weeks of Mark's life. He couldn't sleep and was much more irritable as the pharmaceuticals sweated out of his body. But his loving family and the art community stood by him, allowing Mark to emerge from the ordeal a stronger, healthier person. Mark makes it a point to let his doctors know how cannabis has dramatically improved his quality of life. Sadly, many are uninformed on this subject because the endocannabinoid system is not yet a standard part of the medical school curriculum.

One of our relatives, who did not know that Mark used CBD to wean himself off of opioids and other drugs, saw him a few months later at a family reunion and remarked about how good he looked and how much more like his old self he was. She noticed a big difference in his demeanor and engagement. In essence, Mark came back to life. Cannabis resurrected his soul and provided him with the clarity of mind that motivates him to do more to help others. The impact of medicinal cannabis on Mark's life is reflected in several pieces of Mark's artwork. He also wants people to know about the environmental and economic benefits of industrial hemp and the negative impact marijuana prohibition has on society.

Mark's desire and ability to help others got a boost when the Governor appointed him to Oklahoma's Statewide Independent Living Council (SILC). The SILC works with the Oklahoma Department of

Continued on next page

Rehabilitation Services to help implement the state’s plan for independent living. This includes providing assistance with many things including housing, employment, education, mental health and in-home services.

Mark has continued his recovery and now is even able to take slightly bigger steps and stand upright for longer periods of time. He lost his ability to walk incrementally and he’s regaining some mobility in a similar fashion. Mark’s baby steps of progress mirror Oklahoma’s own emergence into the age of cannabis. A bill authorizing the cultivation of industrial hemp for research was signed into law in April 2018 and Proposition 788, which legalized medical marijuana in Oklahoma, passed in June. Here’s hoping that Mark and other Okies will soon have unfettered access to all of the 100+ therapeutic cannabinoids that have been discovered in cannabis. I no longer take walking for granted. I cherish each step I take and constantly remind myself how lucky I am. We’re stepping into the future and I’m proud to have my little brother Marky Mark leading the way.

The publication of this story does not reflect an agreement by The Spastic Paraplegia Foundation on the benefit of Cannabis related drugs. Please consult with your doctor before considering their use.

“Slip Sliding Away!”

By Tina L. Croghan, Missouri State Ambassador and SPF Board Member

There has been a snowstorm after an ice storm followed by another snowstorm. Just your typical Mid-Western Winter.

I had a doctor’s appointment that I couldn’t reschedule. Large snowflakes fell from a grey sky. I felt like I was in a snow globe. The falling snow already coated Thunder. I found myself caught amidst 6” of new snow on top of some slippery, black ice!

Shuffling my feet, I looked like Tim Conway on the Carol Burnett Show. I am way past looking ridiculous at this point! According to James Hubbard, M.D., M.P.H., publisher of *The Survival Doctor,* recommends that I keep my knees “soft” as I scoot along. This keeps me from hyper-extending my knees.

My latest issue of *New Mobility* magazine has an article on wheelchairs in snow. Since I’m not in a wheelchair 24/7, I found this pretty ingenious and probably “old news.” Their D.I.Y. idea for wheelchair snow tires is:

1. “Get your hands on some sturdy plastic/nylon wire ties that are long enough to go around the thickness of your wheelchair’s tire and wheel. Too long is OK since you can cut the ends.
2. “Tie 25 to 30 ties evenly around each wheel and tire of a manual wheelchair. Powered wheelchairs and smaller tires will require less or may be limited by the wheel style, so use your judgment on those.
3. “Place the tie heads (buckle) on the inside of the wheel...so that you don’t beat up your hands when you push.
4. “Make sure the tie heads (buckle) point slightly away from the tire and not downward under the tire. This will help dig snow while making for a smoother ride.
5. “Cut the excess on each tie away and you’re set. Go getem Nanuk!”

I recommend checking out the article, “Winter Weather Wheelchair Tips,” at https://www.unitedspinal.org/winter-weather-wheelchair-tips/.

A Reaching Hint

By Lewis Sid Clark, Illinois Co-Ambassador

This is not a technical article but I hope it reaches out and grabs you. It is about something I use multiple times every day - a mobility aid reacher.

It started at church, I dropped my car keys. If you are in a scooter like I was or using a rollator, picking something up from the ground is not easy. At one of the medical supply shows I attended, I saw a demonstration of a telescoping magnetic pickup tool. He was picking up cans of peas with ease. That was for me. It could easily pick up my keys. On the internet I found one and it was not expensive. It was great except for one small thing. Most of the things I drop were not metal. It did not pick up paper, crumbs, or plastic. Advantage: not costly & small. Disadvantage: Does not pick up what I have the most of on the floor.

Then I happened upon a collapsible grabble reacher. Great assist tool that picked up paper and crumbs in any room indoors. My son-in-law found he could use it outdoors to pick up trash along his driveway and in the garbage can (thank you very much – keep it). With the rubber suction cups, it will pick up even thin plastics credit cards while not scratching the floor. It extends a person's reach 32" or 36". The reacher ad also offered additional suction cups. Advantage: folds up and picks up even small objects. Disadvantage: those rubber cups break off when you try to pick up anything moderately heavy, much less than a can of peas.

In search of something better, I found there are many grabbers on the market that do not fold up but are very sturdy. I can use them to help in the morning when I get dressed. Some even have magnets embedded in the end to help with metal items. There are many types and options available. Advantage: You can select a different type to fit your requirements. Disadvantage: they do not fold up and do not fit into a scooter basket or rollator pocket.

I have one each of the above reachers. But the one I find most helpful, and don't laugh, is rubber tipped BBQ tongs! It is long enough to reach items on the floor while I am sitting on the scooter and small enough to fit in the basket. It also nicely fits over one of the cross pieces on the rollator. And it's readily available at your local box stores.

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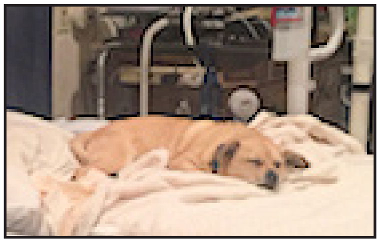
To My Master, Mr. Malin (and Mommy, too)

October 13, 2018

Well, I've been with you since I was 3 years old and now, I'm 8. We've gotten to know each other pretty well, even though when I first came to live with you and have you take care of me, it was Mommy whom I selected to live with. Remember at the SPCA, I was the fourth dog you met, and I was the only one who began by jumping up on Mommy's lap. I chose her and of course, I hoped you would be just as nice to me as she has been.

As you know I'm never more than a foot away from Mommy, except when I'm eating or going outside for what you call a "pee and poop trip." Thank you for helping and taking care of me for both of these things and for feeding me all the time. I am glad you got rid of that cage and let me sleep on the bed next to both of you. Usually I'm next to mom, but sometimes when you come into the bedroom at night, you find me resting on your side of the bed. I've watched the struggle you go through getting in and out of bed using those contraptions you invented and I figured the least I can do is to get your sleeping place warmed up for you ahead of time. I love it when you cuddle me every morning and rub my neck and my tummy. I know about "Therapy Dogs," like Jean Chambers', and I like to think that even though I'm not an official therapy dog, I feel very important to your well-being and peace of mind. I know you are often upset, but when we touch each other you seem to be calmer and more relaxed. I'm very respectful and follow your directions. By the way, I usually bark when people are walking by the house to alert you and warn you. I never bark any other time, even when I am waiting for you to take care of me.



Me Warming Master's Bed

I hope to be with Mommy and you for a long, long time. I know how important I am to her, and how much she depends on me. I try to help her as best as I can: the same with you. I'm also thinking about someday as well, a long time from now, if I get really sick and in poor health (and thank you for taking me to the vet all the time), I hope you will again express your love for me, as I have expressed my love for you, by helping me leave this world for the next one without suffering and pain. You have been a godsend to me, and I thank you. I think I have been a godsend to you, too. I do understand all the words you speak; I can't talk back, but this letter tells you what I want you to know.

With My Love,
from Your Faithful Doggy Pal,
Sparky

TRAVEL TURMOIL

By Malin Dollinger, M.D., HSP SPG4

This month we have an important contribution from Mindy Otlowski reflecting the airline travel experience of her and her husband, Bill Voelker. The following is her advice to avoid turmoil while traveling.

With progression of his HSP over the years, Bill now brings a wheelchair as well as his two canes that he uses for walking short distances. They get waved into the pre-check TSA line which avoids the need to remove his shoes and belt. They are thinking of joining the TSA Known Traveler program which identifies the traveler and enables going through security more quickly. She usually buys a bottle of water and some snacks, should they "get stuck" somewhere at medication time. At the gate, they ask for a gate check tag for the wheelchair (this helps if the airline "loses" it!). They always deny that the chair comes apart (it does!) because that makes it less likely that there's a missing piece on arrival. They also show them how to fold the seat down (problem here is that the next airport person didn't hear that explanation). The wheelchair is usually loaded last so it comes out of the airplane first.

Where to put the canes while flying? Bill wants them nearby, of course, so they store them as unobtrusively as possible. If the flight attendant needs to store them, be sure they are in the overhead bin right over your seat. I, on the other hand, have travel canes that fold into short segments that fit in the magazine pocket.

Mindy wrote, "Be courteous and in a good mood. The people who are there to help you always appreciate it. Treat them like you'd like to be treated. They are not there for your personal service; they've got a lot of other people to look after, too. A little good humor goes a long way. Once they can see that you truly need some accommodations, most people are more than happy to help. The gate attendants notice the people who drive up in wheelchairs and then hop up and run down the concourse to get something to eat. They have seen it hundreds of times. If we are there for a while, Bill usually gets up and walks around (with canes) so he doesn't get too stiff."

wikiHow to Travel with a Person with a Disability

Airport /Hotel vans and shuttles: Always make a point of telling them you need an accessible ride. Not every piece of travel equipment is set up to accommodate a wheelchair, but it's usually just a few extra minutes of waiting. I have been successful in getting the hotel to pay for a handicap taxi, if their shuttle does not take wheelchairs/scooters. Per the Americans with Disability Act, people with disabilities must get the same or equivalent service as non-handicapped people.

Uber/Taxis: This is more hit or miss in our experience. Most drivers want to help, but the chair doesn't always fit! A lot of patience on your part and a willingness to be adaptable helps in these situations. Maybe part of the chair rides in the trunk and the wheels are in the seat area with you. We don't take cruises, but I have heard that they will manually carry you and your wheelchair up and down the gangplank.

Finally, I call your attention to the message elsewhere in this issue, noting the passing of President George H. W. Bush, who on July 26, 1990 signed into law, the original Americans with Disabilities Act of 1990. To humbly paraphrase him, he created "a thousand points of light" for us handicapped folks. Travel access is a key and important part of that gift to us.

Please share your own travel experiences, successes, problems, and solutions, for inclusion in future installments of this column. Send them to me at malind@cox.net.

Balancing Act: Potential Benefits of Physical Therapy

Pam Lanter, PT, DPT, NCS

Board Certified Clinical Specialist in Neurologic Physical Therapy

Balance is an essential part of everyday life. Your balance is made up of three different body systems which work together to keep you upright:

- Vision – your eyes tell you about your environment and your position.
- Vestibular system – your inner ears work to keep you upright when your eyes are closed or when you are moving around in the dark.
- Sensory system – your muscles and nerves in your legs work together to keep you stable and maintain a good base of support.

When one of these systems doesn't work as well as it should, your risk of falling increases. Typically, with Hereditary Spastic Paraplegia (HSP) or Primary Lateral Sclerosis (PLS), your sensory system doesn't function as well as it should. Fortunately, physical therapy can help you work on improving the strength in your legs and your reaction time to decrease your fall risk. You also can work on the remaining systems (vision and vestibular system) to take over for the sensory system to improve your balance and decrease your chance of falling.

When considering physical therapy, ask yourself:

1. Have you fallen more than once in the past year?
2. Do you take medicine for two or more of the following diseases: heart disease, hypertension, arthritis, anxiety or depression?
3. Do you need assistance to get around?
4. Are you inactive? Do you get less than 20 – 30 minutes of activity three times per week?
5. Do you feel unsteady when climbing stairs or walking?
6. Do you have difficulty sitting down or rising from a seated or lying position?

If you answered yes to one or more of these questions, you may benefit from seeing a physical therapist (PT) to work on improving your balance.

Finding the Right PT for Your Needs

For patients with chronic neurological diseases like HSP and PLS, seeing a physical therapist isn't always about making huge improvements or only working on recent changes in function. Sometimes the improvements are small and sometimes the goal of physical therapy is to help maintain a person's current level of function, strength and balance.

When you are choosing a PT, it is important to find a physical therapist who specializes in or has experience with patients with neurological disorders. While all therapists get a basic education in PT school, they often go on to specialize in different areas of physical therapy, such as sports or cardiopulmonary. Physical therapists who focus on treating patients with neurological diseases can get board certified in neurology by sitting for and passing an exam. Once they pass the exam, they can use the initials "NCS" after their name and they often register on the American Physical Therapy Association (APTA) website at www.apta.org. You can find a PT who is board certified in neurology by going to the APTA website and clicking on "Find a PT."

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Yoga and HSP

By Mary B. Schultz, HSP, SPG7, SPF-Missouri

Since first being diagnosed with HSP in 2012, I have benefitted immensely from yoga, both physically and psychologically, and have benefitted from a variety of yoga classes, instructors, and other students. Among the benefits I have had with yoga are:

- Physical balance
- Integration of mind and body
- Strengthening of muscles
- "Opening up" of joints
- Stretching
- Fine motor movement (fingers, hands, toes, feet)
- Breathing
- Energy (Qi)
- Mental alertness/focus
- Better sleep
- Management of stress, anxiety, and depression

Continued on next page

- Movement of fluids in spinal column
- Relief of stiffness/spasticity

There are many "YouTube" videos on adaptive yoga for neurological disorders. Yoga is personal, and every class features asanas (poses) that can be adapted to any level — from beginning to advanced. I had a yoga instructor that reminded us students during every class that, "Every pose is a balance pose."

I heartily recommend yoga as a form of exercise. An article I wrote about HSP and exercise appeared in the Spring 2015 issue of ***Synapse***. In that article, I summarized the exciting neuroscience linking the positive effects of exercise on our brains. Although we each respond to various therapies (drugs, supplements, complementary, integrative, or "alternative") differently, the experience of **everyone** with HSP or PLS is consistent: Everyone, **without exception**, feels better after exercise.

There is now a scientific basis for my own *ad hoc* experience with exercise, and for what I have heard from others with HSP, PLS, and other neurological disorders. Exercise positively affects cell biology, including neurons. Exercise changes the fiber and protein composition of muscles. Exercise actually changes our DNA! Even a single workout benefits our brains! In a word **MOVE**!

One of my favorite books is entitled, "Spark: The Revolutionary New Science of Exercise and the Brain", by John J. Ratey, MD, Associate Clinical Professor of psychiatry at Harvard Medical School. I know of no formula for how frequent or how intense exercise should be. Personally, I have found that it is good for me to exercise at least 3 or 4 times per week, for 30 minutes with my heart rate at a sustained level exceeding 100 bpm. I engage in 3 types of exercise: (1) cardiovascular; (2) resistance (often weights or Thera-Bands®); and (3) yoga/pilates/team sports. Each of my workout sessions do not include all 3 components. I might do "cardio" in one session, weights in another, and yoga or pilates in another.

Yoga has also helped me with the psychological challenges of HSP. In my life before HSP, I was a "weekend warrior" with an unspoken personal rule about my "training" during the week. I allowed myself to run, cycle, swim (whatever) as slow as I wanted as long as NO ONE PASSED ME. In other words, I was constantly comparing myself to others. One of the disciplines of yoga is to focus only on yourself, and what you are able to do on that particular day. As a yogi (student of yoga) I have learned to focus only "on my own mat" and not to compare myself with what other people might be doing on their respective mats. I also learned to focus only on what I am able to do on a particular day. For example, a pose that was easily accessible to me the day before might not be accessible today. With HSP, I am "passed" routinely. Without the discipline of yoga, I would be comparing myself to others and to what I could "do" before HSP. I would be sad all the time. With yoga, I am able to celebrate my own small accomplishments, and not lose my desire to celebrate those small accomplishments by comparing myself to others or to what I could accomplish before HSP.

Recently, I posted on social media about a yoga class specifically for neurological disorders that I discovered in January of this year and have been taking ever since. The yoga class is called, "Yoga for Neuro Health Qi", and is taught by Noel Flynn. I posted the flyer for the class on Facebook. As described on the flyer:

This class is slow paced and concentrates on asanas that support and heal the parasympathetic nervous system. Several supportive props are used: bolsters, bricks, blankets, straps, balls etc. to allow and empower the students to experience various poses. Various healing practices from my training are incorporated i.e., Breath work, meditation, Healing Touch with Essential Oils, Qi Gong, Tai Chi, Yin, etc., to awaken the unbalanced blocked Qi and energy.

I recommend that you try yoga. It has helped me deal with my HSP.

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Shingles Revisited

By Malin Dollinger, M.D., Medical/Research Editor

The subject of shingles (herpes zoster) has come up in the chatrooms so an explanation of this very troublesome medical problem is in order.

As many of you know, shingles is a reaction to the same virus that causes chicken pox in childhood, which reactivates from a latent state, in the "dorsal" (back) roots of nerves attached to the spinal cord. This chicken pox/varicella virus is often left over from a childhood attack of chicken pox and often causes pain, especially "burning" pain, since it involves nerves. Often pain is the first symptom, occurring in the area of the skin corresponding to one or more "dermatomes," that is areas of the body/skin supplied by a nerve. The pain, except for the burning character and the distribution, is not diagnostic in and of itself, but an astute physician may nevertheless suspect shingles is happening, which is confirmed by the appearance of a characteristic skin rash, both in appearance and in distribution, in the same areas as the pain, a few days or a week later.

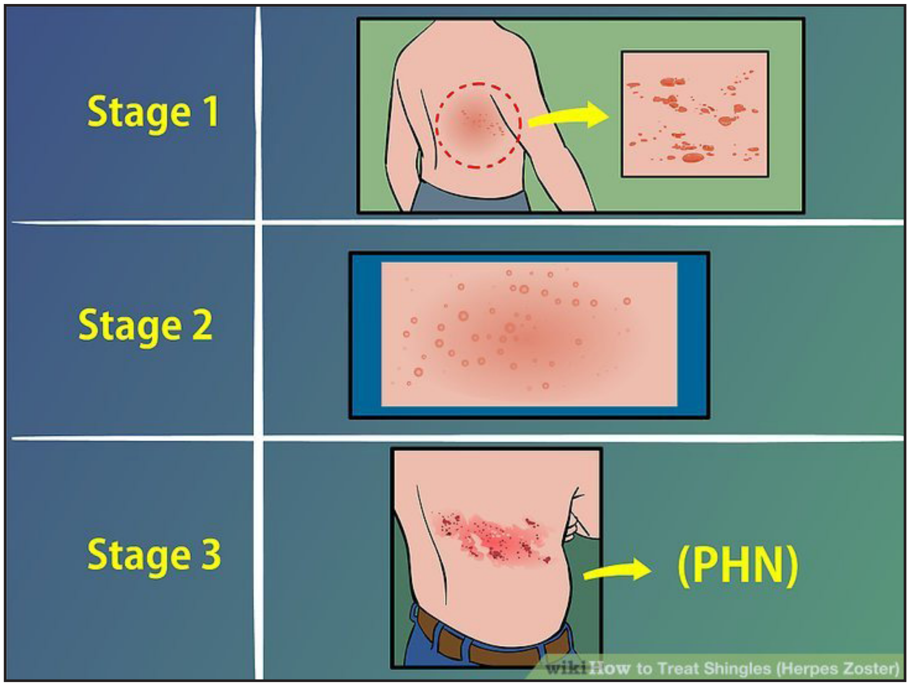
For example, the T4 nerves supply the upper chest/nipple area and when pain first appears in the left side of the chest in an older person, the thought of a possible heart attack may come up, that is until the rash appears on that side of the chest, in the nipple area. As another example, the navel/umbilicus is at the T10 level and if the rash appears there, it's a sign that the T10 nerve is involved. Rash and pain are usually only on one side of the body. Shingles usually involves nerves going to the skin of the chest or abdomen, but can sometimes involve other areas.

When the rash appears, the skin is red and the area is covered with "vesicles," small skin outbreaks that look just like the chicken pox rash. The pain may be severe and new skin lesions continue to occur for 3 to 5 days. Shingles can sometimes occur in the ear or the eye, situations that require a specialist to assist. Fewer than 4% of patients develop another outbreak**,** but many patients, especially elderly ones, have persistent or recurrent pain in the same area, which may last months or years (postherpetic neuralgia).

Treatment involves local compresses, often strong pain medication and antiviral medication. The latter usually helps only if given no later than three days into the rash; a specialist is required to choose this treatment. Management of postherpetic neuralgia is difficult, also requiring a specialist.

Regarding prevention, the most important message is the need to get vaccinated with shingles vaccine, specifically folks whose immunity is intact, which is most of us. The "old vaccine" helps, but the newer one is better. Folks like me, who received the first/old vaccine a few years ago, should still get the new one to give better protection. Specifically, adults over 50 should get the new vaccine, whether or not they have had chickenpox or received the older vaccine. Immunocompromised patients, those whose immunity is impaired, AIDS is an example, are a special situation regarding giving the vaccine, which may have special risks. The weakened live-virus vaccine should not be used in these patients. The recombinant vaccine, which is not the complete active virus, only an inactive part and does not cause the disease, is generally preferred over the live-virus vaccine in adults over age 60 with normal immunity (most of us), The new vaccine, Shingrix, is in short supply and most health care providers, your physician, nurse practitioner or pharmacist, have a waiting list. So, call your provider and ask to have your name added to their list of patients requesting the new vaccine. I called my pharmacy and they are expecting the vaccine in about a week, so I'll receive it there.

Shingles is at least a painful, troublesome annoyance, but some associated problems, e.g. involvement of the face, especially the eye or ear areas, are serious. Thus, get vaccinated against shingles. It's like buying car insurance or fire insurance. You hope you never need to use the insurance and don't mind paying the premium. The shot is a small minor inconvenient moment offering protection. You'll be grateful you didn't get shingles, just like you're grateful there was no house fire or car accident.



Tina's Tips

Compiled by Tina Croghan, Missouri State Ambassador, SPF Board Member

How to Carry Food If You Use Crutches or Canes

I have found several times throughout the day, that I just "DO" something to make my life easier. We ALL take it for granted that accommodation we make. It's just a matter of routine. However, maybe someone can benefit by our ideas!

My question that I put to SPF Facebook users was simple, "What do you do if you want to carry a plate of food if you use crutches or canes? I use a rollator and then utilize the seat or basket."

I got several responses back. Perhaps one of them can help.

<u>Maureen Stroupe</u> added that she, too "… use(s) a rollator seat all the time to carry things. I know I couldn't handle something without dropping it. And my husband will always step in when he sees that I need to move something around."

<u>Linda Gentner</u> agreed that she "… use(s) a husband."

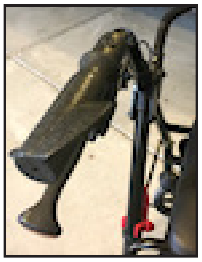
<u>Dorothy Timm</u> says that she, too, uses a husband! "But if he's not with me, I'd like to know, too!"

<u>Dale Fink</u> gave important advice. "People will often help if asked. Alternatively use a tiffin set, they are extremely helpful and can be put (carefully!) in a backpack if needed. Carts are easier if there are no crowds." For more information on Indian Style Tiffin Boxes, go to https://www.amazon.com/Indian-Tiffin-8t8b4-4-Tier-Box/dp/B00A7G7J6U.

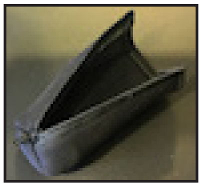
A Better Rollator Handle Grip

Submitted by Hank Chiuppi, Illinois Co-Ambassador, SPF Board Member

I have a rollator with anatomical handle grips. They are supposed to be more comfortable than standard grips. Mine are made out of hard plastic. I was thinking about getting rubber grips and then I found a product that contains a gel insert. The Gel Master ones I found are described here: http://www.com4ort.com/products/-34-5.html. I wish they were softer, but they're a big improvement.



Hard Plastic Grip



Gel Cover

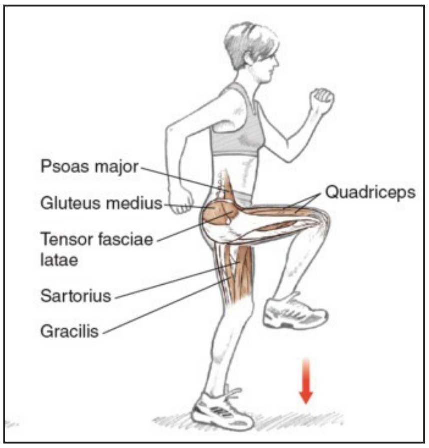
Cover on

ONWARD…MARCH!

Submitted by Tina Croghan

Recently, I participated in a webinar with Dr. Fink. He spoke again of the importance that exercises play with our disabilities. In particular, he noted the need to strengthen hip-flexors. My personal trainer reminds me all of the time to lift my feet or march — pretend I'm stepping over something.

If I slow down and concentrate, I can do this. As soon as I rush (like to the bathroom), I lose the marching and start dragging my feet again. Making a mental note — *I need to continue to work on this!*



Footplate Lifting Ring

Submitted by Malin Dollinger, M.D.

The purpose is to easily lift up the scooter footplate so you can stand close to the scooter. You're going to install a metal ring, attached to one side of the top of the footplate [I suggest the left side, if your joystick control is on the right. The ring will fold down, flat, when not being used, so you can put your left foot on top of it.

You Need:

A metal ring, about 2 inches in diameter, from the hardware store.

Heavy, plastic cable tie about a foot long (you're going to cut most of it off, but you need a strong one, which begins in longer lengths).

Drill bit, slightly larger than the width of the cable tie, and an electric drill.

Instructions (see photos of top and bottom of footplate):

Top View

Bottom View

Pick a spot near the front edge of the footplate, easy to reach with your fingers, and drill a hole all the way through. Pick a spot that is thinner and doesn't have braces or extra material on the bottom side. Drill the hole on the opposite side from the joystick control, large enough for the plastic cable tie to pass through twice.

Be sure you don't drill through any parts of the mechanism. If metal, you will need a drill bit for metal, rather than a wood drill bit. A bit of oil on the drill spot helps.

Thread the plain (male) end of the cable tie up from under the footplate through the hole you drilled, run it through the ring, and then back down the same hole. Then fasten the cable tie together, pull tight, and cut off the extra length. When not being used, the ring lays flat, not in the way of your foot. The cable tie "joint" is hidden under the footplate.

To use, simply reach down and holding onto the ring, pull up the footplate. After a few tries, the ring will loosen up a little and will drop down by itself, to lay flat.

Getting In and Out of a Pickup Truck

Submitted by Julie Ann Samson

Like everyone else with HSP or PLS, I'm always coming upon new challenges every day. My boyfriend drives a pickup truck and while it's not the highest of trucks, it's always been hard for me to get in and out of it. There is a handle on the side, near the door, and while I would hold on to that, he would give me a 'bum boost'.

Recently, he bought side foot rails (running board) so that I would have an extra help to step into the truck. He installed them and I went out to give them a try. While holding the handle, up I went into the truck super easily!

Great, right? Well, time came for me to get out. I normally just slid out with my walking pole in my hand, but doing that this time, my legs rubbed on the rails and kind of held me up. I posted a question about my problem on the Spastic Paraplegia Facebook page to try to get some help. After some suggestions, I basically had to do trial and error. In the end, what seems to work for me is leaving my pole in the truck until I'm out. I have to hold onto the handle (or door depending on the situation), put both feet onto the side rail (my legs are too weak to just put one on), then step down onto the ground, and reach back in for my walking pole. So far, this is working for me, but I'm sure that'll change in the future and there will be a new challenge to figure out.

I hope this helps someone else at some point in their journey!

2018 Northern Ohio Connection

August 11, 2018

By Pamela Jordan-Handley, SPF Ambassador – Northern Ohio

The 2018 Annual Spastic Paraplegia Foundation conference, which was held in Pittsburgh, PA, was a testament to the knowledge, spirit, commitment and support of the attendees, presenters and SPF leadership. To keep the conversation going, a Connections event was hosted in northeast Ohio on a beautiful August day.

A small but mighty group gathered at Fox and Hound restaurant in greater Cleveland to share information, friendship and support. Four of us, Ken and Sue Gleason and Dave Handley and Pamela Jordan-Handley had attended the June 2018 SPF conference and were eager to share thoughts on the learnings from the event. As a longer-term SPF member, Maryann Mayer brought welcomed insight from past conferences. Together, we discussed ways we make daily activities a little easier while navigating the challenges of HSP.

The get-together was highlighted by casual conversation and a question-and-answer opportunity with Board Certified Neurological Physical Therapist Pam Lanter, P.T., DPT, NCS. Pam, who manages Rehabilitation Services for University Hospitals' St. John Medical Center in Westlake, Ohio, addressed the long-term balance, stability and mobility needs of people with disorders such as HSP and PLS. [See the article *Balancing Act: Potential Benefits of Physical Therapy* elsewhere in this issue.]

Left to right: Ken Gleason, Sue Gleason, guest presenter Pam Lanter, Pamela Jordan-Handley, Maryann Mayer. Not shown: Dave Handley

As the afternoon ended, attendees headed home with new friends, useful information and gift bags featuring items from University Hospitals and SPF wristbands.

Interest is already building for a 2019 Ohio Connection event, so watch for details in the coming months.

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Kentucky Connection

By Greg Pruitt, SPF Board Member

Members of the Kentucky SPF delegation met on November 26, 2018, for an enjoyable dinner at a local restaurant to share a little holiday cheer and hear updates. Our delegation discussed the importance of donating to medical research and developing awareness campaigns for the Spastic Paraplegia Foundation. The group also discussed the work for the upcoming 2019 Golfing for Rare Disease Golf Tournament that will be held September 7, 2019. Because of our outreach efforts in the state, we had the pleasure of meeting a new team member that night who was recently diagnosed with HSP. We definitely agree that by meeting on a regular basis we are stronger in our efforts to raise awareness and funds for medical research of both #hspandpls. – Google It.

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Ottawa, Ontario Connection

by Julie Ann Samson, SPF Ambassador - Ontario

On October 14th, 2018 a group of us met in Ottawa, Ontario. There were 4 HSPers, 3 PLSers, and 4 spouses. This was our first SPF meeting and plan to make it an annual event, possibly even twice a year. It

Left to right: Pieter Selst, Brian Green, Christine Hall, Tara Tucker, Mark Woodhead, Donna Woodhead, Mike Wood, Julie Ann Samson, Melanie Green, and Laura Wood. Missing from photo, Allan Ewen.

was the first time some of us had met others with the same condition. We talked about how we were each affected and the difficulties of others understanding. We also talked about how easy it was to talk to each other about our conditions since we 'get it'. At the end of the get together, it was hard to believe that 4 hours had passed. Overall, a great time was had by all. There were a few other locals that couldn't attend, but they showed interest in attending the next meeting.

SPFIllinois Connection

October 20, 2018

By Sid Clark and Hank Chiuppi
Illinois Co-Ambassadors

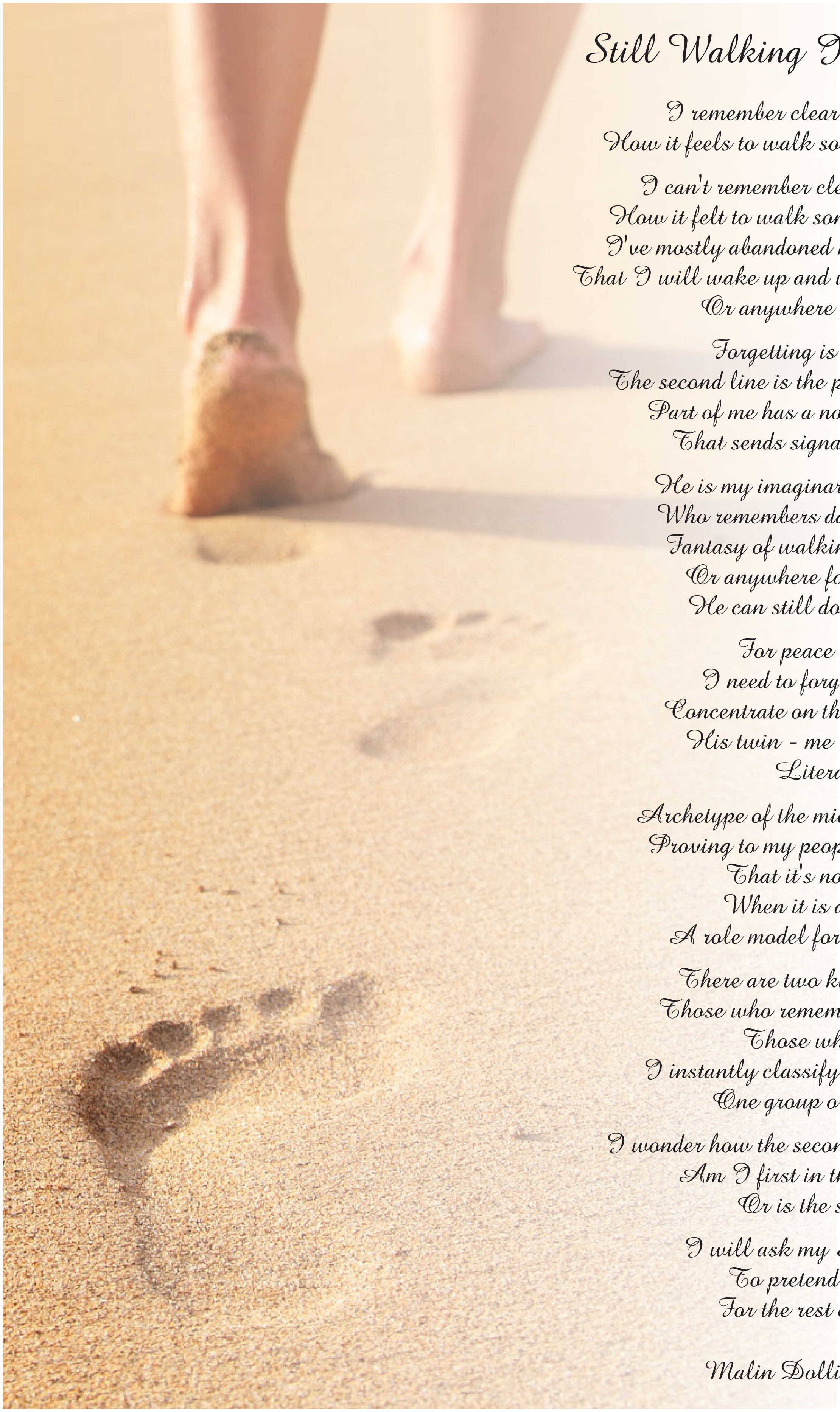
On a chilly Fall day, we had our October 20th Connection. This was our 19th get together which is hard to believe. If you are thinking about having or going to an HSP/PLS get together, all I can say is **DO IT!** At a connection, you meet people who, like you, are being affected by the same disease as you. You are not out of place and in sharing, you can learn much. In addition, you develop friends.

We do have an "agenda" but is really bullet points of conversation starters. We share whatever we want to contribute or things we feel may be of interest. At this connection, some of the things we discussed a wide range of items including:

- Genetics, why and where to get tested. (The MNG lab, see SP-Foundation web site).
- Falling and when to call 911.
- The good and nuisance of WalkAide: a system to help with foot drop.
- Reviewed some of the articles in the recent Synapse. (Great publication / tons of value / sign up if you are not getting it / send in $10 donation.)
- Be careful of catching other diseases (like whooping cough!) while being treated in a hospital.
- We talked about the value of Botox treatments and how the shot placement and strength are determined.
- We talked about some of the drugs we take: the amounts and timing.
- Traveling problems and successes with a disability: you need to stand up for yourself.
- How to listen and partake in Dr. Fink's support group the first Tuesday night of each month.
- We provided links to websites as a follow up from last connection such as applying for and getting Supplemental Security Income.
- Tim Croghan brought some items from the Pittsburg Convention and talked about "Giving Tuesday" coming up after Thanksgiving on November 27.

We covered many subjects which provided thoughts for us to take what we learned and go find out more. Most of all we have made friendships with other HSPers and PLSers.

Group photo includes L-R: Steven Beutelspacher, Frank Madrigali, Tim & Tina Croghan, Lynn Staudacher, Sara Wright, Joan Morris, Carol Clark, Hank Chiupp, Carolyn Wright, Sid Clark, inside the table Phyllis Madrigali and the insert Paulette Chiuppi



Still Walking In My Dreams

I remember clearly…sometimes
How it feels to walk somewhere…anywhere

I can't remember clearly…sometimes
How it felt to walk somewhere…anywhere
I've mostly abandoned my dream fantasy
That I will wake up and walk to the bathroom
Or anywhere I wish

Forgetting is a blessing
The second line is the present tense - "feels"
Part of me has a normal spinal cord
That sends signals as it should

He is my imaginary Siamese twin
Who remembers dancing, clogging
Fantasy of walking on the beach
Or anywhere for that matter
He can still do these things

For peace of mind
I need to forget that twin
Concentrate on the here and now
His twin - me - is on a roll
Literally

Archetype of the microcosm of HSP
Proving to my people and the world
That it's no big deal
When it is a big deal
A role model for others like me

There are two kinds of people
Those who remember me walking
Those who don't
I instantly classify everyone I meet
One group or the other

I wonder how the second group thinks of me
Am I first in their thoughts?
Or is the scooter?

I will ask my Siamese twin
To pretend he is me
For the rest of my life

Malin Dollinger, 2009

Spastic Paraplegia Foundation
Annual Conference
June 21-22, 2019
Join us

Tentative Agenda
June 20, Thursday—Board of Directors Mtg
June 21, Friday
7:30am —Breakfast, plated
8:30am —Welcome, General & Breakout
12:00Noon – Lunch, plated
1:15pm —General & Breakout Sessions
3:00pm —Network on the Riverwalk
thesanantonioriverwalk.com
Dinner (on your own)
June 22, Saturday
7:30am —Breakfast, plated
8:00am —General & Breakout Sessions
12:00Noon – Lunch, plated
1:15pm —General Session w/ Dr John Fink
3:30pm —Network at Morgan's Wonderland
morganswonderland.com
4:00pm —Donor & Sponsor Reception
Dinner (on your own)
SUNDAY—NO SCHEDULED ACTIVITIES
Remember the Alamo—thealamo.org
Enjoy your visit in historic San Antonio—visitsanantonio.com

Hotel Registration

HILTON SAN ANTONIO AIRPORT
611 N.W. Loop 410, San Antonio, TX 78216, Call 210-340-6060
Free Self Parking, Complimentary Airport Transportation, and Wifi
Mention "**SPASTIC PARAPLEGIA**" for discounted room rate of $109
The hotel is conveniently located only 2-miles from the San Antonio International Airport (SAT), 8-miles from downtown, and 8-miles from Morgan's Wonderland. Hotel offers a free shuttle service to destinations

Conference Registration

Pay & Complete Registration Online at **SP-Foundation.org** or Make Check Payable: **SP-Foundation** Mail Payment & Registration form to: **SPF, 1605 Goularte Place, Fremont, CA 94539**.

Registration Fees - No Refunds after May 31st

***To receive discount, payment must be received by SPF.**

Adult Early Discount, Must be Paid by April 15, 2019 …………………………	$140	**QTY:______**	**Total $:_______**
Child Early Discount, Must be Paid by April 15, 2019 (under age 18) ……….	$100	**QTY:______**	**Total $:_______**
Adult Registration April 16th to May 31th, (Must be Paid by May 31, 2019)……	$200	**QTY:______**	**Total $:_______**
Child Registration April 16th to May 31th, (Must be Paid by May 31, 2019) …..	$160	**QTY:______**	**Total $:_______**
Adult Registration June 1st to Onsite……………………………………...........	$250	**QTY:______**	**Total $:_______**
Child Registration June 1st to Onsite …... ……………………………………...	$210	**QTY:______**	**Total $:_______**

Registrant Name#1:______________________________________Disorder: ___N/A___ HSP____ PLS ____SP____ ALS____ Other

Registrant Name #2: ______________________________________Disorder: ___N/A___ HSP____ PLS ____SP____ ALS____ Other

Child Name #1: _________________________________Age: _____ Disorder: ___N/A___ HSP____ PLS ____SP____ ALS____ Other
Child Name #2: _________________________________Age: _____ Disorder: ___N/A___ HSP____ PLS ____SP____ ALS____ Other

Address:____
Mobile Phone while at conference: (_____)______________ Text?: Y / N 2ND:Mobile: (______)________________ Text?: Y / N
E-mail: ____
Are you driving or flying to the conference? _________ What aids are you likely to use a conference? Check all that apply:
Cane_____ Crutches ____ Walker____ Scooter____ Wheelchair ____ Powerchair _____ Animal ____ Other _____
Meal Requirement: Regular ____ Vegan _____ Vegetarian____ Gluten-Free _____ Kosher _____
Food Allergies (List):___________________ Other Allergies :___________________ Other Comments____________________

Register Online & Book Hotel at SP-Foundation.org

Questions, please email us SPFKentucky@gmail.com

SPF SPASTIC PARAPLEGIA FOUNDATION, INC.
Research / Education / Support

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Welcome to San Antonio, Texas!

June 21-22, 2019

HISTORIC MARKET SQUARE

Morgan's WONDERLAND
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www.morganswonderland.com