Synapse

The Newsletter of the Spastic Paraplegia Foundation

Spring 2021

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SYNAPSE

The Newsletter of The Spastic Paraplegia Foundation Inc.

Volume 24, Issue 2 Spring 2021

WHAT'S INSIDE

Letter from the President

Frank Davis

Dear Friend,

2021 is well upon us now and there are lots of things I want to share with you. First of all, I want to give a tribute to an old friend of both myself and SPF, John Staehle, whom we lost from COVID last year. Secondly, I want to give you a run down on how the goals of our Foundation are progressing and give you previews of our upcoming virtual Annual Conference and August's PLS and HSP Awareness Week.

I lived in Dallas, Texas from 2007 to 2017. During that time John Staehle was my SPF North Texas ambassador. John and his wife Carol went to a huge amount of effort to arrange and set up meals and speakers for the North Texas SPF social connections.

For several years they were held in a nice Italian restaurant and were very well received. John, however, kept wanting to have more participation from his SPF community.

So, he arranged with a local church to use one of their meeting rooms. He asked people to each bring a dish for a potluck lunch meeting. Some people brought a casserole; others brought fried chicken, desserts or soft drinks. This turned out to be a great idea and more people began participating. I remember the many great discussions that unfolded.

John had a remarkable talent for being our Synapse editor since 2013. He considered Synapse the heart of our Foundation and strove to provide truly helpful and enlightening information for our members. He was instrumental and patient in soliciting stories from both our membership and scientists and tireless in making sure every story was written in a very readable and succinct manner.

John was asked once if he used the Associated Press Stylebook as his guide to grammar, style and usage and he answered, “no.” He said his definitive source was “Carol's Style,” referring to his wife who taught

English and whose mastery of grammar and punctuation could match any other guide. We thank Carol and John's family for sharing him with us. John's efforts, through Synapse, made people in our community feel that they were not so alone and that there were many steps they could take to improve

John Stahle,
Synapse Editor
from 2013-2019

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Special thanks to Gulf Business Printing,
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Spring 2021 issue of Synapse.

SYNAPSE APPEAL

Synapse is an online and print publication for members and friends of the Spastic Paraplegia Foundation. 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.

SYNAPSE

Volume 24, Issue 2 - Spring 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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President's Letter (continued)

their lives. John was a caring, thoughtful, intelligent and thorough individual with a keen, wry sense of humor that all of us will greatly miss.

Earlier in 2020, when COVID began changing the world in more ways than any of us could anticipate, we realized that the in-person Annual Conference planned for Nashville, TN, would not be possible. Fortunately, Zoom technology had been developed, so we reluctantly switched our conference to a Virtual Conference. Zoom software and people on our Board of Directors, like Norma Pruitt and Hank

Chiuppi, allowed us to have a relatively smooth virtual conference.

I began the conference with an introductory talk which I wrote thinking I would be speaking largely to people in the United States. I soon realized that my perspective was far too limited. People attended from over 16 countries on almost every continent of the world. Our 2021 conference will be a similar virtual event in June. Watch your email for upcoming details.

As you probably know, one of the major goals of our Foundation is to support the world's best research to move us closer to the day when we achieve our mission of having individuals with HSP and PLS be quickly diagnosed, treated and cured. This goal is coming more and more within reach every year. You are a huge part of how we are reaching this goal. Even during these challenging times, you continue to make a positive difference through your generous gifts.

As COVID was striking last year and more and more people were becoming unemployed, many on our SPF Board of Directors wondered if we were going to need to curtail our research goals. They were very worried that the progress of our research might be drastically stalled.

The heartening response to those concerns is a huge tribute to you, for which we are extremely thankful. Although the total number of donations decreased from 3,750 in 2019 to 3,442 in 2020 due to the pandemic, the amount of dollars raised increased by 9.9%. Fundraising efforts garnered $947,438 in 2020 compared to $888,986 in 2019. The average donation rose from $237 to $275. You realized what was going on and you came to the rescue. Thank you so much! Our goal for 2021 is to reach a record total of one million dollars raised. Together, I am confident that we can do it.

> **"EVEN DURING THESE CHALLENGING TIMES, YOU CONTINUE TO MAKE A POSITIVE DIFFERENCE."**

We finished Rare Disease Day on the last day of February. The goal of Rare Disease Day is to increase public awareness of diseases that affect less than 200,000 people worldwide. The term "rare disease” can be misinterpreted by the general public to mean “insignificant.” Nothing could be farther from the truth. There are over 7,000 rare diseases affecting a total of approximately 30 million Americans and 300 million people worldwide. Eighty percent of these rare diseases have an identified genetic origin. As those with HSP or PLS can attest, it can take an average of six to eight years for someone with a rare disease to obtain an accurate diagnosis. Thanks to events such as Rare Disease Day, we are educating health professionals, researchers, policy makers and the public about these diseases and the impact on patients' lives.

Another way we raise awareness is through our Annual Report. Over the next few months we'll be compiling reports on the tremendous progress of the research we have been funding. Our Scientific Advisory Board is about to issue their expert guidance to our Board of Directors on which of the most recent research proposals we should support. We are fortunate to have received almost double the number of research proposals this year and many look very promising.

The annual HSP and PLS Awareness Week will be coming up August 22 to 28. It is a time in which all of us can participate to raise global awareness of two rare diseases that are largely unknown or misunderstood by the general public and, sadly, even by people in the medical field. Watch the SPF website and upcoming communications for ideas on how you can help spread awareness in your local and state communities.

I can only close by saying A GRAND THANK YOU to you for making all that we do possible. You are the reason I feel so confident that people with PLS and HSP will have real relief from their symptoms in the next 5 to 10 years. Alone we are rare. TOGETHER WE ARE STRONG!

Sincerely,

Frank

Frank Davis, President

GENERAL INTEREST

Bon Voyage: 2020 in the Rearview Mirror

By Tina Croghan, HSP SPG7, SPF Board Member

2020 was a year filled with optimism for dealing with my HSP but finished with some unimaginable challenges.

I started my summer with Flexor Tenotomy surgery on the four small toes of my left foot to release them from their “death grip” on the floor when I walked. That went so well, I had Hallux Tenotomy surgery on my left big toe to release it, too. Everything was going great, so I had Ptosis surgery on my eyelids to correct their drooping and impacting my vision. Again I was healing quickly, so it was time to have an Achilles Tendon Lengthening (ATL) procedure on my left leg to give me more dorsiflexion [ability to flex the foot, pushing the heel forward and pulling the toes toward the body. Ed.] and help correct my foot drop.

The toe surgeries were fine but I had significant swelling with the ATL. After being in a boot for two weeks, my podiatrist said that I could tentatively try weight bearing on that foot. Well, after enjoying a wonderful Saturday with friends and family (outdoors, of course) celebrating my 60th birthday with a surprise party, I tried to transfer from my scooter to my car. I fell straight down and injured my ankle on the right foot.

Drats!

At the time of the fall I wasn't sure if the ankle was sprained or broken, so my husband Tim took me home and put me to bed to give my ankle a rest. After a handful of Advil and a nap, reality reared its ugly head. Now 11:00 p.m. on a Saturday night, in a lot of pain and unable to bear any weight on my legs (remember the Achilles tendon was still healing), I knew it was time to head to the Emergency Room. Since Tim couldn't lift/move me, we called for an ambulance. After arriving at the ER, I was faced with explaining about my HSP and its symptoms and limitations to the staff. (I'm use to people not knowing about HSP and having to educate them on the fly!) After a few X-rays, they put a splint on the right ankle and a knee-high boot on the left foot. At 3:00 a.m. they sent me home.

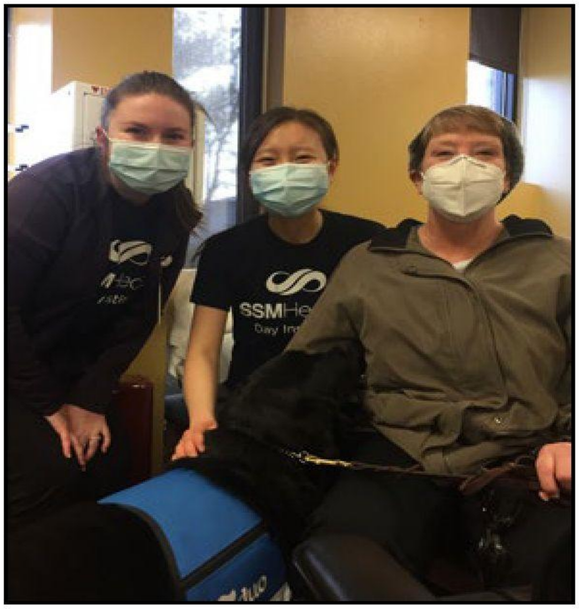
Toes Before: *My toes are all curled under during weight-bearing (standing).*

Toes After: *Nice flat toes on left.*

A few hours later, as the sun rose, I needed to use the restroom. Hopping out of bed, more figuratively than literally, I headed to the bathroom with Tim ever soooo gingerly pushing me on my rollator. I was transferring from the seat of my rollator to the toilet when — double drats! — I fell straight down again. This time I knew I'd broken the right ankle, second time but in a different spot.

There I was on the floor with Tim unable to lift me. I had to get back to the bed so I did my best “commando crawl,” dragging myself the 15 feet to safety. After 20 minutes and rug-burned elbows, I made it to the side of the bed - actually, on the floor next to the bed. In a few hours my son and daughter-in-law were due to come by, so I waited on the floor, comforted by my service dog Thunder, until they arrived and helped Tim lift me onto the bed. After some serious family negotiations and realization that I needed to be admitted to the hospital for a minimum of three days in order to get a serious amount of rehabilitation, the ambulance was called again.

It was now midafternoon and the ER experience was the same: inform the day crew of everything, take X-rays and wait. They finally agreed to admit me but it took until 10:00 p.m. to get to a room. Suffice it to say, no one upstairs knew about HSP or any upper nerve disease, not even the doctors. I was prescribed heavy narcotic painkillers (not until Monday, though) which ironically did nothing for the excruciating pain. Did I mention that my surprise birthday celebration was at a winery? Because I told the hospital staff that my fall happened in the winery parking lot, I was tested and treated like a person who was inebriated (I wasn't.) It didn't help that my speech is slurred due to HSP. I will never be so honest again! HSP can really complicate things, which is why I've learned to carry a stack of SPF “business cards” that display the website address and explain the SPF organization and HSP/PLS.



Thank you to Casie and Sylvia for helping me reach and surpass my goals.

(To print your own cards, go to www.sp-foundation.org and download the file.)

Here's another point: when you call 911, they tell you to put all your medications in a zip-lock bag for transporting to the hospital. I did, and the hospital promptly locked them in my room safe. I had no access to my daily regimen, which meant that soon the leg spasms and pain kicked in. OH! NO! Plus, because this happened on a weekend, I had to wait until Monday morning for the doctor on call to make his rounds and order what I needed to get back on my regular medication schedule. After I did the obligatory three days in hospital number one, I was happy to be off to inpatient rehabilitation at hospital number two. Once there, I spent eight days among doctors and nurses who finally knew what to do with me, my HSP and my injuries! Not only did I get back on my usual Baclofen and Diazepam, I was prescribed Gabapentin for my nerve pain. The nurses even knew how a simple change of leg position could stop a leg spasm before it got to my cast.

After I was discharged from inpatient rehabilitation, I had a month of home health care. I learned new ways to get around home safely on two bum legs. I then moved on to intensive outpatient physical therapy three times a week, six hours a day. When I started on December 1, 2020, I only was able to walk four feet. When I finished on January 29, 2021, I walked 540 feet. I continue to get stronger every day with the help of regular outpatient PT.

I was so glad to wish bon voyage to 2020. Now I'm staying 2021 Strong!

Since my dog Thunder couldn't be with me in the hospital, this plush "Thunder Junior" was the next best thing for lifting my spirits!

Chelsea's Story

By Chelsea Walker, HSP SPG7

Hello, my name is Chelsea and I was diagnosed with Hereditary Spastic Paraplegia, SPG7, on September 29, 2020.

Chelsea believes being a positive role model and an active advocate helps her build awareness of rare diseases such as HSP.

For many years I was considered clumsy or weak. I would often fall, tripping over my own feet. I even tripped walking down the aisle on my wedding day! I had a feeling something was wrong, but I also was building my family and pregnant when I first noticed symptoms. After I gave birth to my daughter in 2016, I continued thinking my legs were just weak and I needed to work out more. Still, I would often fall without explanation and started walking with a slight gait. I remember a time when I was walking home from voting at the town hall and someone asked me if I was bow-legged. It hit me like a ton of bricks!

Fast forward to 2019 when I became pregnant with my son. At nine months pregnant, I fell, hard, and broke my fifth metatarsal (the long bone on the outside of the foot that connects to the little toe.) I knew after I had the baby I needed to seek a diagnosis.

Then a global pandemic hit. I'm a funeral director, who returned to work from maternity leave on March 3, 2020 — right before the world shut down. After several more falls, I went to my primary doctor regarding my “episodes.” I was convinced I had Multiple Sclerosis (MS). She sent me directly to a neurologist, who ordered brain, cervical and thoracic MRIs. All normal. An EMG to check my nerve and muscle function came back fine. Next step was genetic testing which, after four months of tests, came back positive for HSP SPG7, autosomal recessive, pathogenic. I received the results from the lab before my doctor could explain, so I googled and googled and googled some more. I was clearly upset, knowing my life was changing forever, but I also was relieved to know that what's happening is not fully in my control. I'm not going crazy. I truly am different, and that's okay.

Since the diagnosis, I've been seeing a few other neurologists to rule out other diseases. I've always been a vain person (I'll admit it), but I've stopped being quite as stubborn and have started using mobility aids as part of my daily life. I've also started physical therapy which I do daily, plus in person with my PT once a week. I've realized that getting physically hurt from tripping and falling is more harmful than my ego taking a hit.

Being so young and having this disease, especially as a mother, is hard. But I need to advocate, be a leader and show my kids, family and community that I am okay. I don't want my kids to perhaps have this disease and remember me as being miserable because of it. I want them to see me being positive: going to physical therapy to control what I can, spreading awareness and living my new, adaptable life the best way I possibly can. Of course, it won't always be sunshine and rainbows, but it can't always be storms.

But You Did Everything Right

By Tammie Martinez, HSP SPG4

The title of my story are words that often echo in my head.

As a child, I watched my grandma decline in mobility, going from a cane to a walker to knee replacements that didn't improve her ability to walk. Finally, she resorted to a motorized wheel chair. I would ask her if she needed anything and she would say, “some new legs.”

My mother started walking slower and was having pain. I noticed her becoming less active, then her gait became unstable and she needed a cane. I told myself all my life that I wasn't going to let that happen to me. I began educating

Tammie Martinez (left) with daughter Jessica Kremski

Tammie Martinez (left) with daughter Jessica Kremski

> “EVERYTHING HAD HEALED CORRECTLY, BUT I KNEW SOMETHING WASN’T RIGHT.”

myself about health and fitness; eating healthy and staying physically fit was my mindset. I became an aerobics instructor and mail carrier. The muscles in my legs were often tight, but I thought that was expected with my level of activity.

When I was in my late thirties, my left hip and leg were hurting badly. The doctor ordered a MRI and then the orthopedic surgeon recommended a total hip replacement. After the hip surgery, the pain was gone but my leg wasn't moving as it should. It was constantly tight and uncomfortable. A follow-up MRI showed that everything healed correctly, but I knew something wasn't right.

I went to another orthopedic surgeon and learned I have spinal stenosis. After a reflex check, he recommended I see a neurologist. There were many visits and feelings during this time. It was exhausting and stressful, but thankfully I ended up going to a neurologist who knew about HSP. I took the blood test and the results came back positive. All my life I was running from HSP and didn't even know what it was. Now I can no longer run, literally.

When I told my daughter, she was in shock and said, “But you did everything right.” All of my life I have tried to stay healthy and strong. It is hard to accept that I have no control over my strength and mobility. When I'm struggling with movement or feeling weak, I hear my daughter's voice telling me I did everything right. She and I are close, and I am sad to say that she has also tested positive for HSP.

I have been diagnosed for over a year. The HSP support group on Facebook has been helpful and I appreciate the personal stories and helpful strategies that are shared. Through this online group, I have met a dear friend and we email each other weekly. She has helped me to stay positive and know that I'm not alone in this. She has said, “I do as much as I can, as well as I can, as long as I can.” So, my inner dialogue is being reprogrammed. Instead of trying to be invincible, I will try to take my friend's words to heart. I will continue to do everything that is right for me today.

The Path to a Diagnosis with SPG7

By Dina Landphair, HSP SPG7, SPF Education Committee Chair

It is amazing how many different types of HSP have been found in the last decade. Currently, there are over 90 types. If it were not for the advances in technology and the medical field, I'm not sure I would have been diagnosed — especially since I have a recessive type and there is not anyone else in my immediate or extended family with similar issues.

My journey totaled 13 years. Over the years, I was misdiagnosed many times. The only way I was able to be correctly diagnosed was by never giving up, listening to my body, and being my own advocate.

My story began in the summer of 2000. I first saw a neurologist. He examined me and ran a few tests but did not think anything was wrong. I then proceeded to see four different ENT doctors. The last one referred me back to the neurologist I saw originally. This time he could see I was having problems, so he asked, “What have you been doing for the last seven years?” He ordered a few more tests (MRI, spinal tap, blood tests, etc.), without a diagnosis.

He then sent me to see another doctor who ran a huge number of blood tests. I received a letter telling me they did not find anything and I should continue with my treatment. What treatment? I did not have a diagnosis; no one had told me anything. I went back to see him again and at the end of the appointment, I was told, “You have Ataxia and here's a website.” Nothing else. That was all I was told.

I learned Ataxia is a rare neurological disease like HSP. It is progressive and affects a person's balance, ability to walk, talk, and use fine motor skills. I now know it is one of the symptoms associated with SPG7.

Dina and her sons take a break along the bike trail.

Dina (middle)
and friends

I made an appointment at an Ataxia Center at the University of Minnesota, one of only five such centers in the United States. I really liked everyone from the nurse to the genetic counselor to the doctor and they explained everything so well.

My next appointment was a year later, and the doctor asked, “How do you think you are doing? Same? Worse? Better?”

I said, “You're probably not going to believe this, but I think I'm doing better.”

After he examined me, he said, “I think you might be right. What are you doing?”

I answered, “Seeing a chiropractor and taking a B-complex vitamin.”

He responded, “That's not it.”

A year later my appointment was similar but this time the doctor said, “I don't know what you're doing but keep doing it.”

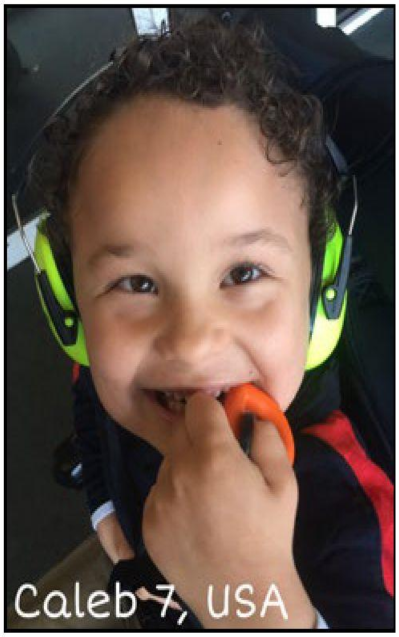
After that, the Ataxia Center started a research study. They took 20+ patients with no results from the Ataxia genetic tests and no family history. The study performed a larger number of genetic tests. In August 2013, the study found four patients with HSP, specifically SPG7.

I joined the Spastic Paraplegia Foundation in the Spring of 2014 and went to the SPF Annual Conference in Dallas, Texas. It was a wonderful experience. I learned so much and met others like me. I WASN'T ALONE! Now I attend every year, whether it is in person or on online, to learn about the newest information regarding HSP and PLS. I look forward to enjoying the company of old friends and meeting new ones.

Find Your Family

By Tia Marie Bragg

In 2016 our son Caleb was diagnosed with KIDINS220 and SMARCC1. We were so excited for this appointment. Finally, after more than a year of MRIs, EEGs, referrals, specialists, and traveling from hospital to hospital, we would have some answers. The doctors would know what to do and there would be a clear path to helping our baby. Then the genetic counselor said, “There is only one other child located in the databases with the KIDINS220 gene change. The child is much older than Caleb, so it is not really possible for us to tell at this point whether this gene change could be contributing to Caleb's clinical picture or not.” The counselor continued, “We were unable to locate any other patients with SMARCC1.”



We sat trying to process these words while in a hospital room, with my two-year-old son bored and fussing and squirming in my lap. The room seemed darker around the edges and for a brief moment words didn't make sense. We finally had a diagnosis, but no answers. They are both “newly discovered” genes. We never felt so alone and confused.

Caleb's pathogenic variant is KIDINS220 resulting in SINO Syndrome: spastic paraplegia, intellectual disability, nystagmus (repetitive, uncontrolled eye movements) and obesity.

When we went back a year later, we were handed an article published just 15 days after Caleb was diagnosed (Josifova et al 2016), giving a brief case study of three children with KIDINS220/ SINO Syndrome.

We briefly were again full of hope. But there was no way to contact these other families. We went on alone and heartbroken for two long years. Caleb's genetic counselor suggested starting a Facebook page for KIDINS220. I thought, “Are you telling me to throw a line into the ocean and pray that the extremely rare fish we are seeking happens to bite?” Little did I realize how brilliant the genetic counselor truly was.

> **“I SPENT TWO YEARS BELIEVING MY SON WAS ALONE IN THE WORLD.”**

In July 2018 it happened! I found a mom through Facebook whose daughter also has SINO Syndrome. Due to a tragic lack of communication among medical facilities, her daughter's doctors were unable to see there was another SINO Syndrome family only 12 hours away. It was then I finally decided to take the genetic counselor's advice and start a Facebook page for KIDINS220.

Since 2018, we have grown from two families in the United States to a group of 15 “zebras” in ten countries (U.S., Denmark, Canada, The United Kingdom, Brazil, The United Arab Emirates, Qatar, Malaysia, France and Taiwan.) While more research is needed, we are seeing cases of Hereditary Spastic Paraplegia (HSP) and Spastic Paraplegia among our group and in research articles.

And quite unexpectedly, a network of physicians and researchers found us. Researchers like the amazing Fabrizia Cesca who has researched KIDINS220 and authored/co-authored many articles on its functions, and Miao Zhao, who joined on behalf of her patients in China (a five generation family with HPS resulting from KIDINS220).

After two years of believing my son was alone in the world, I now welcome messages from new families requesting to join our SINO group. It's an amazing feeling to know they will not have to spend years thinking their child is alone.

Sadly, nearly every parent has told me almost the same story: their doctors told them there are only three known cases, handed them the article and sent them home feeling alone and confused. One was told not to talk to other parents because all kids are different and the doctor saw no benefit in sharing information. Wrong! There is a huge benefit to having a group of people you can talk with who understand your family. We share information, things that work for us, how we cope. We share each other's pain; the pain of rejection of family, friends and society; the pain of feeling that we fail our kids every single day; the pain of watching our beautiful children struggle so hard to do so many things. Of course, we also share the overwhelming joy of seeing our children prevail and succeed.

So, fish for that rare fish. It may take time, lots of time. The medical system isn't set up to bring patients together. Find your family.

Everyone has a Story to Tell. What's YOURS?

Work on the Summer edition of the Synapse is underway and we want to share your story!

Synapse, the Spastic Paraplegia Foundation's quarterly publication, reaches people across the country and around the globe. Readers are eager to hear from others with Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS).

Your story can let them know they are not alone in their quest for a diagnosis. Your knowledge and insight gained along the way can help others thrive.

Your articles, poems and musings can brighten their day.

Articles can be any text format; photos can be any picture format.

Here are some topics to spark your creativity:

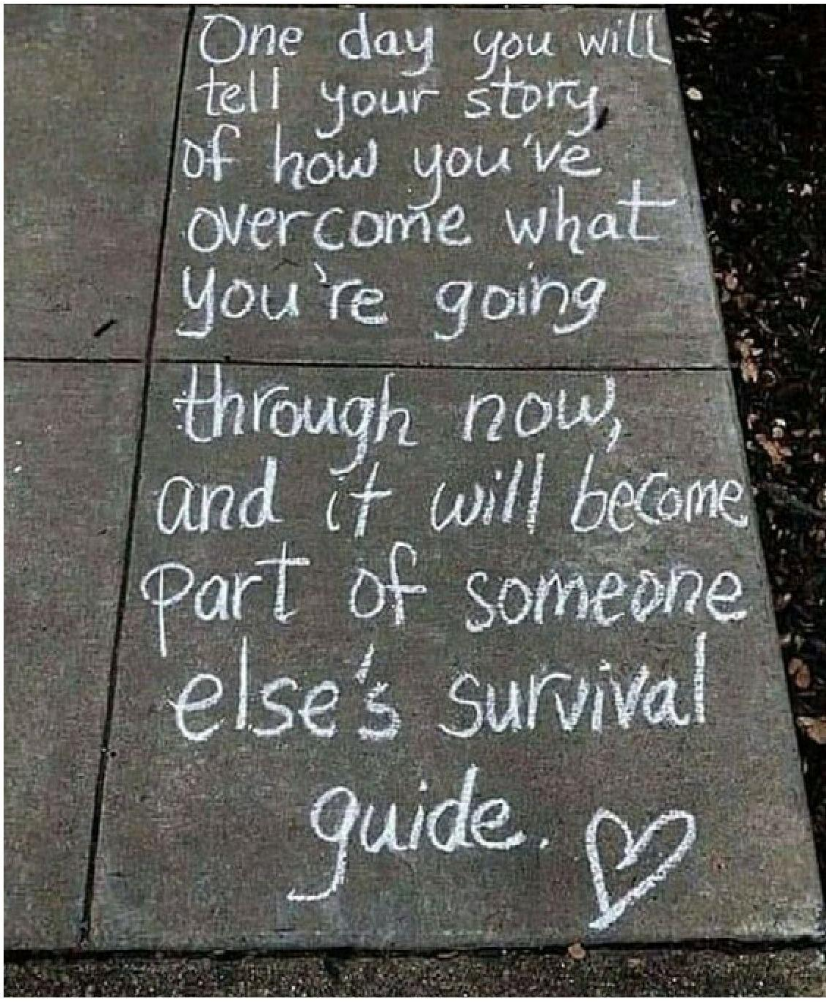
- Ways you keep doing what you love — modifications you make to keep active and stay in the game.
- Technologies and devices that can help make life easier.
- Tips for stretching, exercising, balancing and staying as physically active as possible.
- Sharing a different perspective — how caregivers, partners or children experience and support their loved ones with HSP or PLS.
- How you keep your sense of humor and view the absurdities of life.
- Fundraisers, Connection get-togethers and other events you do to promote awareness and support the Spastic Paraplegia Foundation's mission of finding a cure.
- Milestones celebrated on your journey.

- Proving that a picture is worth a thousand words — share your photos from Rare Disease Day or other special events.

You don't have to be a writer to submit an article! You just need a passion for sharing what keeps you going and growing while living with PLS or HSP.

To submit an article or discuss your ideas contact synapsenewsletter.spf@gmail.com

We look forward to hearing from you!



Artist: @carrychalk

LIVING WITH HSP/PLS

There's No Place Like Home: Tips for Creating a Home Gym

By Pam Lanter, PT, DPT, NCS

It is easy to buy into the ads that feature amazing products touted by amazing actors claiming amazing results. It is also amazing how much you can spend on products that end up becoming clothes racks or dust collectors. There is nothing wrong with getting expensive fitness equipment. You just need to be a smart consumer, knowing upfront what you are getting into and how you can best invest your time and dollars. Your home fitness program and home gym equipment should meet your fitness goals and level of mobility.

Right now with COVID-19 making it more challenging to go to a public gym, a home gym is a great way to address your fitness goals and avoid the setbacks and overall decline that occur with long periods of inactivity and a sedentary lifestyle.

A good home fitness program should be a balanced workout that includes strength training, stretching, balance training and cardio fitness that can be done indoors or outdoors at home. Once you know what kind of fitness program you are after, equipment should complement your workout and allow you to make progress.

Consider Your Fitness Program Needs

Barbells, dumbbells and elastic resistance bands are relatively inexpensive and can provide the same benefits as an expensive weight machine for strength training. Plus, they are more versatile and are easier to manage. There is a degree of control that one has to learn when using them, but they can improve movement, combat spasticity and reduce asymmetry in your body.

A yoga strap and yoga block can help maximize ankle stretches.

TheraBands, a balance board, yoga blocks and free weights are cost-effective ways to supplement major home workout equipment.

Cardio equipment, such as treadmills, stationary bikes and elliptical machines, can be expensive purchases but are good to have as an alternative to exercising outside or going to a gym. If you decide to buy any cardio equipment, make sure you choose something that you can do safely. For example, if you want to purchase a stationary bike, consider getting a recumbent bike instead of an upright one so you have more support during the activity. Or if you want to buy a treadmill, make sure the one that you buy goes slow enough for you to safely use it. You can also complete cardio training by sustaining activity, such as marching, walking around the house or using the stairs, for a set amount of time. No need to purchase any new equipment.

Balance training and stretching typically can be accomplished by just using basic items from around the house. If you want to amp up your equipment with little cost, yoga blocks and a yoga strap are inexpensive and easily available on AmazonSmile.

There are also a lot of instructor-led online or streaming classes or recorded workouts that can be helpful, but make sure you know your limits and don't overdo.

Do Your Research

Before purchasing home gym equipment, do your homework to be sure you get the best value for your money. Make sure you look at reviews, talk to people who have considered or bought that type of equipment, and utilize professionals for advice. Don't just buy what looks good or what the ad on TV is selling you. Keep in mind, in most cases you will not need a commercial grade product or need to pay that much for equipment.

In regards to online or recorded workouts, research which ones might work best for you. If there is a cost involved, find ways to try them out before spending your dollars on something that might end up in the literal or virtual trash. Along with affordability, space is another consideration in buying home gym equipment. Most equipment has specifications and dimensions. Make sure you measure and visualize where you will locate the equipment to ensure it will fit, as well as think through the arrival and installation or setup process.

Ask an Expert

A physical therapist can help you get the most out of your home gym and is a great resource to consult on options to optimize your set up. Most physical therapists are now offering virtual sessions during the COVID-19 crisis. A virtual session can help your PT see your home space to assist with setting up your home gym and creating your home exercise routine. Working with trained professionals, even for a visit or two, can help you design a routine that meets your particular goals while optimizing the equipment you have, or are acquiring, in the most productive way.

When it comes to physical fitness, I have found that internal motivation and external accountability are the keys to success. Your internal motivation (e.g., improving balance to avoid falling, stretching muscles to lessen spasms) is the basis for your goals. Your fitness program and equipment should support achieving them. External accountability keeps you on track. Finding someone or something that helps keep you motivated prevents the dreaded “diminishing New Year's resolution” effect. Once you have those things in place, the rest is just action.

Knees Bang Together?

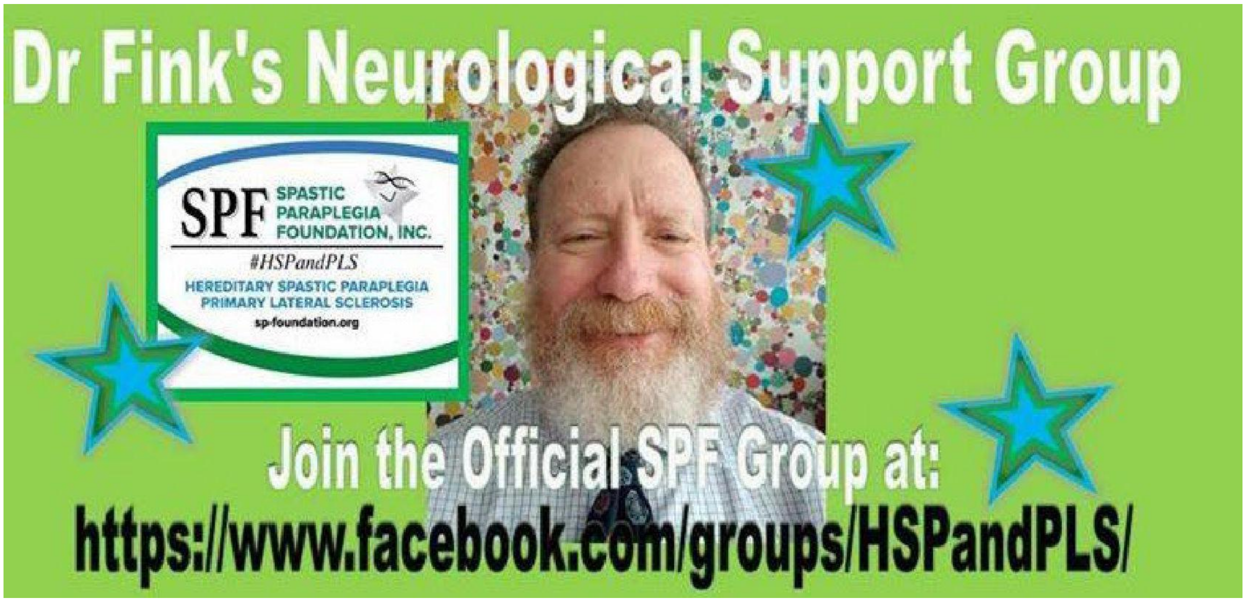
By Jackie Wellman, HSP, SPF Board Member and Co-Ambassador in Iowa

Every time I squatted down my knees banged together. When I walked there was a distinct scissor gait. When I woke up in the morning the spasticity had caused my legs to cross. I felt like I was tied in a knot and it was not pleasant or easy to untie that knot.

I have gotten Botox for years but never to address this issue. After telling my neurologist, who administers my Botox, about my problem knees we decided to give it a shot. Pun intended. The Botox shots were given in the thigh adductors which do not affect my balance at all. Problem solved. The adductors (inner thighs) are the muscles that bring the thighs together. You also can help the “knee-banging” situation by strengthening the abductors (outer thighs) which pull the legs apart. Think clamshells opening and closing! Just look on You Tube for abductor strengthening exercises.

In two weeks, I go back for my second shot and I am definitely in need. I love my Botox! For me, it is a pain-free solution to many of the problems HSP gives me.

Jackie and Snoop



Tips to Limit Fatigue for Persons with HSP or PLS

Adapted from ALS website https://www.als.org/navigating-als/ resources/fyi-minimizing-fatigue

Submitted by Mary Ann Inman, PLS

Learn methods to make life easier.

- Use assistive devices when needed.
- See a physical or occupational therapist for determining what assistance is best for your needs.
- If you have trouble walking get a wheelchair.
- A motorized wheelchair will spare you the exertion of manually wheeling around in a standard mode.

Make your home environment accessible for daily activities.

- Remove barriers to conserve your energy. For example, moving your bed to the first floor of your home may spare the exertion of using stairs.

- Install grab bars to make your shower accessible.
- Use a terrycloth robe to avoid towel drying.

Pace yourself.

Move slowly and safely.

- Stop and rest often and take a few breaths before you start again.
- If you become breathless during a task, it is time to stop.
- Schedule heavier tasks during times that you predict you'll have higher energy.
- Plan your activities and gather everything you need before you start.
- Don't stand when you can sit.
- Utilize possible shortcuts and mobility aids.
- Obtain assistance in completing tasks if you need help.
- Always allow enough energy to enjoy at least one valued experience each day.

Mary Ann Inman

Rest when you are tired.

- Alternate periods of activity with periods of rest.
- Schedule regular rest periods each day, perhaps a half an hour after morning care and an hour in the early afternoon.
- Rest before going away.
- Avoid overexertion.

Get good sleep.

- If you have problems sleeping, such as waking up during the night, determine why and what to do about it.
- Consider having a sleep test.
- Successful use of nasal ventilation may prevent disrupted sleep.
- Seek relief for pain, restless legs or spasms.
- Try to establish a regular sleeping pattern.

Obtain an accessible parking permit.

- Your local Bureau of Motor Vehicles has a form that your physician needs to complete to obtain permission to park in accessible spaces.

Avoid becoming too hot or too cold since this can worsen muscle fatigue and aggravate breathing.

- Use air conditioner in your home if the climate is warm.
- Avoid prolonged bathing in water that is too warm, or prolonged use of hot tubs and steam baths.

Maintain your nutritional requirements each day to help prevent excessive weight loss, resulting in muscle loss that can cause increased fatigue.

- Seek nutritional counseling if necessary.
- People with swallowing impairment might benefit from insertion of a feeding tube into the stomach, a minor surgical procedure for optimal management of nutrition, weight and fatigue.

Avoid stressful situations as much as possible.

- Implementing methods for making tasks easier will help reduce physical and emotional stress.

- By understanding fatigue, family members might cope better with your emotional upsets and realize they are not personal attacks, but normal responses to fatigue.

Recognize medicine side effects.

- If you feel noticeably weaker or have difficulty breathing after taking medication, notify your physician; your medicine might need to be substituted with another one or the dosage might need to be altered.
- Trouble breathing, however, might be related to respiratory muscle weakness, resulting in hypoventilation or the inability to take a deep breath; this might warrant a pulmonary evaluation and treatment of symptoms.

Consider nasal or mouthpiece ventilation to help alleviate fatigue and boost energy in people with respiratory impairment.

- Shortness of breath signals the need to use nasal ventilation or to discuss the option with your physician.

STAY CONNECTED

Visit https://www.facebook.com/SpasticParaplegiaFoundation For Information and Updates about Advances in Research, SPF Events, Living with PLS and HSP, and More.

QR Code for Ease of Donations!

Using your smartphone, 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.

Ascending and Descending a Staircase

By Tina Croghan, SPF Board Member, HSP SPG7

Afew weeks ago I was rehabilitating from two bum ankles (that's another story!) I did my rehab at the SSM Lake St. Louis Day Institute where one of the exercises I did was lifting my feet up and marching. This was to help me go up stairs.

To one side of the room was a mock staircase. One side of the stairs was a 4-inch step and the other side was a 6-inch step. I eyed those steps from the first day; they represented a mountain that I must climb and conquer. On the last week, Sylvia, my Physical Therapist, had me approach the mock staircase. I looked at the 4-inch step side with trepidation. I took a deep breath and was able to get my right leg up on the stair tread. The left leg posed a real struggle. It seemed like it took an eternity to do, but I was able to reach the top (just three steps.)

> **"I LEARNED TO FACE THE STAIRCASE WHILE DESCENDING. IN OTHER WORDS, COME DOWN BACKWARD."**

To come down was another story! I learned to face the staircase while descending. In other words, come down BACKWARD. I tried this. It worked! I held onto the railings and faced the steps rather than the landing at the bottom of the stairs. Because I wasn't looking down at the landing, I knew that if I fell, I wouldn't go far; I could lean into the stairs and use them like a ladder.

On my last day at the Day Institute, I conquered the 6-inch side of the staircase and reached the summit. Remembering my new trick to descend the stairs, I came down backward. I was so happy about my accomplishment; I wanted to share this with you!

CONNECTIONS

SPFIllinois Connection

By Sid Clark, HSP and Hank Chiuppi, PLS

The Winter 2021 issue of the Synapse featured an article on one of several SPFIllinois Zoom Connections. Our virtual Connections have allowed us to share helpful tips, emotions and caring, plus a few much-needed laughs during these challenging times.

At the SPFIllinios January 23, 2021 Zoom Connection, we had 12 people attend. A few more had trouble connecting and said they'd catch us next time. Topics we discussed included:

- COVID-19 vaccine and its distribution. Dr. Fink said, to the best of his knowledge, having HSP or PLS does not place someone at increased risk from side effects of COVID-19 vaccine.
- Exercise and the value of including yoga in a fitness program. It was pointed out you need to ease into a program and not overdo exercise by trying to do everything all at once.
- Drugs such as Baclofen; amounts, and timing.
- The effect of cold weather on spasticity.
- The importance of spiritual insight and direction. Henri Nouwen's book Reaching Out: The Three Movements of the Spiritual Life was recommended to the group.
- The value of experience with a chiropractor. Personal insight and considerations were shared, including ensuring he or she has neuromuscular training.

- A review of physicians in the Illinois area who treat HSP/PLS.
- The possibility and value of cannabidiol (CBD oil) as a part of your program.
- The value of Zoom's chat function. PLSers and some HSPers can have speech problems and by using Zoom's chat function, questions or contributions to conversation can be typed in.
- Online voice studies. Hank sent out the links to three of the ongoing studies.

Attendees at the January 23 SPFIllinios Zoom Connection were: (top row) Sid Clark, Hank Chiuppi, BJ Irwin, Mary Levi; (middle row) Heidi Swanson, Joan Morris, Anne Gongwer (not shown), Mary Shultz; (bottom row) Chris King, Kathy Hlavacek, Steve Beutelspacher; (not pictured) Bryan Caspersen

Choose Your Way to Support Finding a Cure for HSP and PLS

Ways to support the Spastic Paraplegia Foundation's goal of raising money to support medical research and find a cure for

HSP and PLS are as varied as those who donate. You can:

- Donate by check, credit card or PayPal
- Set up a monthly donation plan
- Arrange for Planned Giving through financial or estate planning
- Shop online at AmazonSmile
- Visit sp-foundation.org and choose to help fund research for the cure
- Create a Fundraiser on Facebook
- Use eBay for Charity
- Access the online SPF donation page by scanning the SPF QR code with your smartphone using your QR reader app
- Design your own virtual, personal challenge or community engagement fundraiser

- Select SPF as your charity of choice if you are eligible for the Combined Federal Campaign for Federal employees

Your Smartphone Just Got Smarter

Now you have two additional, convenient ways to support SPF by using your smartphone.

First, and easiest: text us at 956-666-7954. Type Donate in the text message field and send. You will receive a “thank you” message and a link. Simply follow the link and complete your donation information.

Second, turn your everyday purchases into support for SPF by using the Benefit app. Benefit is a mobile payment app that turns everyday transactions into opportunities to support SPF - at no additional cost to you. Getting started is simple:

1. Download the Benefit app,
2. Name Spastic Paraplegia Foundation as your non-profit organization of choice, and
3. Link your preferred payment method.

SPF will receive a percent of purchases when you use the Benefit app in-store or online at leading retailers, home stores, restaurants, grocery stores and more. Check out the retailers that accept the Benefit app at https://www.benefit-mobile.com/our-retailers.

To learn more about SPF and the many ways you can make a difference, visit www.sp-foundation.org.

Look Good. Do Good.

Shop the New Online SPF Store.

Fun, functional and fashionable items are just a click away with the Spastic Paraplegia Foundation's online SPF Store. Items from the official site for branded SPF items help raise awareness of HSP and PLS. Additionally, a portion of each purchase benefits medical research through SPF. Show Your SPF Style

There are so many different items being added all the time, including:

- T-shirts, Hoodies and other logo wear for men, women and children

- Tech Accessories such as Phone and Tablet Cases
- Tote Bags and Backpacks
- Mugs for Home, Office and Travel
- Stationary and Stickers
- Plus so Much More

See all of the products, designs and colors by visiting sp-foundation.org/SPF-STORE and then clicking on the yellow “SHOP” icon.

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