

Synapse

Volume 18, Issue 2

Spring 2015

Newsletter of the Spastic Paraplegia Foundation

"Singing in the Rain in Seattle"



SPF 15th Annual
CONFERENCE
June 26-28, 2015
Seattle, Washington

How to Help

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

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

Support Research to Speed Our Cures by Volunteering

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

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

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

Conference Organizers: The SPF seeks event coordinators in or near metropolitan areas who can work with us to organize Conferences for our 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. Conferences can be half-day or full-day events.

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

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

Business and Administrative Support:

Volunteers with business and administrative skills can play a valuable role in administering the work of the SPF. Most of the help is coordinated through email correspondence and uses popular Office applications.



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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

John Staehle.....Senior Editor

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P.O. Box 1208

Fortson, GA 31808

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Falls Church, VA 22043

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Letter from the President



Dear Friend,

I've got two quotes for you this month. Isaac Asimov once said, "The most exciting phrase to hear in science, the one that heralds the most discoveries, is not, 'Eureka!' (I found it!), but, 'That's funny....'" The second

quote is from Macrina Wiederkehr who once said: "We live in a world of theophanies. Holiness comes wrapped in the ordinary. There are burning bushes all around you. ... Life wants to lead you from crumbs to angels, but this can happen only if you are willing to unwrap the ordinary by staying with it long enough to harvest its treasure."

I'll tie these two quotes together by saying that I consider the incredible number of times I have heard and felt the phrase "that's funny," as of late, to be theophanies. I want to thank "God" or "Reality" (which ever name you are the most comfortable with) and you, for your donations, so much, for making it all happen. Thank You!

I have been traveling on SPF business the last few months (at my expense) and the excitement of the progress that is taking place is almost overwhelming. In early March I attended Dr. Michael Benatar's CREATe conference in Miami. He recently received a large 5 year grant from The National Institute of Health to study the related disorders of ALS, PLS, HSP, FTD, PMA and MSP. Scientists from all over the world spoke about a particular aspect of the study they were working on. Many of the scientists spoke about their HSP and PLS research.

In mid-April, my son Adam and I travelled to Graz, Austria, to attend the Tom Wahlig Foundation annual Symposium. Tom Wahlig and his son, Henry (who has HSP), have been hosting this Symposium since 1998 where leading scientists from around the world gather to speak about the latest research on HSP. I did not understand all of the scientific language but the

excitement in the room could be cut with a butter knife. The rate of discovery about HSP and PLS is happening so fast that even the brightest minds are just keeping up with the pace as the pieces of the puzzle keep falling into place.

I just finished putting together our Spastic Paraplegia Foundation 2014 Annual Report which you may have received by the time you read this *Synapse* Newsletter. It was fun working with Dr. Aarnoud van der Spoel with Dalhousie University in Halifax, Canada, to put together a report of just some of the progress that is taking place with HSP and PLS research. It was difficult to choose from the hundreds of research reports that are stepping forward toward a cure. This is not "pie in the sky" science folks. We are working on actual treatments for real people.

In early June, I'll be traveling, again at my expense, to Madrid Spain where HSP/PLS patient groups from all over the world will be meeting to discuss how we can better work together toward a cure. We are particularly excited about the possibility of developing an international, multi-lingual HSP/PLS Patient Registry that will not only provide worlds of information for researchers but will let pharmaceutical companies know that we have all of our "ducks in a row" so they will take us very seriously.

To top all of this off, our SPF Annual Conference is coming up very shortly, June 26-28th in Seattle Washington and I'm so looking forward to seeing you there. We will hear even more about just what is happening with HSP/PLS research and how to manage our conditions. Many fun events are planned too, so don't miss it. Information about this conference can be found in this newsletter and on our website, sp-foundation.org.

Sincerely,

Frank Davis
President, SPF

SYNAPSE APPEAL

Synapse costs lots of money to print and mail, and we need your help to keep it going for another year. Please use the enclosed response envelope to make a donation. Every little bit helps.

Board Business

This is a new recurring column that highlights significant items acted upon by the SPF Board of Directors since the previous issue of Synapse. For this initial column, it covers October through April. Rest assured, there are many more things being worked by the Board, but only the significant, completed items will be highlighted in this column. Selection of those items is solely the responsibility of the Senior Editor.

Tina Croghan reported that she has finished short versions of the HSP and the PLS Handbooks. She has also completed a “long version” of the HSP Handbook that has more details. Tina will be seeing Dr. Fink on October 15th and will take the handbook material to show him. (Oct. 2014)

Linda Gentner and Jean Chambers reported the California TeamWalk held last month raised \$29,700. Money is still trickling in. Fewer people participated this year but were more generous. This was Linda’s 13th year of doing the California TW. Kris Brocchini bought lots of raffle tickets and consequently won lots of prizes! (Oct. 2014)

Frank Davis reported the Year End Letter was finished but still needed Mark Weber’s review/edit. He also told the Board that the anonymous donors will do their matching gift programs again this year. (Oct. 2014)

Athena Alliance: Affiliated with Athena Diagnostics to allow people to have gene testing done at a lower cost. Applicants with lower incomes can apply for testing – fees will be significantly lower if they qualify. (Nov. 2014)

A motion was passed to ratify a previous vote by email in which all Board members unanimously voted to award the 2015 Virginia Freer-Sweeney Clinical Research Training Fellowship in Primary Lateral Sclerosis (VFS Fellowship) to Sabrina Paganoni, MD, PhD, of Harvard University, for her proposal entitled, “Imaging of Inflammation in People with PLS.” (Feb. 2015)

The Board passed a motion to increase SPF Research Grants from \$60,000/year to \$75,000/year. (Feb. 2015)

Launched SPF’s new website, developed by Firespring. It gives us more control of content without having to rely on the paid services of a contract webmaster. (Mar 2015)

State Ambassador - It's Easier Than You Think

The states of Massachusetts, Minnesota, Alaska, North Dakota, South Dakota, Mississippi, and New Mexico do not have an SPF state ambassador. Being a state ambassador is not a daunting volunteer job at all. It is very gratifying if you do it right.

My name is Jackie Wellman and I live in Iowa. I am the Iowa state ambassador. I can just share with you what I do. Some ambassadors do so much more. When a new member that lives in Iowa joins SPF, I get an e-mail from Linda telling me their name, address, phone number, e-mail and diagnosis. This is maybe once every three months or less. It all depends on your state. I contact them either by calling or sending an e-mail to welcome them. I let them know my contact information, so they can call or email me anytime. This is very important. We all remember just learning we have one of these diseases and feeling like we were alone. I keep a spreadsheet of all the Iowa members... I think I am up to 34 now. There are not many of us. Some of the larger, more populated states have several ambassadors that cover different areas.

Also please let your doctors or physical therapists know about our foundation so they can tell their patients. We want no one to feel all alone.

I send out emails now and then when there is important information to share like the Annual Conference. Once a year (I should do it more), we all meet for lunch at a central Iowa location. Very casual and we all buy our own lunch. It is mainly a social gathering but we do talk HSP or PLS now and then.

I think that people do not want to do this job because they feel it is overwhelming. Was what I described just now overwhelming at all? Some ambassadors do their job better than I. They get speakers for connections or gatherings. You can do whatever you want. Some ambassadors do fundraising events. That is wonderful, but the most important part of being an ambassador is welcoming people to SPF and helping them to not feel alone.

If you live in one of the states listed above and are interested in becoming its state ambassador, please contact me, Jackie Wellman, or Linda Gentner. Our contact information is hoppywell@gmail.com or lindagenter83@gmail.com. We are both on Facebook as well.

Annual Conference Update

Dear SPF Family,

If you haven't already registered for the 2015 Seattle Conference, it is not too late. The Seattle Airport Marriott still has rooms but they are now at a higher rate of \$199.00. You may call the hotel directly at 206-241-2000. It is a beautiful hotel in an incredible city. This is the first time we have ever sold out our entire block of rooms. Some people who are coming to the conference have decided to make it a family holiday.

We have a full schedule of incredible speakers that have so much to offer. What's more, we are all in store for a great time and a beautiful view of the Seattle skyline on the Sunday Seattle Argosy Cruise.

On Friday evening, after the welcome Reception and dinner, our speakers will be Cory Weiser, Investment Advisor and Special Needs Planner and Kelly Piacenti, Assistant VP, MetLife Center for Special Needs Planning. On Saturday, we will have our very own Dr. John Fink, Para-Olympic Equestrian Rebecca Hart, Dr. Catherine Lomen-Hoerth, UCSF, Dr. Christina Fournier, Emory University, and Corey Braastad PhD, Athena Diagnostics.

I would also like to thank Athena Diagnostics and MetLife for being generous sponsors of our Annual Conference. Please let their representatives at the conference know how much you appreciate their contributions.

I guarantee that you will leave our conference this year with not only new and very hopeful knowledge of current state-of-the-art PLS and HSP research but you will also have made new friends and created great memories to take home with you. I am wanting this 2015 SPF Annual Conference experience to get you excited to attend our 2016 conference.

I look forward to seeing everyone in Seattle. Please feel free to call or email me if there is anything I can help you with.

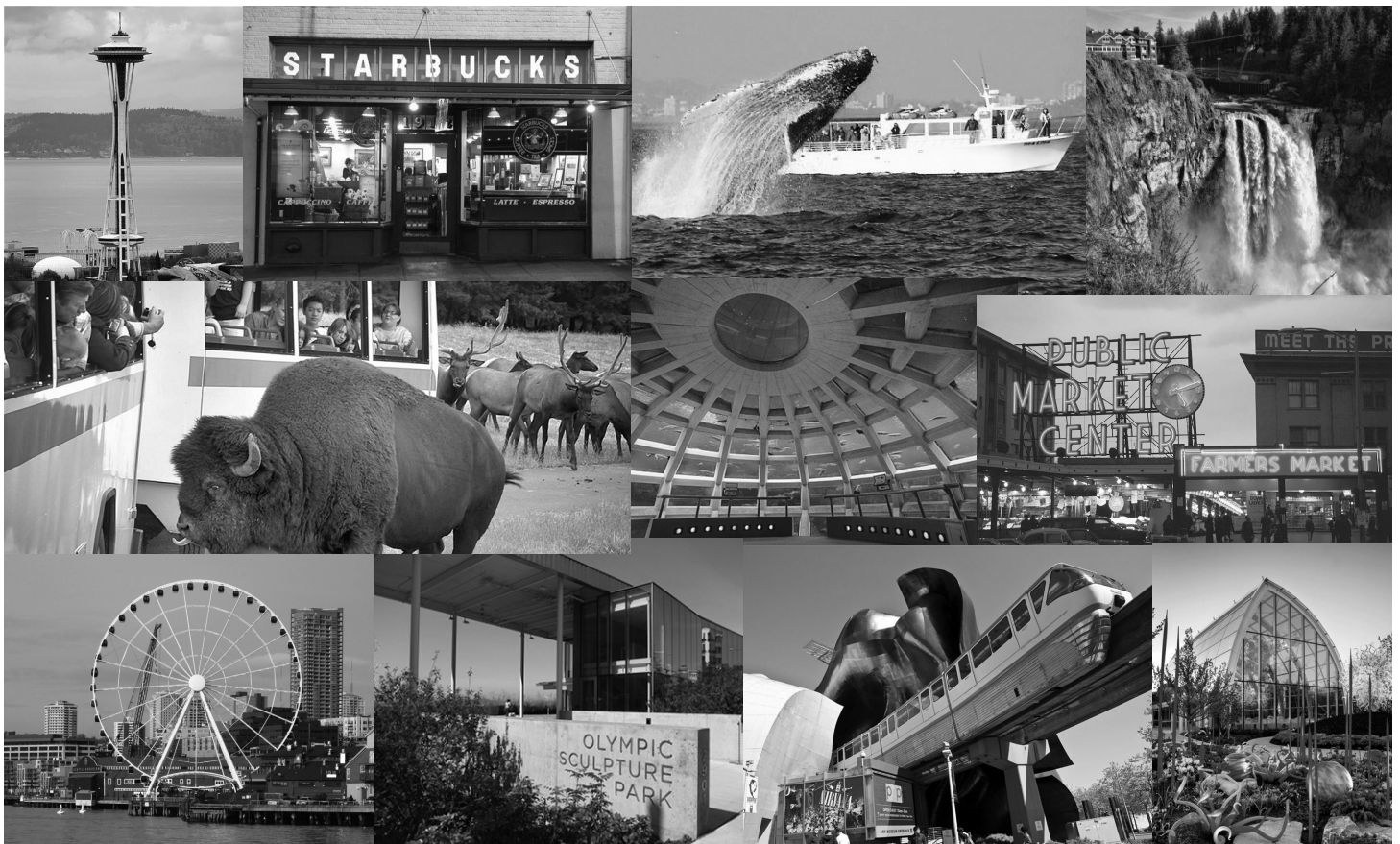
Sincerely,

Claudia Davis

SPF Conference Coordinator

ph: 956-454-5837

e: claudiadavis6@yahoo.com



How Can I Help?

By Jackie Wellman
Iowa State Ambassador

We can all do a little without donating huge amounts of money which most of us do not have. If we all did a little, that cure that we all want would be closer to being a reality. Research is expensive and Spastic Paraplegia Foundation wants to fund as many research grants as possible.

The first 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 us use a search engine 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.

Before you know it, we will be 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, those retail outlets donate a percentage of your purchases to SPF. Target, drugstore.com, Walgreens, Amazon, Barnes & Noble 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. Goodsearch, “private foundation in [enter 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. Most foundations are very particular in what they fund. For example, some

may just support childhood obesity, etc. Write them a letter asking if we could apply for a grant. Not for money, but just if we can apply. Applying for the actual grant is a big deal and we have people on the 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... which means in the eyes of the government, we are a real non-profit foundation. If you do not say this than your letter will surely find the garbage can as its new home. In the next paragraph of the letter, 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 will do whatever I can to find it. Keep it all short and sweet. This is just the first step in the grant process...the letter of inquiry. Then if so inclined, go beyond your own county.

There are so many other ways to help research out. You can participate in research yourself, you can have a bake sale, have a car wash, get your church involved in fundraising, participate in a TeamWalk, walk by proxy in one, 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. So you are not only helping fund research but helping yourself.

Be the change you want to see in the world.

The banner features the Goodsearch logo at the top left, with a search bar and the text "Powered by Yahoo!". Below the logo is the slogan "you're making a difference keep searching with us". A circular badge on the left says "register now". The background shows a close-up of hands holding a small plant. On the right, it displays "total member earnings for all causes \$9,239,060". The banner is divided into three columns:

- what have you raised?**
track your impact!
\$ [] [] [] [] []
total raised
\$ **1,550.07**
for Spastic Paraplegia Foundation - SPF
- you're supporting**
SPF SPASTIC PARAPLEGIA FOUNDATION, INC.
see how much you've raised for your cause
[change cause](#)
- you can raise more with**
goodshop
[shop now](#)
Shop at 2500+ retailers like Amazon, Target or Staples and up to 30% will be donated to your cause. Plus, give back and save with over 100,000 coupons!

Connections

Georgia Connection

By Elizabeth Woolridge

Thank you all who were able to attend. It was wonderful to put names to faces. Randy Hortman, Rick Thompson, Kathy Tomaschik, myself along with my daughter, Anna Woolridge and our wonderful presenter, Dr. Christine Fournier were in attendance. We spent the two hours (plus) sharing experiences with each other, asking each other and Christina questions. Christina shared that the research currently being conducted is set up in the hopes of being able to turn on/off certain genes that are responsible for neurological problems. I was so excited to meet everyone. The goal is to try to have the next meeting in Columbus or around Macon. If anyone has any ideas or suggestions, please email me at spf.gaambassador@gmail.com.

We had 20 in our group for this meeting which was held in the Buffalo Grove Arboretum clubhouse. New attendees included Ann & Ed Sopala and Sue Beutelspacher. For lunch we tried Corner Bakery boxes and had the driver take the connection picture. (Not shown are Candy Cotsiomitis via phone conf and Rich Fairbairn) For information on future meetings email us at SPFIllinois@gmail.com.



North Texas SPF Connection May 16, 2015

John Staehle, North Texas Ambassador, hosted the Spring HSP/PLS Connection on Saturday, May 16th in the private dining room at i Fratelli Ristorante in Irving. Our group for this Connection numbered eighteen including eight first-time attendees. After introductions and lunch, Claudia Davis updated the group on the upcoming SPF Annual Conference being held this year in Seattle from June 26-28. On Saturday, speakers will include John Fink, MD, the University of Michigan and SPF's Medical Advisor, Para-Olympic Equestrian Rebecca Hart, Dr. Catherine Lomen-Hoerth, UCSF, Dr. Christina Fournier, Emory University, and Corey Braastad PhD, Athena Diagnostics.

John reported the current number of SPF contacts in the North Texas region has grown to a total of 82, of which 60 have either a diagnosis of HSP or PLS or are a spouse/caregiver or an immediate family member of someone diagnosed with HSP or PLS.

As Editor of SPF's newsletter, *Synapse*, John asked those in attendance to consider writing an article for a future issue about an experience, good or bad,

SPF Illinois Connection May 2, 2015

Hosted by Sid Clark (HSP) and Hank Chiuppi (PLS)

We held our spring connection Saturday under a beautiful blue spring sky. And we had a beautiful get together. We tried something new in doing a round robin and sharing with each other. What we had as individual challenges and how we dealt with them. In sharing we had some good takeaways and ideas to try in our own lives. You can learn a lot by listening to what others have tried and what works for them. Also mentioned in the connection was the Medtronic Pump issue, Cardin-Vitter Therapy Amendment, traveling with HSP/PLS among many other items. You needed to be there. There was a discussion about holding a summer Connection.

they or one of their children had as a consequence of having their condition (HSP or PLS). They can send the article to me via email at jstaehle@swbell.net. Personal stories are well-liked by the readership.

John and Frank Davis led a discussion on how to increase attendance at future North Texas Connections. One suggestion was to have a meeting at a suitable and convenient location where everyone brings a snack to share. Another was to make it a potluck lunch where the main course is provided and attendees bring a side dish to share. John will investigate organizing a trial meeting using one of these alternate formats to be held between the dates of our regular semi-annual meetings.

Other subjects discussed included the medications we take and their side effects, walking aids, 3-versus 4-wheel rollators and scooters and the variety of symptoms we have experienced. One drug that generated a lot of discussion was Ampyra (dalfampidine). It's a drug developed for MS patients that, "in a small proof-of-concept study, 50% of patients with HSP improved on several measures of walking ability."



Accepting Your Diagnosis

In response to a post on facebook by a person having a hard time dealing with HSP, Mark Weber, Esq., Legal Counsel and SPF Board Member, replied, "That process of getting to acceptance is called grief. Grief because the able-bodied you is dying along with your dreams of the future. But you will still live. And you will still have a future. Your future will be a little different than you imagined it. The trick is to imagine a future worth living with HSP and then going out and living it."

Tina's Tips

By Tina Croghan

Missouri SPF State Ambassador

In my short 15 years dealing with HSP, I've tried and failed and tried again with many things. Here are just some of the things I learned that works for me. I wished I had the guidance of someone who had "been-there-done-that."

TIPS

- When going down a ramp or incline, keep knees soft or "squishy." Avoid "locking" them by sinking down in your "seat." Shifting your center of gravity by thinking of a big baby with a load in his/her diaper helps me.
- You should go down stairs **BACKWARD**. Hold onto the railing. If the railing is too low, brace your every step with your hand on the wall. **NEVER** "lock" your knees while going down steps!
- It is easy to form a "death grip" on the handles of your rollator, walker or canes. It happens to me when I'm trying to go too fast. I'm pushing my rollator way out front. The solution: **STOP!** Take a deep breath. Bring the rollator back. Step within the frame. Let your shoulders sink down. They were climbing up to your ears! Think of pulling your shoulder blades together in the back. Pretend you are trying to hold a pencil in between your shoulder blades (scapula). (For women this is "showing the girls!") Careful of sticking your ribs out though.) This is not an automatic thing for me! Maybe one day!
- I was given the idea to take a piece of thick foam purchased at a fabric store and tape it to the handgrips. I don't know if this works, but I'll try anything to give my hands relief!
- To avoid a leg cramp or "Charlie horse" in the middle of the night, I make sure I drink **PLENTY** of water during the day. I stretch right before bed. I take magnesium before bed. When a cramp hits, point your toe up to your head.

Let me know of tips you have. Think about it. I'm sure you've found an easier way to do something. Send your tips to tinacroghan@yahoo.com.

Exercise and You

HSP AND EXERCISE



By Mary B. Schultz

A few years ago, I had not even heard of the rare neurological disease that has become a major part of my life. I have HSP (Hereditary Spastic Paraplegia), and remain astounded that there is no treatment or cure for HSP or PLS (Primary Lateral

Sclerosis). We all just muddle along, day by day, remain as healthy as we can be, and hope that one day, not in the too distant future, there will be a treatment or cure for one or both of these diseases. Until then, through SPF (Spastic Paraplegia Foundation), I have learned that each of us responds differently to various drugs, supplements, complimentary or “alternative” therapies. However, without exception, everyone with HSP or PLS that I have heard from, either directly from friendships I have made through SPF, or indirectly from SPF’s Facebook page or the HSP listserv, feels better after exercise. After we exercise, we feel better. When we don’t exercise, we feel sluggish.

Now, there is a scientific basis for our *ad hoc* experiences with exercise. Exercise benefits cell biology, including neurons in our brains. Exercise changes the fiber and protein composition of muscles. Exercise actually changes our DNA!

Epigenetics is the study of changes in organisms caused by changes in gene expression rather than changes in genetic code itself. Epigenetic changes occur as a result of factors like age, environment, lifestyle and disease. A recent study confirmed that epigenetic changes occur with exercise.

The Karolinska Institute / Stockholm Study

Francesca Merabita of the Computational Medical Unit at the Karolinska University Hospital in Stockholm, Sweden, collaborated with members of the Carl Johan Sunberg lab in the Department of Physiology and Pharmacology at the Karolinska Institute. They recruited 12 men and 11 women who did not regularly exercise for a three-month study. In order to study epigenetic changes without confounding systemic influences like diet, stress, sleep patterns, hormones,

and other environmental factors, the volunteers performed knee extension training with only one leg. (The volunteers rode a stationary bicycle, but only pedaled with one leg.) The non-trained leg operated as a “control”. The volunteers pedaled with only one leg at a moderate pace for 45 minutes, 4 times per week, for 3 months.

Both prior to and after the workout program, the volunteers allowed muscles biopsies from quadriceps muscles in both legs. The researchers discovered significant changes in key enzymes in muscle metabolism. In other words, exercise resulted in significant epigenetic changes. An intricate biochemical process called methylation was enhanced across the genome. Methylation patterns were not significantly changed in the unexercised leg.

Many questions remain. For example, we do not know the effect of stopping an exercise program. However, the Karolinska Institute study underscores that exercise benefits the brain.

Dr. Ratey’s SPARK: Exercise as “Miracle-Gro” for the Brain

In a book entitled, “SPARK: The Revolutionary New Science of Exercise and the Brain”, John J. Ratey MD, Associate clinical professor of psychiatry at Harvard Medical School, concluded that exercise turns our brains on, and is a form of self-medication. It is finally generally accepted in the medical community that exercise is good for depression and anxiety. However, not so generally accepted is that exercise is good for all cognitive function and, indeed, for neurodegenerative diseases. Dr. Ratey has described exercise as “Miracle-Gro” for the brain.

BDNF (Brain Derived Neurotrophic Factor) is produced by exercise. Exercise results in a three-fold increase in BDNF production. BDNF is tantamount to fertilizer for the brain. BDNF is a protein that acts on neurons, supporting the survival of existing neurons and encourages the growth and differentiation of new neurons and synapses.

A single exercise session results in immediate changes in methylation patterns of certain genes in muscle cells. The message is clear: EXERCISE!

Please check with your doctor prior to starting an exercise program.

IT'S ALL ABOUT YOUR BASE!

By Tina Croghan
Missouri State Ambassador

Meagan Trainor wasn't talking about your toes with her hit song, but your toes are very crucial to your whole body's balance no matter if you have an MND or not.

I've noticed that my toes are like a bird's claws—grasping for dear life not to fall. But it's those same toes that sabotage my balance. The more area we have to balance, the better. Plus, our toes are constantly making minor adjustments to our balance. This is so slight, we really don't notice it. However, we really notice it when we don't have it!

There are several things that I do. I enjoy stretching them. Really stretching them! When I get on the floor, I'll stretch one leg out curling my toes underneath and press down as hard as I can. (see picture)



I'll do this on both sides.

For several years I picked up marbles with my toes and placed them in a cup. While this had the added benefit of strengthening my thigh muscles, the opposing stretch to my toes wasn't enough to counter them "hooking" or "clawing". (see picture)



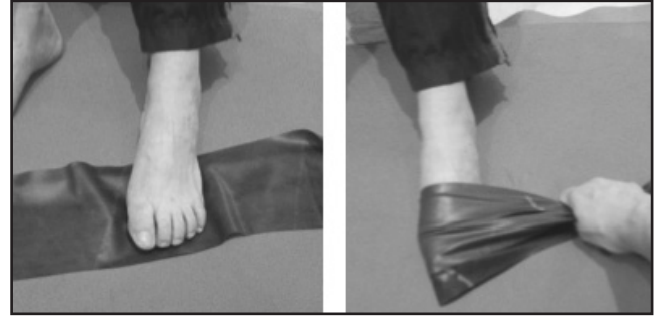
Toe raises are another stretch I do. I do this morning and evening while I brush my teeth. While your feet are flat, try to raise up and spread just your

toes. I count to 30, but start with 15.

Next, I do calf raises. That's going up on your tip-toes. I hold on to the handles of my rollator. Make sure your knees aren't locked! (Make your knees soft.) This part is challenging for me.

Now with your feet shoulder-width apart, raise up on your toes 10 times. Now try it going up with both feet and just coming down with your right. Do this 10 times and repeat it on the left.

It's important to strengthen and stretch our feet, too. My service dog, Thunder, likes to help me with this! While sitting on the floor, use an elastic band (or old belt or tie), pivot on your heel and try to resist against the band to bring your foot in for 30 times then out for another 30 times. Repeat this action on the other side.

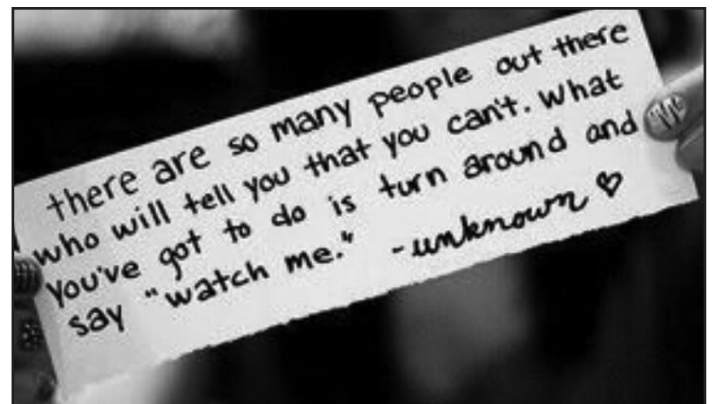


Now that your toes and feet are stretched, try standing (freely). Make sure your feet are both parallel and only a shoulder-width apart. (I find this hard for me!) To aid in the correct placement of your toes, Amazon sells gel toe spreaders. http://www.amazon.com/Separators-Stretchers-Straighteners-Alignment-Bunion/dp/B00L7P4Y4U/ref=sr_1_18?ie=UTF8&qid=1426800149&sr=8-18&keywords=yoga+toes

Toe spreaders are a lot like the ones you get at the spa when having a pedicure! Only these are gel (more comfortable) and cover the top, too. (like brass knuckles) Anyway, if you do get the toe spreaders don't forget to use www.goodshop.com.

Here are the ones I bought. You can spend lots of money and buy the YogaToes, but I just got the cheaper ones! (\$5.59) They seem to work just fine for me. I only use them for when I'm doing Yoga.

Now try standing again. I do these stretches several times a day. I especially find them helpful upon rising and before bed to alleviate muscle cramps during the night.



LIFE WITH ADAPTIVE SPORTS

By Amy Saffell

Many people will tell you that their lives were changed when they discovered adaptive sports. I'm not one of those people, but that's only because I'm very fortunate to say I don't ever remember life without adaptive sports. Growing up with spina bifida in Atlanta, a city that has had numerous adaptive sports opportunities for many years, and in a family that values fitness, I pretty much always had adaptive sports options at my fingertips and a family who encouraged me to get involved. I learned to play tennis from my parents even before a structured youth wheelchair tennis program started in elementary school, which I continued with through high school. The wheelchair basketball and handball programs already in existence in one school system were expanded to counties throughout Georgia, so I had a regular practice and a weekly game, just like other high school teams. It's safe to say that my childhood was filled with adaptive sports.

The benefits of my participation in adaptive sports from a young age were crucial to my development as a person. I learned to think critically, to effectively communicate with my teammates and coaches and to work hard towards a goal. One of the most profound influences that adaptive sports played in my childhood was that it minimized how often I saw myself as being different from my school classmates. They played sports and I did, too, and it didn't really matter that the rules were slightly different. The other most profound influence of adaptive sports was that I never really questioned my ability to become successful in adulthood. I saw coaches and mentors who had disabilities living successful lives and I saw older peers who I played adaptive sports with and against carve a path to independence. Adaptive sports were and are more than sports. It gave me the ability to believe in myself in all areas of life.

In college, I made the decision to go where I wanted to go based on academics and campus living above continuing in a sports program, a decision that I don't regret. I didn't let my own fitness fall by the wayside either. I worked on my strength training at our campus gym and pushed miles on campus for exercise.

I live in Nashville now, a city with strong and growing adaptive sports options. In my adulthood, I've had the opportunity to water ski, snow ski, participate in

adaptive climbing, and play sled hockey. Those miles I pushed in college turned out to be a gateway into the adaptive sport in which I'm most active currently. Several years ago, I got involved in running through Achilles International, which pairs people with and without disabilities to train for and run mainstream races. I have run (anything is running in Achilles!) dozens of races of varying distances and will complete my 5th half marathon at the end of this month.

As an adult, one of the most influential aspects of adaptive sports has been that it has allowed other people to see me as a capable individual. People learn pretty quickly after meeting me that I play sports and I often think they easily draw the conclusion, if I'm able to play sports, then I must also be able to be an independent, successful member of society. Sports in adulthood have also given me the opportunity to make friends that I never would have made otherwise. The running community is welcoming and inclusive, and because I'm often participating among people with and without disabilities, I have a diverse group of friends and acquaintances.

I may not have risen to an elite level in any of the sports that I've participated in, but that doesn't matter to me. Having continuous opportunities to try something new, to increase my levels of fitness, and to influence the people around me just by doing what I love, is most important. I now work for ABLE Youth, a Nashville-based wheelchair sports and independence group for kids. I see myself in a lot of the kids in the program. I want them to never know what it's like not to have adaptive sports in their lives. It has worked well for me!

About author, Amy Saffell: Amy Saffell lives in Franklin, TN, just outside of Nashville. She loves exploring new adaptive sports opportunities and running with Achilles International's Nashville chapter. Amy works for a record label and also for a wheelchair sports and independence organization for youth in Nashville. In her free time, she loves spending time with friends and family and enjoying Nashville's rich music scene.



www.wheelchairsportsfederation.org

Up Close and Personal

My Wheelchair Experience

By Dolores Carron
d.carron@sbcglobal.net

I am still in the process of getting a new wheelchair which began almost a year ago. Dealing with the one and only DME Medicare approved vendor in my town has been a nightmare, details of which I can share at another time. The chair that was delivered on September 26, 2014 sits unused in my home. The footplates touch the ground, are devoid of heel restraints to avoid slippage, and have been modified so my ankles are out of alignment with hips/knees. The backrest is too high which significantly limits my upper body for dressing and mobility and won't get me any closer than 5 inches to the shampoo sink. Most importantly is what I want to share with you today, that the user's manual adamantly warns "has not been tested to the requirements of ISO 7176-19:2001 or ANSI/RESNA WC-19 and may not under any circumstances be used as a vehicle seat or to transport the user in a vehicle. Using a wheelchair that does not fulfill these criteria as a vehicle seat can lead to the most severe injuries and even death in the event of a traffic accident."

I have learned a lot about wheelchair safety standards despite this being my second power wheelchair; my first was in 2008 from the same vendor. Being a trusting novice, I accepted the vendor's decisions not realizing that they are not medical caregivers; although there is some training involved in becoming an ATP (Assistive Technology Professional), they are working as salesmen for profit driven businesses. Some are great but some are not.

Safety is important—VERY IMPORTANT. It is to your advantage to be informed and expect that yours will be a key factor in the choice of your wheelchair, not profit-driven compromised. I've listed a number of links that I've found helpful, including one that's an up-to-date list of WC19 compliant chairs.

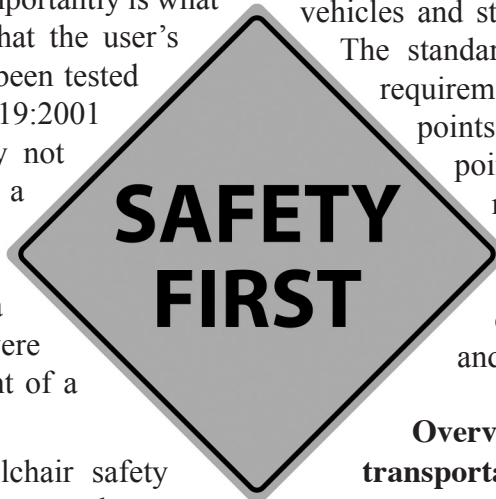
The purpose of the ANSI/RESNA WC19 standard is to promote occupant safety and reduce the risk of injury for motor-vehicle occupants who remain seated in their wheelchair during transit. This is accomplished

by applying basic occupant protection principles to the development of design and performance criteria for wheelchairs that will be used as seats when their occupants are traveling in a motor vehicle.

A wheelchair that complies with all the requirements of this standard is considered to provide a reasonable measure of safe and effective seating during vehicle ingress/egress, during normal transportation, and during a vehicle collision.

The (WC 19) standard places particular emphasis on design requirements, test procedures, and performance criteria related to frontal impact performance. However, it also includes design and performance requirements for wheelchairs with regard to accessibility to motor-vehicles and stability during normal vehicle travel.

The standard specifies strength and geometric requirements for wheelchair securement points and occupant restraint anchorage points on the wheelchair. It also provides requirements and information for wheelchair accessory components, seat inserts, and postural support devices with regard to their design and use in motor vehicles.



Overview of new RESNA standards for transportation safety of occupants seated in wheelchairs:

<https://www.youtube.com/watch?v=jcxVlh1HA4>

New Transit Wheelchair Standard-ANSI/RESNA WC-19:

http://www.wheelchairnet.org/WCN_WCU/Departments/Docs/WCN_WC19PR.html

Wheelchairs & Seating Systems successfully crash tested with 4-point strap-type securement as of: October 21, 2014:

http://www.ercwts.org/erc_wts2_kt/RERC_WTS2_19_Chart.html

Wheelchair Transportation Safety Frequently Asked Questions:

http://www.ercwts.org/RERC_WTS2_FAQ/RERC_WTS_FAQ.html#WTS_FAQ_Q_Csection_anchor

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Typical clinical applications and evidence from the literature supporting the use of wheelchairs designed to function as a motor vehicle seat that will assist in decision-making and justification.

<http://www.resna.org/sites/default/files/legacy/resources/positionpapers/>

Watch all 4 minutes to see the unsafe vs. safe scenarios:

<https://www.youtube.com/watch?v=WBvdKsuo8Xc>

This video is about New Jersey but the pictures serve well to demonstrate the need for ANSI/RESNA WC 19 compliance.

<https://www.youtube.com/watch?v=EZJVUpk0kA>

This video shows what happened when the necessary safety components were damaged and no longer functional.

<https://www.youtube.com/watch?v=vn7Ch1FAHJY>

If a wheelchair is WC 19 (ISO ANSI RESNA) compliant, alternatives to the belt tie downs such as the ones in this video can render the same level of safety as a vehicle seat with today's seatbelts.

https://www.youtube.com/watch?v=V_T3SIduHI0

Your Second Power Chair: What You Need, How To Get It

Mark E. Smith | Nov 01, 2014

<http://www.newmobility.com/2014/11/powerchair-shopping/>

Mark Smith also has this website with a wealth of helpful information. Don't let the website name fool you because he offers extensive guidance in many aspects of wheelchair procurement, selection, use and more:
www.wheelchairjunkie.com

Electric Wheelchairs Review – Top 10 Best

<http://electric-wheelchairs-review.toptenreviews.com/>

Fact Sheet on Powered Wheelchairs

http://www.abledata.com/abledata_docs/Powered_Wheelchairs.htm

Front, Middle or Rear? Finding the Power Chair Drive System That's Right for You

<http://quest.mda.org/article/front-middle-or-rear-finding-power-chair-drive-system-thats-right-you>

Medicare's Wheelchair & Scooter Benefit

www.medicare.gov/Pubs/pdf/11046.pdf

Be Your Own Best Advocate

By Tina L. Croghan

Missouri State Ambassador

It seems, while scanning Facebook that many SPFers deal with a common problem - self-advocacy in the doctor's office! I was recently alerted to a website that I feel everyone needs to checkout, it's from the Eastern Oregon Council for Independent Living: www.eocil.org/medconsum.html

This article explains that you need to take charge and be responsible for your own health. You know your body best. "You are not your disability, and many health problems have nothing to do with your disability!" In other words, not everything can be discounted as HSP/PLS. Some things can be attributed to HSP/PLS, but don't just automatically assume that they are. Your doctor or healthcare provider shouldn't either. You know in your "gut" when you have a strange feeling or pain. It is up to you - and you alone - to find out what it is!

Here are some guidelines you should always follow:

Ultimately, you employ the doctor! So, in a sense, you are the boss!

You have the right to respectful, considerate treatment. You have the right to **ask questions** and to receive meaningful and respectful responses. If you don't understand, say, "I don't understand." Then try to restate what you've been told. "So let me get this straight. I hear you say..." or "So this is what is happening." And, "This is what I'm to do," or, "This is what we're going to try first. If that doesn't work, I'm to let you know then we'll try...?"

Help your healthcare provider give you the best care!

Don't complain that, "My doctor knows nothing about HSP/PLS." Before you started on this nightmarish journey, you didn't know anything about them either! Use this opportunity to educate your doctor! Print out articles and give them to your doctor. Don't forget the receptionist/nurse. A lot of times they are your doctor's "gatekeeper!" They should get printouts, too. I give my doctor's office staff cookies or candy then I bring an article on HSP with me to the visit. I've made some business cards with the SPF logo and website address. My doctor asks for a stack of them whenever I come in (every 90 days for Botox).

Continued on next page

You have the right to an office visit within 20 minutes of your scheduled time, unless something unanticipated affected the doctor's schedule. I know for some doctors your appointment time is only a suggestion and not the time in reality.

When you make the appointment ask:

- “What time will I be seen by the doctor?” Add, “I can only sit for so long and I get stiff.” This is the truth! “I need to be the first patient of the morning or right after lunch.” Then arrive on time! Figure in the added time it takes you to park; walk (slower because you’ll be stiff!).
- Ask about the parking. Is there plenty of accessible parking? Or even better—valet?
- Where is the accessible entrance? (This is VERY important! One time in a restaurant I was wheeled through the kitchen! The Missouri State Capitol Building is so situated that I couldn’t visit my representative’s office the usual way, but round-about through a maze of obscure elevators!)
- How wide is the doorway?
- Where are the accessible restrooms?

There’s ALWAYS paperwork to fill out!

- Ask if there is an online form you can fill out ahead of time. If not, allow for 20 minutes to do this.
- Bring your glasses, your insurance card. I always carry with me a card that has a list of all of my prescriptions and supplements, allergies and reactions.

The “takeaway” from this is, “No one is going to champion this but you!”

We are all fighting this fight together. However, we stand alone in our individual fight. Eleanor Roosevelt once said, “No one can make you feel inferior without your consent.” Never give it.

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>

To Parents of Kids with HSP

From Mari White

Kansas State Ambassador

I wanted to write something that was geared toward parents of kids with HSP or any neurological disorder for that matter. I am no expert, only a parent, but I have learned so much from my kids who I both admire and love. My journey of self-discovery and advocacy started 17 years ago when I heard the doctors tell me that my son had Asperger’s syndrome which is a form of autism. I was a single parent at the time and working full time as a nurse. I learned a great deal from him about the importance of believing in oneself and not being afraid to live in the moment. My son has no fears or worries. Life is what it is and he does not compare himself to some artificial norm. He is who he is and that is that. I wish I could be that confident and not really care what others think. I started advocating for him and learning the hard way on how to talk at IEP meetings and how to stand up to groups of teachers. I learned a whole new vocabulary. Fast forward 17 years and now he is 22 and just about ready to venture out on his own. He is a college student and doing well. I still worry and I still advocate for him, but I have learned the whole concept of team work. I learned a lot from Ben.

Throughout this complex, Alex came along and he has HSP. By now I am much more comfortable in knowing what to ask for and how to pull together a team. If anything, I learned to trust my gut and I learned to ask. The worst anyone could say was NO and maybe I could get a yes. I also learned to let my kids lead the way and to trust them. This is hard for me, to let go of the control. I have learned to go with the flow and to trust in their strengths and not their weaknesses. I never focus on those. As far as they are concerned and as far as I am concerned, they are not broken and do not need to be fixed. I have taught them that just because they think different or walk different does not make them bad, defective, or broken. I never deny them the chance to try things, even if they fail or can’t do it. At least they have tried. I actually have had more adults question me on this whole concept. I set the bar high for my boys and I want them to find the path to a meaningful career and independent life.

Continued on next page

As far as resources for kids, you just need to ask and listen. I have procured a list of wonderful places to start but each location should glean something for you.

1. Your local library. Give them the love of reading and exploring. I can't speak to all libraries but ours has fabulous year round programs for all ages, especially summer fun. These are free.

2. Your local zoo or discovery center

3. Challenge Air. This is a national program allowing children with any kind of disability from age 7 -21 a chance to fly a real plane as well as learn science and have a ton of fun. It is entirely volunteer run and pilots come from all over and donate their planes for the day. They teach the kids (even ones with significant disabilities) and then take them up in the plane and fly around. The pilots fly and once they get to a certain altitude they put it on auto pilot and let the kids help fly. This program initiated in Dallas and was started by a veteran with a spinal cord war injury who loved kids and had a can-do attitude. His whole motto is that nothing should get in your way to leading a fulfilling life. He flew with hand controls. They usually have tons of food, science experiments, simulators, local dance teams, volunteers from all the schools and cheer leaders, and even the police force and drug dog teams/robot teams. They often provide a motivational speaker with a disability or a young adult with a disability. The beauty of it is that this is an annual event and its free. They are now national and are all over the country.

4. Mid America Games is a big para Olympic organization of adaptive sports for kids and adults with disabilities. They also bring in speakers from the actual paralympics and they put on all kinds of events for a 3 day event every May.

5. Muscular Dystrophy Association has a phenomenal camp program for kids with all kinds of neuromuscular disabilities. MDA also offers free clinics and other resources depending upon where you live. Some states allow HSP under the umbrella and some don't. You can advocate and fight if your local one does not. That is how we got Kansas to accept HSP. I simply asked if they accepted PLS and ALS, why not HSP since they are all in the same family. They are one of the largest research organizations raising money

and research dollars towards ALS and Charcot Tooth Marie Disease. But, the camp is fantastic. Now I just need to get them to move the date of camp so that it does not run into the National HSP conference. Trying to pull a child away from camp, albeit just a day early is really tough.

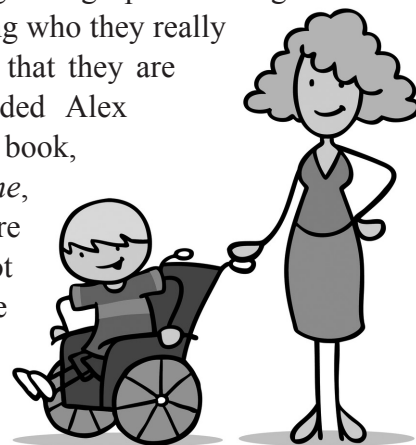
6. Angel Flight is an organization that flies kids (and parents) free to medical appointments and camps. They are a national organization.

7. Mercy Medical is another organization that flies for free that we just learned about.

When Alex was little he did all kinds of tumbling and gymnastics when it was not competitive but just a bunch of kids rolling around and having fun. Now he does theater, orchestra, and scouts. The bottom line is to find out what your children enjoy and go with it. Just because they have weak legs does not mean they can't participate in things or debate or write or lead groups. We have also done horseback therapy which really helps the muscles and balance. He also finds that playing on the trampoline and playing Wii Fit sports is a fun way to be with his friends and work on his balance. We incorporate as much neurotypical activity as possible. Swimming is another fun activity.

Other things that have proved to be fun is Space Camp out of Hutchinson Kansas at the Cosmosphere. This is a fantastic program. It is a little more costly, but well worth it. Other camps include music and orchestra camps, theater camps, and of course Camp Grandma (L.O.L.)

In conclusion, by allowing my kids to live a full and active life and to test the water and to fit in where possible and to find their greatest gifts, they have a chance of growing up not seeing the disability, but seeing who they really are. It matters not that they are different. I reminded Alex of the famous kids book, *A Wrinkle In Time*, the planet where everyone is a robot and everyone is the same. He agreed that life would be awfully boring.



Earth Angels

By John Staehle

North Texas State Ambassador

Author Note: I wrote this in September 2006, one month before my HSP reached the point when I became 100% dependent on wheels for mobility. I still remember these events like they happened yesterday. JS

I know there are lots of horror stories about able-bodied people that seem to turn away and ignore us when we look towards them, but stare at us when we're not looking. Not all people are like that. I have a few personal experiences to tell about the unnamed heroes that have come to my assistance.

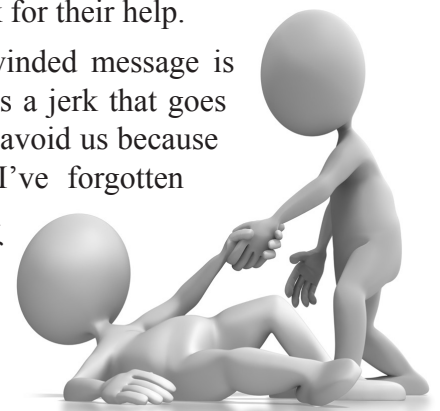
Last fall I had to renew my driver's license. I dreaded going to the DMV office as I knew there would be a long line. Furthermore, I now had hand controls on my vehicle and I was worried that I'd have to take and pass a driving skills test before I could get my new license. Since my birthday was just around the corner, I grit my teeth and headed to the local DMV office right after lunch. Needless to say, the lines were long, filled with 30 or so people who looked like they had been standing in line a long time. On top of that, both the Men's and the Ladies' restrooms were "out of order." I was a little suspicious about that since there were waiting room chairs lined up in front of both doors like they had been there a while. Fortunately, I rode my scooter into the waiting area expecting a long wait. I even brought a magazine to read. While I was flipping through the pages, I heard, "Sir? Sir?" I looked up to see the person behind the counter waving for me to come forward. I was thinking, "Oh, oh. I'll probably have to come back for a special appointment because I'm handicapped and they only take handicapped applicants on Tuesdays and today's Thursday (or something like that)." Instead, they processed my application for a renewal on the spot, took a new picture, if you can call a DMV photo a picture, collected my money and sent me on my way. Done in 20 minutes. Unfortunately I left 30 or so people behind who were probably a bit angry. I didn't let it bother me, though. Believe me, I'd rather be able to stand in line with them for an hour or two than have HSP and have to use a scooter just to get around.

This past week, I stopped to get gas on the way to work. After I pulled up to the pump, threw open my door and set up my walker so I could hop back to my vehicle's filler cap, a complete stranger whose vehicle was on the other side of the pump, asked if she could be of assistance. I was having a tough morning that day so I said, "I'd appreciate that very much." She insisted I stay in the car and proceeded to fill my car for me (of course, I paid for it). I was profoundly grateful and thanked her several times. I just wish I had asked her name.

Last year, when I was still using my forearm crutches, I was taking a pair of shoes in for repair (the toes of the soles had worn almost to the under sole). As I tried to step up onto the curb (no handicapped spot nearby) I lost my balance and down I went on the sidewalk. In a matter of seconds, two people, a husband and wife, rushed to my aid and helped me get back up. They said they were leaving the parking lot and saw that I was struggling a bit to get up the curb. So they stopped to make sure I made it all right. When I fell, they got out of their car and came immediately to my aid. They were so concerned I was okay. I assured them I was, though I was a little embarrassed – I still get that way when I do those graceful moves in public that we all know as falls.

There have also been numerous occasions when I've dropped my keys, my glasses and other such objects on the floor or the ground, well out of reach when I'm in a standing position aided by my walker. There has always been someone to pick them up for me without asking or who are willing to go out of their way to pick them up when I ask for their help.

I guess my long-winded message is that not everyone is a jerk that goes out of their way to avoid us because we're different. I've forgotten about those people. There are a lot of "earth angels" out there, too, and I'll never forget them.



iPhone Medical ID

by Hank Chiuppi

SPF Co-Ambassador, Illinois

One of the lesser known, but potentially most important, features of Apple's newly released iPhone mobile operating system, iOS 8, is a digital "Medical ID" which can provide important personal health related information in the event of an emergency. iOS 8 is available for iPhone 4S and up.

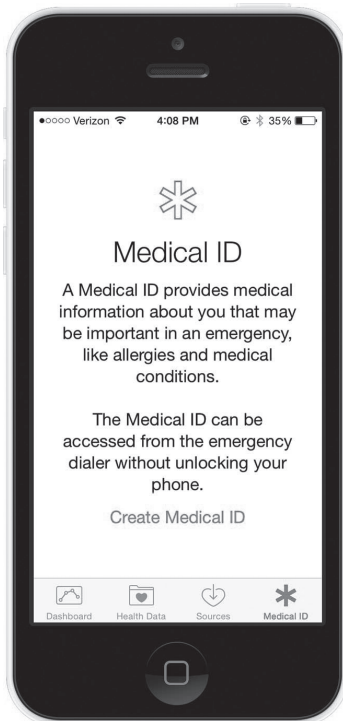
The Medical ID feature is built in to the new Health application found in iOS 8 for iPhone. Users can configure it by launching Health app, tapping the Medical ID menu in the bottom right, and then choosing "Create Medical ID."

iPhone users with a pass code-locked handset can consider enabling the "Show When Locked" function, providing first responders or anyone else with emergency access to their Medical ID. Enabling this feature allows the Medical ID to be viewed by swiping the lock screen, tapping "Emergency," and then viewing the digital information.

A user's Medical ID can be configured with a custom picture and name, date of birth, list of medical conditions, notes, allergies, reactions and medications. It also allows users to display an emergency contact with name, telephone number, and relationship.

The Medical ID also allows users to enter their blood type, height and weight, and whether they are an organ donor. And if someone changes their mind about having such information available from their lock screen, all of the Medical ID information can be deleted via one button at the bottom of the editing page.

After the Medical ID has been created, users can always go back and make changes at any time through the Health app.



Medical ID is just one function of the new Health application in iOS 8. It aims to become a centralized repository for all of a user's health information, whether input manually or automatically collected through iPhone accessories.

If you have a phone with the Android operating system, there are many similar Apps available that are free or have a nominal cost. Some that I found, but cannot attest to their functionality or value, are:

Medical Files & Health Records by STARTSMALL, Free, 4.0 (out of 5.0) user rating;

Family Health Info by APPVENTIVE, \$1.99, 4.6 user rating;

My Medical by Hyrax, Inc., \$4.99, 4.1 user rating.

Ed.

Useful Tips

From Ronnie Grove



I have PLS and it is all on my left side. I only have the use of one hand. Here are two quick hints I could not live without.

I took a pack of the rubber bathtub things that stick to the bottom of the tub with all over little suction cups. I stapled the whole set

together, top to top, to stick in my sink. Now I can hold down a plate, stove burner pan, skillet, etc. as I scrub away. I think they must come 6 in a pack as I have three sticking to the side of my sink when not in use. A bath mat cut in half and put back together with grommets is also good. It covers the whole sink bottom.

My maybe favorite is the newspaper. Try reading one with one hand and not saying bad words. The first thing I do is have my aide (or myself) take a plain peeling knife and run it down the center of the paper's spine. Now I have a sheet that is manageable and it doesn't hurt the paper one bit for others that may want to read it. My aides have told me that they now do this for several of their other clients and they love it.

Our Spirit Animal

By Galen Hekhuis

I realize some of you may feel this is a bit strange, but I think it is important that we recognize our spirit animal. After careful examination and consideration of a number of critters, it is clear that the bat is the animal most like us.

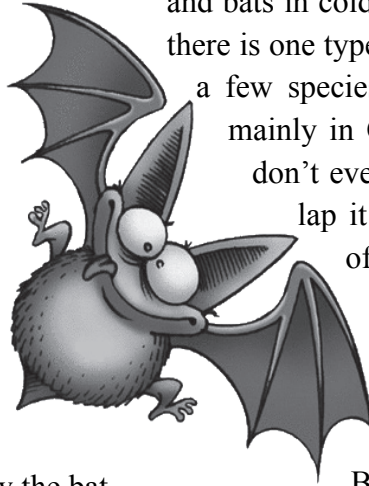
Forget everything you know about bats. Except that they can fly, that's true. Everything else though... Bats cannot walk. Any one of us seeing a bat trying to get up after falling on the ground knows exactly how the bat must feel. We all know what flopping around on the ground is like.

Bats, like us, are quite often subject to erroneous conclusions. For example, bats are often thought to be "flying mice" or something like that. Bats aren't even related to mice, or rats, or gerbils, or raccoons, or weasels, or much of anything, really. They occupy their own order among mammals. There just isn't another creature quite like them. They sort of resemble cats, in that the time they don't spend sleeping is often spent on grooming, so that they usually have soft, clean, luxurious fur coats. I've even heard them called "cave kittens." But there the resemblance ends.

Like us, bats have had to do other things besides walk. Just like they have to rely on their wings (hands, actually) to fly, so a lot of us rely on our minds to let ourselves soar.

Bats are intelligent, often highly social critters. To be sure, there are "solitary" bats, but those that live in groups often form fairly long-lived social interactions. It is not at all uncommon to find a little brown bat that is over 20 years old, as a matter of fact one was just found in Wisconsin that was banded some 32 years ago, and they aren't sure how old it was back when it was banded.

Bats speak to each other using "syllables" which actually change meaning with context. This used to be thought pretty much exclusive to human speech.



Still reading? In general, bats in the tropics eat fruit, and bats in colder areas eat nothing but insects. True, there is one type of bat that catches fish, and there are a few species of "vampire" bats, but they reside mainly in Central and South America, and they don't even "suck your blood," they most often lap it up from cuts on livestock. As many of you know, I'm a caver, and have seen oodles and oodles of bats. I've seen exactly three "vampire" bats in 50 years of caving, and they were in a zoo in San Antonio, TX.

Bats are like us. We may not be able to walk, but like them, we find other ways. Just like we have to adapt to travel anywhere, bats have had to adapt their hands into wings to cover any distance. Bats, like us, are often terribly misunderstood. Bats are not threatening; they are cute and adorable, just like us.

The Truest Art of Falling

*why, does gravity hate me,
I am constantly wondering;*

*as, I think, I've been doing
my very best, stepping out*

*amongst the thorns and thistles
that this universe forever throws...*

*but, as soon as my balance is hindered,
it seems, down I rightfully flip and flow*

*I guess I'll just have to learn all about
the truest art of falling, forevermore*

james k. blaylock
1-25-15

*James is a writer/lyricist/poet/spoken word and
recording artist. He lives in Tyler, Texas, and has
HSP. Ed.*



2015 ANNUAL CONFERENCE REGISTRATION FORM

Friday, June 26

"Raining Down a Cure" Welcome Reception with Dinner to follow.

Saturday, June 27

Speakers include:

Dr. John Fink, Director Neurogenetic Disorders, University of Michigan
 Dr. Christina Fournier, Neuromuscular Division, Emory University Department of Neurology
 Dr. Catherine Lomen-Hoerth, Neurologist and Director of the ALS Center, UCSF
 Rebecca Hart, 5 time USEF National Para-Olympic Equestrian Champion
 Fun and incredible break out sessions to look forward to also!

Sunday, June 28

Sunday Seattle Tour – More details to follow!

Friday Night Dinner \$50.00
 Children (12 & under) \$10.00
 Saturday Conference \$70.00 (Plated lunch and snacks included)
 Children (12 & under) \$10.00
 Sunday Seattle Tour \$20.00 per person (transportation included)

SPF Conference Registration ends June 20, 2015

Hotel reservations for the Seattle Airport Marriott, call 206.241.2000
SPF Hotel Rate Reservations end June 4, 2015 – NO EXCEPTIONS!

Please contact claudiadavis6@yahoo.com with any questions.

2015 SPF Annual Conference online payment:

<https://sp-foundation.org/donate-now-old/>

Name #1: _____ Disorder: HSP _____ PLS _____ SP _____

Name #2: _____ Name #3: _____

Child/ren Name: _____ Age: _____ Name: _____ Age: _____

Address: _____ City: _____ ST: _____ Zip: _____

Phone: _____ Text: Y/N E-mail: _____

I will be using a: Cane _____ Walker _____ Scooter _____ Wheelchair _____

Friday Night Dinner: Number adults attending: _____ @ \$50.00 per person = \$ _____

Number children attending: _____ @ \$10.00 per person = \$ _____

Conference: Number attending: _____ @ \$70.00 per person = \$ _____

Number children attending: _____ @ \$10.00 per person = \$ _____

Sunday Seattle Tour: Number attending: _____ @ \$20.00 per person = \$ _____ (transportation included)

SPF Donation: \$ _____

Payment Type: _____ Check _____ Credit Card

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