

Synapse

Volume 17, Issue 1 Fall/Winter, 2013

Newsletter of the Spastic Paraplegia Foundation

Letter from the President

Dear Friends,



Welcome to the Fall/Winter issue of our *Synapse* Newsletter. Before you explore all of the many interesting articles in this issue, I would like to share a feeling with you.

This past June, as our annual conference in St. Louis that Tina and Tim Croghan worked so hard to put together was closing, many attendees, with tears in their eyes, said they had gained a renewed sense of hope.

Our annual conference is one of the things that keeps me going. It is not just all of the new information and all of the people that I have a chance to meet, laugh and talk with, I am also grateful for the encouraging and stirring sense of hope I walk away with.

This hope is one that I can just feel in my stomach as our research continues to develop new and more profound insights into just what HSP and PLS are, how they work. The more these researchers discover, the more hope I feel. It is a light that is becoming brighter and brighter at the end of our tunnel.

I hope all of you can share in this hope. Alexander Solzhenitsyn said “Hope is a matter of choice.” It is not the same as optimism or wishful thinking, which can at times feel almost insulting. Hope resembles courage more than cheerfulness. For those of us working on a cure for HSP and PLS, hope is a leap much like faith. We all benefit from hope. As Samuel Smiles said “Hope is the companion of power, and the mother of success; for who so hopes has within him the gift of miracles.”

The Mayo Clinic stresses the healthful aspects of hope as we strive together to find a treatment or a cure. They report that hope increases strength, resistance, reduces your risk of heart disease, and improves your coping skills. You can even catch hope from others. Please join us in our adventure; in our quest toward the day when treatments will be found for HSP and PLS.

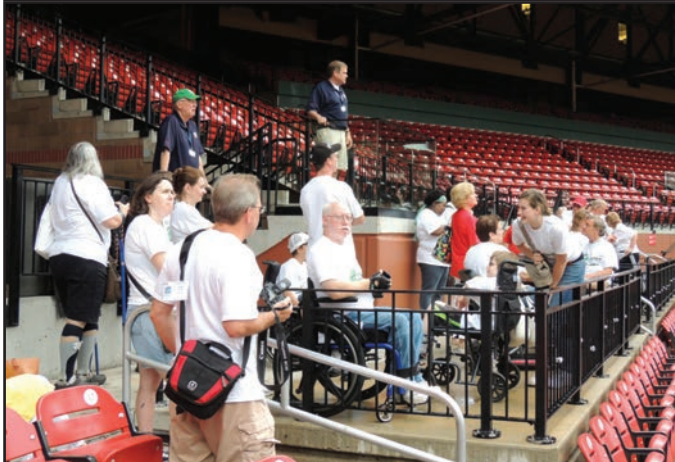
Sincerely,

Frank Davis

President, SPF

PS - Put our 2014 Annual Conference on your calendar! It will be in Dallas, June 13-15. More information about the location and how to register will be on the website soon.





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Volume 17, Issue 1 - Fall/Winter 2013

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).

Synapse Editor

Allen Bernard.....Senior Editor

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ANNUAL CONFERENCE 2013

Reflections from the St. Louis Annual Conference

by Allen Bernard

This June's conference in St. Louis was great experience for everyone involved. Yes, you hear that a lot -- especially from the folks that threw the party -- but it's true.

Para-Olympian medalist Rebecca Hart gave an uplifting and very personal talk about her experiences growing up with HSP. You may remember Rebecca from her trip to New York City for an appearance on "Good Morning America" with Ann Romney during the 2012 presidential campaign.

Having a five-year-old girl with infant onset HSP just like Rebecca, I was particularly moved when she said there was a day where she had had enough with trying to fit in, trying to be like everyone else -- trying to be "ordinary" as she put it. On that day, she decided was going to be "extraordinary." Well, she certainly succeeded and is working hard on her next shot at gold.

After spending some time with her fellow HSPers and having lunch with the board, Rebecca has agreed to represent SPF wherever she can. We will be looking for opportunities for her to speak and spread the word as the year progresses.

On Monday morning, my wife, Karen Prior-Bernard, gave a great talk on what it is like "Being Brianna's Mom." Of course, I'm a little biased but I think she did a great job with a very tough assignment. Particularly moving was how she described our daughter's reaction to "running" a foot race with a bunch of other kids one day this summer. Brianna of course was so far behind Karen and I helped her along by holding hands. When we came upon a feather Brianna stopped, picked it up and said, "You know, none of the other kids saw this. They were going too fast."

Karen tells it better as you will see if you go to our AC video page on the website but, basically, when a five year old gets philosophical about her untreatable rare disorder there's hardly a dry eye in the room.

We also had some of the smartest minds in medicine come to share their work with us. They are making great strides in understanding HSP and PLS. I won't go into what they said here since that would be too difficult. The most important thing I learned is, for HSPers in particular, there is more research being done and published today

than any other time in history. Dr. John Fink's first slide shows this clearly. If you take nothing else away with you from these videos or if you attended the conference, this is the most important.

More research will hopefully become self-fulfilling: attracting more researchers and more money to the field. PLSers can also take heart from this trend since HSP, PLS, ALS and host of other upper motor neuron diseases are closely related. The hope is advancements in one will lead to better understanding of all.

As for the conference itself, a big round of applause needs to go to board member and HSPer Tina Croghan and her family and friends for making the event such a huge success. The Airport Marriott was great. Tina, who lives in St. Louis, and her "red shirts" (all them former drama students from Tina's days as a teacher) gave the event a professional flare that is extremely hard to do. They made it look easy. So hats off to Tina! Thanks so much for all the hard work. (I personally parted with more than a few dollars at the silent auction, which was full of fun and useful items, like a Starbucks gift pack!)

In fact, in honor of all her hard work and dedication to our cause, the board has named her Honorary Chair for all upcoming conferences so we can learn from her sage advice and experience to make each one better than the last.

Of course, thank you to everyone who put forth the considerable time and effort to attend. Traveling with HSP or PLS is not easy but over 135 of you made the effort and that means a lot to everyone. Without you there wouldn't be a conference -- speakers don't generally give talks to empty rooms. So give yourselves a pat on the back. Your continued participation keeps everyone in the medical community interested and committed to helping find treatments so don't under-value your efforts. It really means a lot.

Next year we will be in Dallas. The dates are still being worked out but it will be most like be the 3rd or 4th weekend in June. We'll post this on the Website so check back soon.

Until then, please take the time to watch these compelling videos to learn about the latest research and also to know you are not alone. There are many tens of thousands of us out there so take heart and, hopefully, we'll see you next June.

Connections

North Texas Spring HSP/PLS Connection

by John Staehle

As the north Texas state ambassador I hosted our Spring HSP/PLS Connection on Saturday, May 4th in the private dining room at iFratelli Ristorante in Irving, Texas. Our group for this connection numbered 20, including three first-time attendees, two guest presenters and four visitors from neighboring Oklahoma.

After introductions and lunch, I updated the group on the then upcoming annual conference being held this year in St. Louis from June 14-16. I also reported on the current number of contacts in the North Texas region: there are now a total of 73 names on our list of which 50 have either a diagnosis of HSP or PLS or are a spouse or an immediate family member of someone with HSP or PLS.

Our first guest presenter was Linsley Smith, RN, BSN, who is the Pediatric HSP Clinic Coordinator at Texas Scottish Rite Hospital for Children in Dallas. She walked us through a presentation that summarized the four active HSP research projects in work at the hospital:

1. A database of children with HSP (*currently they have 116 patients in the database*);
2. Diffusion tensor imaging (DTI) findings for HSP;
3. Genomic characterization of HSP; and
4. Community ambulation, energy efficiency and gait kinematics in patients with HSP.

Linsley informed the group that even though eligibility for the monthly clinic was limited to children in Texas, they have expanded it to include children with HSP in other states on a case-by-case basis.

Our second guest presenter, Janet Witter, was introduced by one of our local PLSers, Jack Overly. Jack has been taking Protandim, a patented antioxidant therapy, for almost a year. After eight months, he noticed an improvement in both his speech and his walking ability. Janet introduced us to the supplement Protandim using a video of an ABC Prime Time report, followed by a question-and-answer period. Interested individuals were directed to contact Jack for more information or to order Protandim for themselves.

Other subjects of discussion included the medications we take and their side-effects, physical therapy, exercise routines, caregivers' perspectives, HSP/PLS support websites and any personal experiences or best practices we wanted to share for the benefit of others. At the conclusion of our discussions, we agreed to meet again for a Fall Connection on November 9, 2013. More on that in the next issue.

If you would like more information on how to hold your own connection, go to our website, www.sp-foundation.org or contact your state ambassador or use the information@sp-foundation.org email.



Our Connections Group having lunch at the iFratelli Ristorante in Irving, Texas on May 4.



Wheelchair-Accessible Travels

Hi, my name is Bonnie Guzelf. I have had PLS/ALS for 13 years. I use a power wheelchair and can no longer walk, drive or work. I do still live to travel and refuse to let this stop me.

My husband and I took a wheelchair accessible tour to Israel last year and had the most amazing time. Next summer in 2014 we are planning a wheelchair accessible tour to Ireland. It will be a small group, about 8-10 people. For people with wheelchairs, walkers, canes, slow walkers etc. or anyone who wants a smaller group and slower pace this is the trip to take.

I also write a blog about my experience so please stop by: <http://wheelchairaztravel.blogspot.com/2010/05/bonnies-blog.html>

The Israel Trip

In March 2012, my husband and I took a long awaited tour to Israel. My only issue was that I use a wheelchair full time. But it turned out not to be a problem. I found a tour company -- www.Israel4all.com -- that specializes in tours for people with extra needs. Best of all the owner/operator Eli Meiri knew where all the wheelchair accessible bathrooms were!

It was a small group, seven strangers who soon became like family. The tour bus was an oversized van with a lift in the back, individual seats on each side and space in the middle to tie down wheelchairs.

Traveling with a group of people in wheelchairs was, for me, very empowering. I didn't have to worry about keeping up with the group or being embarrassed about using special eating utensils. Unlike most standard tours, we began our days a little later to give us the extra morning time we needed to get ready.

Our tour guide, Eli, was sensitive to our needs and flexible enough that if the day was getting too long for us, we could rearrange the schedule to push something off until the next day.

Our room in Tel Aviv was big with a very large accessible bathroom. The hotel in Jerusalem was also very user friendly. Friends tried to tell us not to go because of all the political unrest there. Rest assured there aren't soldiers with machine guns at every corner and we never felt threatened or afraid in any way.

Accessibility varied among the tourist sites we visited, but generally it was pretty good. The Israeli government is trying very hard to make things accessible for people with disabilities without destroying the ancient sites they came to see.

We found good accessibility at sites such as The Sea of Galilee and Jerusalem, which has an accessible route developed by the Jewish Quarter's Center for Tourists with Disabilities. At Masada, where Jewish rebels made an epic stand against the Romans nearly 2,000 years ago, we took an accessible cable car to the top of the fortress and accessible pathways led us around the site as our guide explained the history.

The whole trip was an incredible experience. It was a trip of a lifetime and something I will never forget.

The Ireland Trip

The eight day tour of Ireland will include accommodations at accessible hotels, transportation on a luxury fully accessible coach, airport transfers in a fully accessible coach, full Irish breakfast daily, dinner on four evenings. A Dinner show in Dublin is also planned and the services of a wonderful Irish driver guide who will be with you throughout the tour. The tour includes all baggage handling and gratuities ... except for the meals on your own, and the tip for the guide.

For more information on full itinerary etc. contact me directly at bguzelf@cox.net or 480 838-1184. The price will be between \$3,000 and \$3,200 per-person double occupancy, depending on how many people we get. The more people the lower the cost. Airfare is not included.

All are welcome including able-bodied folks who do not require an accessible room are also welcome. The date will most likely be in June 2014.

Support SPF with One Step a Month

Consider making a monthly donation to help SPF move a step closer to a cure. Our One Step a Month Program is a win-win! Recurring gifts allow us to plan ahead with confidence, making sure we take the best steps towards finding the cures for HSP and PLS. Plus, recurring donations allow you to give in a convenient, safe and secure way.

Go to <http://www.spf-foundation.org/donate.htm>

Abilities Expos Spread the Word

by Frank Davis

The Abilities Expo is held every year in many cities around the country. Each expo is a series of about 150 booths offering all sorts of equipment, and help for people with limited abilities. They also have talks and demonstrations throughout the day on everything from caretaking to travel to horseback riding.

The cities where they are held include, Atlanta, Boston, Chicago, Houston, Los Angeles, New York, and San Jose. To find out about specific dates for these Expos, you will find their website www.AbilitiesExpo.com.

My wife, Claudia & I have attended the show in Houston held every August for the last couple of years. Last year, in 2012 we were exiting the show and waiting for an elevator, when we struck up a conversation with David Korse, the owner and founder. I told him about SPF and how we were trying to come up with avenues for spreading the word about HSP and PLS. He suggested that we set up a booth at the next Houston Show as it would not cost us a thing. We agreed.

We soon reserved a booth for the 2013 show. Claudia and I showed up this past August 2-4 with SPF banners, table cloth, flyers, brochures. Hundreds of people walked past our booth for three days, not one missed reading about SPF on our many banners and many stopped to find out more about us.

We attracted interest from businesses, magazine writers, government agencies and spinal cord injury associations. We also attracted interest from people with spasticity of different kinds, many students and nurses from Houston-area physical therapy colleges and many people with HSP and PLS who attended, several of whom had met only a few other people with their conditions.

Claudia and I took turns visiting the other booths. It was very interesting for me to see companies offering all sorts of very clever and handy tools for improving mobility. I stopped at booths with aids and medicine for incontinence, exercise equipment, computer tools for people with speaking problems and problems with their hands, travel companies who specialize in arranging travel for the disabled. A few are even talking with us about coming to our annual conference in Dallas next June.

Overall, we found the Abilities Expo to be a very valuable experience and hopefully we spread the word about PLS and HSP so more people, pharmaceutical companies, magazine writers, philanthropists and medical people are aware of us.

If you would like to do this at an Abilities Expo near you, please get in touch via our website and we'll see about getting set up with what you need to staff a table.

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SUPPORT SPF WHILE YOU SEARCH

Raise money by using GoodSearch as your default search engine which will donate about a penny per search to SPF. You use it just as you would any search engine, and it's powered by Yahoo!, so you get great results. Just go to <http://www.goodsearch.com/> and enter Spastic Paraplegia Foundation as the charity that you want to support.

Exercise and You

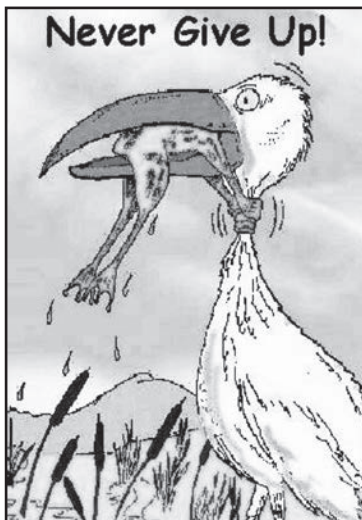
Never Give Up!

by Tina Haag

There are times in your life when it is easy to dispense advice, but very rarely do we follow it. My husband Troy is a rare example of someone who takes the advice he gives to heart. A favorite example of this advice is “never give up”. This is how he lives his life. He has preached this to our two children who have HSP from very early on. He has taught them, by example, that if there is something you want to do you can no matter the obstacles in their way.

Having HSP since birth, Troy has learned quickly that his life would follow a different or modified path from others. He has taken all of this in stride and daily he amazes those around him with his positive attitude and zest for life. He never gives up even when it would be easier to throw in the towel and call it a day.

Recently, Troy has taken on a new challenge: competitive wheel chair racing and wheel chair basketball. We are so blessed to have a local organization that helps make this goal a reality. As many of the readers know, a competitive wheelchair is very expensive and without the support of Turnstone Center for Disabled Youth and Adults, training for the Troy's upcoming half-marathon would be impossible.



Accommodation without Surrender

by Kenny Hersh

For my 60th birthday my kids wanted to do something special for me. They all know I've always wanted to sky dive but after some research (and my wife's veto), they decided that it wasn't a good plan. The landing, even if attached to an instructor, would require me to lift my legs or suffer a broken leg. Not a good plan.

So they began to research other alternatives that would somehow involve flying and be reasonably safe. While we were on vacation in New Hampshire, they took me on a “mystery ride.” Of all things, we ended up at a hang gliding place! (They somehow got my wife's approval.) The staff was so nice to me and my kids had given them a heads up on what to expect. They treated me with respect and enthusiasm.

I was attached to the harness of the glider and then attached to the instructor. He gave some instructions and then the tow plane took off with our hang glider attached. We were towed to over 3000 feet and then released.

They generously allow Troy to borrow the chair so he can train whenever he gets the chance. We cannot be more thankful for this service until we can save up enough money to buy Troy his very own chair.

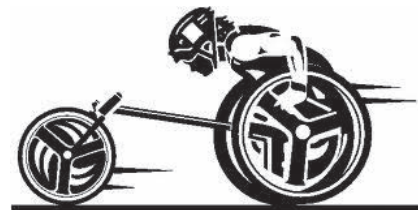
When I first approached Troy about writing this article I will admit he was reluctant. He doesn't always feel that he is doing anything special. Ultimately though, he decided that if he could inspire someone else to try something new it was worth it. His determination is contagious.

I could not be more proud of my husband. He is amazing. Although he was never in a chair before this (typically he walks with a cane) he is up to 8-10 miles in just a few months. He wheels circles around me and I have been training for close to a year.

This September will be our first race. We plan on using this opportunity to raise awareness for HSP but, more importantly, this is yet another opportunity for Troy to show everyone that it doesn't matter what stands in your way -- if you have the will you can overcome anything.

If you'd like to get in touch our contact information is:

Troy and Tina Haag
Fort Wayne, Indiana
(260) 744-3658



It was pure heaven. So peaceful and the vistas were amazing. The instructor and I were talking the whole time. Somehow, the adrenalin must have improved my speech as he was able to understand me. The only noise was the gentle whoosh of the wind. We circled around over Vermont and New Hampshire with the peaks of the mountains clearly visible. We were airborne for about 20 minutes, but it seemed like just a minute or two. The landing was flawless.

When we landed, all of my kids and grandkids ran up to the glider and we all cried tears of joy. I love flying and have spent many an hour on a computer flight simulator. This was a dream come true and the best part was being surrounded by my wife and kids as I did this.

I am sharing this story so that all in PLS-land will not be afraid to follow their passions and figure out a way to accomplish them.

As I always say: Accommodation without surrender.

Fundraising

CFC: Finding More Money for Research

As you probably know, medical research can be very expensive. Funding research to find cures for HSP and PLS is the main purpose of the Spastic Paraplegia Foundation (SPF). One resource we can take advantage of is the Combined Federal Campaign (CFC).

The CFC is a fundraising campaign the federal government offers its employees to participate in in each year. It is like a United Way campaign where employees pick the non-profits they would like to support. This amount comes out of their paycheck pre-taxed, so they may not even notice the difference. The CFC enrollment days and fairs start on September 1 and run through December 15.

Each year millions of dollars are raised through the CFC campaign. Unfortunately, the SPF doesn't get much of that money, usually around \$5,000.

Your help is needed. Please ask a federal employee you know to pick the SPF to contribute to. The best way to get a commitment is to ask personally. If that is uncomfortable, feel free to send a letter or email.

Our CFC number is 12554. Donors will need to know this number so they can designate the SPF on their forms.

The following are examples of federal employees: law enforcement, mail personnel, VA or employees, Medicare, Medicaid, military and many types of governmental jobs. If donors want to know more, please have them go to www.sp-foundation.org

We are also looking for volunteers to attend CFC fair days. If you are interested, you would sit by a table and hand out SPF literature and answer questions. Most people do not know what HSP or PLS are or what purpose the SPF is. We need volunteers to man these booths and help educate participants about what we are dealing with so employees will pick us to contribute to. Dates and locations of the CFC fairs will be communicated soon through our state ambassadors.

If you have any questions, suggestions or would like to help with a CFC fair, please contact Jim Sheorn at jmsheorn@comcast.net.

Fair dates will be posted on our website.



NEW MOBILITY: THE MAGAZINE FOR ACTIVE WHEELCHAIR USERS

www.newmobility.com

"New Mobility" encourages the integration of active-lifestyle wheelchair users into mainstream society, while simultaneously reflecting the vibrant world of disability-related arts, media, advocacy and philosophy. Our stories foster a sense of community and empower readers to:

- Participate in all areas of life, including education, work, love, sex, home ownership, parenting, sports, recreation, travel and entertainment;
- Be informed of and take charge of health concerns;
- Obtain appropriate technology; and
- Assert legal rights.

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CALLING ALL MOMS!!!
Check out a new web site

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Do you have a child suffering from any type of spastic paraplegia? HSP? PLS? Then this is the site for you.

www.cafemom.com/group/116957

A place where moms can come together – to share, encourage, and support one another!

Come Check Us Out!

Created by: Jessica Barlow-Anderson

How Can I Help?

by Jackie Wellman

We can all do a little without donating the huge amounts of money most of us do not have. If we all did a little, the cure we all seek will become a reality. Research is expensive and the Spastic Paraplegia Foundation (SPF) wants to fund as many early-stage research grants as possible. Our grants fund the ideas that eventually lead to full-fledge National Institutes of Health (NIH) grants that can be in the hundreds of thousands of dollars or more.

The first and simplest thing we can all do is use Goodsearch. Goodsearch is a search engine powered by Yahoo! Every time that it is used one penny is donated to SPF. Some of use search 10 times a day and some of us 100 times a day. Just think if everyone reading this used Goodsearch every time they searched the Internet. We could fund a grant just by Goodsearchers! If you are a person who is already using the Internet, then why would you not do this? Donating to help yourselves and future generations of us this way costs you nothing. Tell all your friends and family.

Now we are entering the time of year when holiday shopping happens. As people who do not love to be on our feet, I am betting there are many of us who use online shopping. Goodshop is a way to earn money for SPF and it does not cost you a penny. If you Goodsearch, Goodshop and enter the sites you want though these search engines those retail outlets donate a percentage of your purchases to SPF. Target, Drugstore.com, Walgreens, Amazon, Barnes & Noble, etc. are among the many stores included. Again, there is no reason not to shop this way and tell all your friends and family.



The next idea is for people wanting to make a little more effort. Use Goodsearch to look for private foundations in your county (Type in “private foundation [the name of your county]”). You will be shocked at how many rich people are in your neighborhood that you did not know about! People with lots of money form a private foundation as a tax shelter but they must give away a certain amount each year by law.

This takes a little investigating on the Internet and most foundations are very particular in what they fund. Write them a letter asking if we could apply for a grant. Don't ask for money right away but just if you can apply. Applying for the actual grant is a big deal and we have people on the SPF board that can do that after you get an initial “Yes.”

In the letters just introduce yourself and ask if SPF could apply for a grant. Always say that we are a 501(c)3. That tells them we are a bonafide non-profit foundation. If you do not say this, your letter will surely find the garbage can. In the next paragraph I briefly talk about HSP, PLS and SPF. In the last paragraph I give a few personal sentences about myself, why I want a cure, and that I will do whatever I can to find it. Keep it all short and sweet. The letter of inquiry is just the first step in the grant process. Many more will come.

There are so many other ways to help research out. You can participate in clinical research, you can have a bake sale, a car wash, get your church involved in fundraising, participate in a TeamWalk, walk by proxy, have one yourself, have a golf tournament, have a donation jar at local restaurants, etc. Really there are hundreds of ways.

Having a purpose really makes it easier to deal with having a neurodegenerative disease. Be the change you want to see in the world. You are not only helping fund research but helping yourself.



Up Close and Personal

Unconventional Tactics: A Decade with HSP

by *Harvey Mover*

Nearly 10 years ago I was searching for solutions as to why I was walking so poorly and why it was getting worse. After seeing the chief neurologist at Indiana University Health in Indianapolis Dr. Robert Pascuzzi, he suggested that meet with Dr. John Fink who was coming to the University the following month. A couple of months later we found out my wife was pregnant and then the following week we got the results that were positive for HSP.

Talk about Yin and Yang!

When I found this out, I looked for ways to fight what I referred to as an “inconvenience not a disability.” As an out-of-the-box thinker, I always try to find solutions to problems and, as an alpha male, I try to fix things. I became frustrated with the medical information I found that offered no real solutions so I focused on solving this “inconvenience.”

Having worked out with weights beginning at 16 (I am 51 today and at 40 I bench pressed 525 lbs.), I focused on leg strengthening exercises, doing leg extensions, curls and calf raises keeping my legs strong and also riding a stationary recumbent bicycle.

One of the questions I had because this occurred in my mid-thirties was if there was a correlation with a decrease in hormones, which occurs at this time. I began taking over-the-counter supplements like creatine to compensate for this. Eventually, I went to a D.O. who agreed and, he provided alternatives that would be more impactful.

Additionally, to fight the cramping in the middle of the night, I began to take chelated magnesium, calcium, omega 3 along with several other vitamins. Today, my cramping is about 10% of what it used to be.

During the past decade, I have experimented with countless things that worked and some not so much. Still others were very painful like acupuncture and wet cupping. Today, I make regular visits to a chiropractic neurologist Dr. Brad Ralston in Indianapolis who has background in brained-based therapy. Although this may seem unconventional, he has been able to identify what therapy is needed to impact certain areas of the brain to provide better balance and stability.

Most recently, I found a local organization that focuses on private training, therapy and flexibility. Michael Cochard of Flexfitt has identified that a majority of the muscles in my legs have scar tissue and knotting and, he is working with me on aggressive therapy to stretch and loosen them using a combination of techniques and a soft tissue tool called Fuzion. It's been just a couple of months and I am seeing a noticeable improvement. I am also becoming more aware of how I am walking and what muscles are being used. This helps me focus on having a better gait.

I know the battle will continue but I am optimistic that using unconventional tactics will both show positive results and slow or minimize the progress of HSP until a cure is discovered.

How I Got Annie

by *Jean Chambers*

I started my application for a service dog in the winter of 2011-2012 with Canine Companions for Independence (www.cci.org) and went down to Santa Rosa, CA for my personal interview after our 2012 annual conference in Washington D.C. During the initial application process, I was asked if I could come on short notice if needed and that's exactly what happened. Someone withdrew and I was called one week before I had to drive down there.

I chose to drive because I wanted to do the training with my walker and my power chair. I have a very little car, so had to go by myself -- no room for anyone else -- but it all worked out okay.

Two weeks of very intense team training started on August 5. At first, we worked with several different dogs but on Wednesday morning they did pre-matching with the dog that most suited our needs. I totally lucked out.

I wanted a large black lab because I had grown up with one and I got a petite little yellow lab named Annie. She is such a great dog and very big in what counts. We had a two-and-a-half day drive home after the graduation on Friday the 16th. It was hot, the traffic was heavy but Annie was a real trooper.

I hope that you will look at their site. They have centers all around the country. The kids program is called Skilled Companion Team. We had six kids in our team training. Three boys with autism, three with with CP and one boy who was pretty complex.

LSVT Speech Therapy

by Hank Chiuppi

When I was diagnosed with PLS, it was my voice that was affected first. The doctors call it dysarthria and it was the start of my disability.

I was working in information technology (IT) then and it began to affect my daily conversations and interactions. My wife, of course, noticed, too. My colleges noticed but they didn't want to say anything. They may have thought I had a drinking problem. I don't know. My speech was slurred and definitely not articulate.

When I saw my doctor he said "It's definitely not mechanical." He thought I should see a neurologist. I did and she had me come back for an EMG and then sent me for a MRI. After the results came back, she recommended me to a university neurologist. Now, after five years, lots of tests and seeing two other neurologists, they say I have PLS ... probably.

Getting back to the speech situation, I had five sessions of speech therapy at a local hospital four years ago. It wasn't that productive.

LSVT Approach

I recently started speech therapy again with a new therapist at the same hospital. She was more understanding and she had a more practical approach. It is a form of Lee Silverman Voice Treatment or LSVT.

It is a proven rehabilitation method in treating speech disorders in people with Parkinson's disease. Treatment targets loud clear speech. There is a very intensive program in LSVT by certified instructors. We are doing a simplified approach emphasizing loudness and breath control.

She advised me of key issues of my speech. Namely poor breath support from my weakened diaphragm and a weak soft palate. The soft palate is the soft muscular part of the roof of your mouth, behind your teeth. It closes off the nasal cavity when swallowing. She said I was losing air out my nose when talking because the soft palate wasn't moving like it should.

So she gave me a basic breathing exercises. To help with the lazy soft palate she told me to fill a bottle half full of water and put a straw in it, then blow through the straw and make bubbles.

When I first tried, I couldn't do it. She told me to hold my nose closed and try again. I managed to blow a few bubbles for less than a second. With practice I am up to nine seconds now. I now know why I can't blow up a balloon or whistle.

Also part of my daily homework is taking a deep breath and saying "Ah" for as long and loud as I can. I then try to reach my highest pitch and sustain it for 2-3 seconds. I then try to reach my lowest pitch and sustain that for 2-3 seconds. I repeat all of these exercises six times.

This is an abbreviated account of what we are doing but it is the most important part for strengthening the diaphragm and the soft palate and the vocal chords.

The other thing my therapist recommended is an oral prosthesis to help hold up the soft palate. I am seeing a prosthodontist next week to examine the possibilities and costs. It won't be a total fix but it should improve my clarity of speech.

Research Sound Bytes

New Comprehensive HSP Test on the Horizon

by Dr. Rebecca Schuele and Prof. Dr. Peter Bauer, Institute of Medical Genetics and Applied Genomics, University of Tübingen, Germany

While the genetic causes for the HSP are varied -- at least 39 different HSP genes are known at the moment and about one third of it have anew been discovered the last year -- up to now the genetic testing community has mostly searched gene by gene for the one responsible for a person's disorder.

This process can stretch about many years and is very expensive. For those affected, this can be a very tedious and difficult process.

Now the development of next-generation sequencing will permit genic labs to test for almost all known HSP genes at the same time. This will shorten diagnosis time by years for many patients. The new HSP panels are expected to cost about the same as testing for two or three HSP genes.

The panels are not widely available yet but they are expected to become so in 2014.

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