Synapse

Volume 20, Issue 1
Winter 2017
Newsletter of the Spastic Paraplegia Foundation

SPF 2017 ANNUAL CONFERENCE

June 23 - 25

Save the Date

ATLANTA AIRPORT MARRIOTT GATEWAY
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ATLANTA, GA

How to Help

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

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

Support Research to Speed Our Cures by Volunteering

Below you'll find information about some of the ways you can help the SP Foundation in their search for cures for PLS and HSP.

Raise Funds: The primary focus of SPF is to raise funds to support research to find the causes, treatments and cures for Hereditary Spastic Paraplegia and Primary Lateral Sclerosis. Our fundraising activities include: SPF TeamWalks (actual and "virtual"); Golf Tournaments; national and international fundraising events like Rare Disease Day (the last day of February each year) and Giving Tuesday; and local special fundraisers. Individuals like you can help organize local fundraisers. Volunteers are also needed to secure corporate sponsorships and help with grant applications.

Patient Connections: Organizing a Connection, a social gathering for people to meet, share stories and help one another, is a great service. Events can be as simple as meeting for coffee! In many states, the SPF State Ambassador organizes and hosts their respective Connections (see below).

Conference Organizers: The SPF seeks event coordinators in or near metropolitan areas who can work with us to organize Conferences for our SPF community. These events feature speakers and programs on special topics of interest to our community as well as provide the opportunities for individuals to meet others with similar conditions. Conferences can be half-day or full-day events..

Communications: Individuals with writing, research, website or graphic design skills are needed to assist with various communication initiatives, including SPF's closed Facebook group and this newsletter, *Synapse*.

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

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

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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).

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Letter from the President

Dear Friend,

I have all sorts of feelings as we enter a new year. Those emotions include gratitude, excitement and tremendous hope.

First of all, I am so grateful to you for your generous donations. Thank you! We set a new record for the amount of much needed funds we raised to support getting closer to a cure for HSP and PLS. Your donations are the stepping stones we walk on carefully and painstakingly to get to a place where people with HSP and PLS will WALK NORMALLY. Please let me quickly remind you that 93 cents of every dollar you donate goes to our mission of research and service. All of the hard workers in our Foundation are volunteers.

The reason I am so excited is that your donations bring us ever closer to the day we reach our goal of A CURE. Just this week, our SPF Board of Directors voted on what we will sponsor for this year. Because of you, we are sponsoring 5 projects that cost more than $600,000, over a two year period.

Due to the secrecy that these scientists have to work under, I can't tell you much about what they are doing, but let me tell you that it is incredibly promising and exciting. One of the scientists will be working on a specific kind of HSP that he considers the low hanging fruit. He thinks he can get to a relatively inexpensive cure for it in the next couple of years. Another, is actually using the CRISPR/cas9 technique that many of us are hopeful about. Still another will be using a new process to run an HSP gene against a very long list of very promising drugs that stand a hugely hopeful chance of being effective. These scientists have a stellar background of doing this successfully with other conditions. I was at a NEALS conference last Fall in Miami where a large group of scientists were very enthusiastic about a study that Dr. Mitsumoto is planning to do for PLS. He needed a sponsor for this study and you and I are going to make it possible.

With the incredible speed that science and the knowledge of HSP and PLS is progressing, it makes me very hopeful that we will be at a place in the next few years where we will be curing one HSP gene after another and PLS will become a worry of the past.

We all make new year's resolutions and let me tell you that my resolution for SPF is this: that we will be there for one another under our motto of "Research, Education and Support"; that we will work together in a positive, productive way that doesn't waste a penny of your most appreciated donations; and that we make great strides toward our goal to cure HSP and PLS. Thank you again for making all of this possible and I hope you will continue to join me in this effort.

All the Best,

Frank Davis

President

Board Business (Sept. to Dec. 2016)

Compiled by John Staehle

SEPTEMBER

- Welcomed three new members to the Board, Laurie LeBlanc, Davis Ress, PhD and Ben Robinson.
- Gregg Pruitt reported that the Kentucky Golf Tournament fundraiser was very successful. He expected total funds raised for SPF to be around $17,000.

OCTOBER

- Mark Weber reported the receipt of 22 proposals for research grants. All were HSP proposals. The Board agreed to discuss potential PLS proposals with known PLS researchers.
- Frank Davis reported that an anonymous donor committed $175,000 in matching gifts for this year's year-end fundraising effort.
- Linda Gentner reported another successful California Virtual Walk 'n Roll fundraiser, collecting more than $35,000 for SPF.

NOVEMBER

- John Cobb reported another successful Cobb Classic Fore SPF golf tournament. Total raised is expected to be around $18,000.
- Frank Davis reported the year-end fundraising letter is ready to be mailed to more than 6,000 recipients this year.

DECEMBER

- Mark Weber reported that we finally received a grant proposal for PLS.
- Norma Pruitt, coordinator for the 2017 Annual Conference, reported that the conference program will start Friday afternoon with multiple breakout sessions. This change is the result of the 2016 AC surveys returned by last year's conference attendees.

SPF Kentucky Group Hosts 2nd Annual Golf Fundraiser

By Greg Pruitt, SPF Board Member

On a beautiful west Kentucky Saturday morning in September the SPF Kentucky group hosted an event to raise funds for research aimed at finding a cure for hereditary spastic paraplegia and primary lateral sclerosis. Drake Creek Golf Course in Ledbetter, Kentucky, was the site for the second annual Golfing for Rare Disease Golf Scramble. The 2016 event raised nearly $17,000.

The SPF Kentucky committee includes SPF Board Member and wife, Greg and Norma Pruitt; SPF State Ambassador Kari Atkinson Averill; Tim Vaughan and Mike and Joanne Faihst.

More than fifty sponsors and seventy golfers participated and assisted in the fundraising effort. "As a result of a lot of hard work by our committee and the generosity of so many sponsors and golfers, we were able to increase our donation base by more than 40% from year one to year two. We will hope to improve a little more as we work on year three," stated Greg Pruitt.

"We had a great day. A few of our sponsors came and spent the entire day with us, and they have already committed to help us with our next year's golf event. They are even talking about helping us recruit additional sponsors," stated Kari Atkinson Averill.

The committee is already planning a third annual event, tentatively scheduled for September, 2017.

2016 Cobb Classic Fore SPF

By John Cobb, SPF Board Member

The 3rd Annual Cobb Classic Fore SPF was held on November 5th in Alexandria, Virginia, at Belle Haven Country Club. The Cobb Classic was inspired by the RGM for SPF Golf Tournament created by Rick Easterling and his family to honor Richard G. Milbourne and their extended family affected by HSP. It was wonderful playing in their tournament and the Cobb Classic includes many of the features they did so well - food stations scattered around the golf course serving oysters, chili, and barbecue as well as fun gimmicks and challenges that included a putting contest, closest to the pin prizes and mulligans for sale. A unique feature of the Cobb Classic is to have a bagpiper play as golfers finish their round and return to the clubhouse. In addition to golf, the Cobb Classic hosted a reception for non-golfers that included food and a live band. Attendance has ranged between 92 and 124 golfers and the event has raised between $17,000 and $20,000 each year for SPF from golfers, sponsors and donations. We hope to continue this annual fun event for many years to come.

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

California WALK 'n' ROLL & Connection

By Linda Gentner, VP SPF

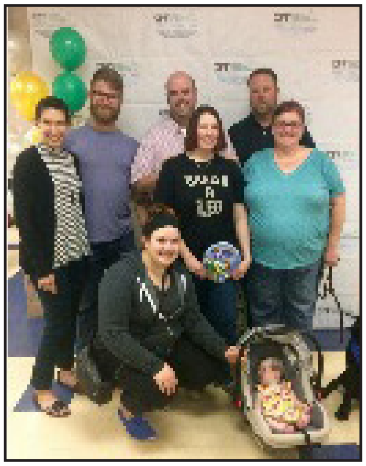
September 24, 2016 was the date for the 16th California fundraiser. This year's WALK 'n ROLL & Connection was attended by 37 people. After lunch there was a SHARE AND COMPARE discussion while friends and family cleaned up. PLSers and HSPers really appreciate the opportunity to "share and compare" their progression from the previous year. It seemed people enjoyed not having to go on an actual walk or roll. Attendees were encouraged to bring a raffle item or two so there were many more raffle items donated this year. The raffle seemed to be the highlight of the day and it alone raised an additional $775. We had changed the venue and location this year and fewer people attended, but the money raised, $35,450, was comparable to prior years. Many were already talking about next year.

The "walk," for those who wanted, toured the Little Church, 1874, and Craig gave a brief history. Four members did their annual letter campaign and were Walkers-by-Proxy. All four contributed greatly to the bottom line. Linda walked for the PLSers (Hank, Lee and Dave) and Jean walked for Jackie. Jean also made the tags.

We have a very committed group and "members" came from southern California, northern California, Oregon and Jean came from Vancouver, British Columbia.

Missouri Trivia Night

By Tina Croghan, Missouri State Ambassador and SPF Board Member



Missouri held its 2nd Annual SPF Trivia Night on Saturday, October 8th at Maryland Heights Community Center (St. Louis area). Everyone there enjoyed the trivia competition and bid on the many Silent Auction items donated to SPF.

The evening began with a brief PSA video about SPF and then on to the ten rounds of trivia, with one round dedicated to bringing awareness to the audience.

Tim Croghan demonstrated the Potato Pants made by Mary Schultz as he told everyone about the history and importance of the Potato Pants. People were offered a chance to wear the pants and feel what it's like to have HSP or PLS.

The winning table was comprised of Hugh O'Brian Scholarship winners (HOBY). They were gracious enough to donate the evenings winnings to SPF.

The Trivia Night yielded $2,300 for SPF.

Southern Maine Connection
October 15, 2016

By Jeff Stern, Maine State Ambassador

A small but enthusiastic southern Maine lunch connection was held in Portland last week. We gathered at DiMillo's restaurant on the water. The event was very enjoyable and we made new friends! We also held a connection in northern Maine earlier in September.

New York SPF Fundraiser

By Ann-Marie Lakin

On September 30, 2016 I held my third annual Spastic Paraplegia Foundation fundraiser in Mt. Kisco, NY, at the American Legion, who generously donated the use of their venue free of charge. This year the event was dedicated to my sister Helen Kienlen who died suddenly last year at age 48. She did a lot for SPF in her home state of Pennsylvania where she served as an SPF State Ambassador.

Entertainment for the evening was provided by the acoustic duo of Chris and Adam and by singers Patricia O. and Stevie B.

Food was potluck and, as with all potlucks, we had many delicious dishes and more than we could eat.

I also ran a silent auction. Most of the items in the auction were donated by local vendors, but friends also made generous donations. Origami Owl and Tupperware each had tables set up with their products and creations. A percentage of what they sold was donated to SPF.

Sandy Daly from Origami Owl created a beautiful custom bracelet for me in memory of Helen. She gave this to me when I became very emotional speaking about my late sister.

The event was a HUGE success. We had a great turnout and raised over $1,000 that night and a couple more thousand from letters I sent to family and friends asking for donations if they couldn't attend the fundraiser. This was my 3rd year doing this type of fundraiser and it definitely was the most successful. I hope more people will attend next year, especially more who are members of the SP-Foundation, to not only help raise money but to help raise awareness about HSP and PLS.

SPFIllinois Connection
October 15, 2016

HSP: Sid Clark PLS: Hank Chiuppi

We met at the Buffalo Grove Arboretum clubhouse. For lunch we ordered delivery from the Corner Bakery and had the driver take the Connection picture. We had 13 in attendance at this our fall meeting. Amazingly we have been meeting two to three times a year for over 5 years!! Organize a connection for your area – great benefits and you find out **"You are not alone."**

We do make up an agenda based on the hot topics for HSP/PLS at the moment discussing questions and concerns that may be of interest to those present. We share, ask, and answer. Hank and Paulette told us about Hank's participation in Massachusetts General's PLS research program which will require trips to Boston for 4 years. We also discussed Foot and Toe care. We talked about asking for help when you need it with Community resources such as the Department of Aging, state and community-based services' resource centers and programs, Churches, high schools and colleges. We examined the importance of attitudes, staying positive and not forgetting the caring of caregivers. Don't forget to say "Thank you". Debbie showed us pictures of a beautifully remodeled bathroom they just finished and gave us some resources used in its planning. Additionally we also talked about some doctors' reluctance to write Rx for cannabis, handling of getting out of a car in icy conditions by having throw rug available, types of walkers and rollators and handicap traveling. Finally we considered a tipping schedule and how much to give airport pushers.

We never have enough time to cover and share all that we want. For the next meeting we are looking for suggestions on topics to be discussed. By each of us sharing we learn a lot. Our next meeting will be in the spring. For information on future meetings email us at SPFIllinois@gmail.com.

Tina's Tips…Special Edition

The following two articles were written by Dana Larsen and appeared in the October 25, 2016 issue of "A Place for Mom" senior living newsletter. They are used here with permission. The advice in these articles is applicable to all and especially to those of us with HSP or PLS. [Tina]

Tips to "Fall-Proof" Your Home and Avoid Falls Indoors

An important step toward preventing falls at home is to remove anything that could cause you to trip or slip while walking. Tripping on clutter, small furniture, pet bowls, electrical or phone cords, or other things can cause you to fall. Slipping on rugs or slick floors can also cause falls.

Arrange furniture to give you plenty of room to walk freely. Also remove items from stairs, hallways, and pathways.

Be sure that carpets are secured to the floor and stairs. Remove throw rugs, use non-slip rugs, or attach rugs to the floor with double-sided tape.

Put non-slip strips on floors and steps. Put non-slip strips or a rubber mat on the floor of your bathtub or shower, as well. You can buy these items at a home center or hardware store.

At home and elsewhere, try to avoid wet floors and clean up spills right away. Use only non-skid wax on waxed floors at home.

Be careful when walking outdoors, and avoid going out alone on ice or snow. A simple slip on a slick sidewalk, a curb, or icy stairs could result in a serious injury.

During the winter, ask someone to spread sand or salt on icy surfaces. Be sure to wear boots with good traction if you must go out when it snows. Better yet, don't take chances walking on icy or slippery surfaces.

Poor lighting -- inside and outdoors -- can increase your risk of falls. Make sure you have enough lighting in each room, at entrances, and on outdoor walkways. Use light bulbs that have the highest wattage recommended for the fixture.

Good lighting on stairways is especially important. Light switches at both the top and bottom of stairs can help.

Have handrails installed on both sides of stairs and walkways. If you must carry something while walking up or down stairs, hold the item in one hand and use the handrail with the other. When you're carrying something, be sure you can see where your feet are stepping.

Place a lamp within easy reach of your bed. Put night lights in the bathroom, hallways, bedroom, and kitchen. Also keep a flashlight by your bed in case the power is out and you need to get up.

Properly placed grab bars in your tub and shower, and next to the toilet, can help you avoid falls, too. Have grab bars installed, and use them every time you get in and out of the tub or shower. Be sure the grab bars are securely attached to the wall.

You might find it helpful to rearrange often-used items in your home to make them more accessible. Store food boxes, cans, dishes, clothing, and other everyday items within easy reach. This simple change could prevent a fall that might come from standing on a stool to get to an item.

If you have fallen, your doctor might suggest that an occupational therapist, physical therapist, or nurse visit your home. These health care providers can assess your home' safety and advise you about making changes to prevent falls.

How to Avoid Falling Outdoors

Whether you are walking around the park to stay active or just going to the store, falls can happen outdoors. In public places, there are many things you can do to reduce your risk of falls.

1. Be aware of where and when you walk

In the evenings, walk where there is plenty of light to help you see where you are going.

If you see a tree ahead in your path, look for fallen leaves or tree roots that might push up the sidewalk.

Continued on next page

How to Avoid Falling Outdoors *Continued*

Watch out for cracks in sidewalks, holes, and changes in sidewalk levels.

Be extra careful during and after stormy weather. Rain, snow, and ice can make any surface slippery.

Be sure you are wearing the correct eyewear while walking. Bifocals or reading glasses make it harder to see hazards on the ground. Wear sunglasses on bright days to reduce glare.

2. Tips for physical activity

When walking for exercise, consider going to well-maintained places such as the mall or the track at a local high school.

Walk in pairs or groups so you can alert each other of potential hazards.

Wear shoes with firm soles and low heels. Make sure to wear sturdy shoes when exercising.

3. Travel safely

Hold hand rails and move slowly when climbing outdoor stairs.

Use caution in parking lots and parking garages. Be aware of curbs, car stops, and changes in elevation.

While riding public transportation such as buses and trains, always use handrails when available.

When crossing the street, walk in crosswalks and use curb cuts or ramps when they are present.

Stop at islands in the middle of the street when available and wait for the next walk sign.

Always take your time - hurrying across streets puts you at risk of falling.

<u>About the Author</u>: Dana Larsen is a writer, artist, editor, dancer and food-enthusiast living in the Pacific Northwest. Originally from Alaska, Dana has a passion for the outdoors and finding life's next adventure. She graduated with honors from the University of Washington with a degree in English and Communications, and her writing has appeared in a variety of digital and print publications. She loves connecting audiences with ideas and is also an advocate for enhancing care and support for those affected by Alzheimer's and other dementias.

New Words For Auld Lang Syne

By Malin Dollinger

[Sung to the tune of Auld Lang Syne]

May all of us now gathered here
Remember who we love
And not forget to thank the one
Who loves us from above

For all of us are bless'd indeed
To live another year
We'll raise our voices thankfully
With those we hold most dear

Next year we'll try to be the best
That we know how to be
And spend more time in song and joy
Especially with thee

For Auld Lang Syne, my dear
For Auld Lang Syne
We'll make next year the best one yet
For Auld Lang Syne

Para-Transportation by MARTA

If you plan to attend the 2017 Annual Conference, MARTA, the Metropolitan Atlanta Rapid Transit Authority, can provide para-transportation services for handicap persons at a reduced cost, however customers must be registered with MARTA to use this service. If you are already registered with a paratransit service in your area, you can ask your local paratransit service to fax "Visitor's Status" information to MARTA Mobility, 404-848-6900. If you are not registered with a local service, it is very important to answer <u>all</u> the questions on the Conference Registration Form. A copy of the form can be found at the end of this newsletter. Your information will be provided to MARTA to meet their registration requirements.

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I'm Not a Cripple!

By Tina Croghan, Missouri State Ambassador and SPF Board Member

I have been wrestling with this term for quite some time. I was told on Facebook when I admonished a user of this moniker that I didn't like this term. "We park in 'Handicapped' parking spots. We use an 'accessible' bathroom. I consider myself 'disabled,' but NOT 'crippled!'" I said. I was told to lighten up and laugh at myself.

I remember several years ago taking my father (now deceased) to one of his doctor's appointments. I pulled into a "handicap" parking space. As I was reaching for my disabled hangtag, my father exclaimed, "Oh no! You don't want to park here—you'll get in trouble. This is for the crippled!" It took everything I had not to lose my cool. I just told myself he came from a different era. I tried politely as I could muster and said, "I'm not crippled, Dad—I'm disabled. Please don't use that term again." He never did!

I believe in receiving as much help as I need, but I don't want to have special attention either. You know those people who smother you with looks of pity.

There has to be an in-between!

I would like to have others take my mobility into consideration. I don't want to be left out or ignored. I have HSP. It's not a figment of my imagination—but then again, I don't want to be treated with kid gloves or that I have leprosy.

I will say it is much easier to be recognized as disabled because I have a VISIBLE disability now—beyond that of walking funny.

Thank you for letting me vent. Perhaps the Facebook person was right in that I need to lighten up and learn to laugh at myself!

I'm not there yet.

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.

Shine Your Heart

By Tina Croghan, Missouri State Ambassador and SPF Board Member

It was three simple words—I had an epiphany—an "Ah Ha!" moment! Suddenly, it all clicked. My Pilates instructor said for me to *shine my heart* when I was doing a particular exercise. I lifted my head, my gaze looked up. My shoulders went down I no longer had a "death grip" on my exercise equipment my elbows went naturally to my sides. I grew taller. My spine elongated—I added a cushion of air between my vertebrae.

I was treated by a visit from one of my Missouri SPF friends. I mentioned this "Ah Ha!" moment. She said, "Oh yes! I've heard something similar from my Yoga Instructor. She said to, 'Let my Heart Center Blossom.' I'm very familiar with that phrase."

Here I thought I had stumbled on a unique phrase. Maybe it will help you as it has me!

When To Dial 911

By Tina Croghan, Missouri State Ambassador and SPF Board Member

I'm guilty of this—thinking that, "Oh, I've fallen but, I don't think anything is broken, I don't want to create anymore of a scene." Or this is the best one—"I don't want to be a bother."

Recently I read a post about an individual that got his wheelchair stuck in the rocks outside of his apartment building.

First of, let me just say—kudos to that person for living by himself in his own apartment and propelling himself in a wheelchair! I don't think I would have either the courage or the upper body strength to do that!

In talking with Firefighter/Paramedic, Paul McReynolds of St. Louis, MO, he says that he routinely gets calls to help individuals that have fallen and can't get up on their own. He went on to say that emergency personnel would rather help an individual that has fallen, than to rescue an individual that has sustained injuries from trying to "just do it" themselves.

We need to rethink what constitutes an emergency!

DISABILITY LAW: Copyright, Fair Use

By Mary B. Schultz

In a previous column, I provided a very general overview of copyright law in the United States. The Copyright Act of 1976 is the codification of copyright law in the United States. 17 U.S.C. § 102 *et seq*. The 1976 Copyright Act confers on the owner of a copyright the exclusive right to do certain things, including making copies of copyrighted material. 17 U.S.C. §102(a). However, in addition to codifying copyright protection, the 1976 Copyright Act also provides for limitations on copyright, including "fair use". 17 U.S.C. §107. Generally, fair use is a limitation on copyright. The statute, together with case law that has followed, is called "Fair Use Doctrine". (The "innocent infringement" defense to a lawsuit asserting copyright infringement, will be addressed in a later column.)

The language of the statute is helpful. Section 107 of the Copyright Act provides in part:

> **[T]he fair use of a copyrighted work, including such use by reproduction in copies …, for purposes such as … comment, … teaching …, scholarship, or research, is not an infringement of copyright.**
>
> **In determining whether the use made of a work in any particular case is a fair use the factors to be considered shall include—**
>
> **(1) the purpose and character of the use, including whether such use is of a commercial nature or is for nonprofit educational purposes;**
> **(2) the nature of the copyrighted work;**
> **(3) the amount and substantiality of the portion used in relation to the copyrighted work as a whole; and**
> **(4) the effect of the use upon the potential market for or value of the copyrighted work.**
>
> **The fact that a work is unpublished shall not itself bar finding of fair use if such finding is made upon consideration of all the above factors.**

The seminal case in this area is <u>American Geophysical Union v. Texaco</u>. 37 F.3d 882 (2d Cir. 1994 ("Texaco case"). The Texaco case involved a longstanding copyright infringement lawsuit that had been initiated in 1985 by publishers in a class action lawsuit against Texaco. Individual scientists who were employed by Texaco copied articles from scientific journals to which Texaco subscribed, but for which no royalties were paid to the publishers for the additional copying and distribution to Texaco employees. Scientists employed by Texaco copied the scientific articles for their own files and personal use. In 1992, a federal district court ruled against Texaco reasoning that its use was not "fair use" under the 1976 Copyright Act. 802 F. Supp. 1 (SDNY 1992). On appeal, the United States Court of Appeals for the Second Circuit affirmed the federal district court. (The appellate court reached the same result as the district court, but for different reasons.) In April of 1995, Texaco filed a petition for *certiorari* ["a writ or order by which a higher court reviews a decision of a lower court." Oxford Dictionary] to the United States Supreme Court. However, before the case was considered by the United States Supreme Court, Texaco reached a settlement agreement with the publishers, and the lawsuit was eventually dismissed. The decision of the United States Court of Appeals for the Second Circuit became controlling.

The analysis of the United States Court of Appeals for the Second Circuit was that:

(1) Although the court stated that the focus should be on the USE of the material, and NOT on the USER, it emphasized that Texaco is a for-profit corporation. The court ruled against Texaco on the first fair use factor of §107 of the Copy-

right Act, the purpose and character of the use. In other words, the for-profit motive was controlling. Although the scientists employed by Texaco placed the copied articles in their own files, for personal use as needed, Texaco itself is for-profit.

(2) Because the copied articles were scientific, the court ruled in favor of Texaco on the second fair use factor of §107 of the Copyright Act, the nature of the work.

(3) The court ruled against Texaco on the third fair use factor, the amount of the work copied. The court noted that Texaco copied entire articles rather than just a portion.

(4) The court ruled against Texaco of the fourth fair use factor of §107 of the Copyright Act, reasoning that the market was affected by Texaco's actions because publishers lost the right to license the scientific articles for reproduction.

In summary, the Second Circuit seemed to focus on the first fair use factor, the purpose and character of the use. The status of Texaco as a for-profit corporation appears significant.

> We do not consider Texaco's status as a for-profit company irrelevant to the fair use analysis…Ultimately, the somewhat cryptic suggestion in section 107(1) to consider whether the secondary use "is of a commercial nature or is for nonprofit educational purposes" connotes that the court should examine, among other factors, the value obtained by the secondary user from the use of the copyrighted material…The commercial/nonprofit dichotomy concerns the unfairness that arises when a secondary user makes unauthorized use of the copyrighted material to capture significant revenues as a direct consequence of copying the original work…Consistent with these principles, courts will not sustain a claimed defense of fair use when the secondary use can fairly be characterized as a form of "commercial exploitation," i.e., when the copier directly and exclusively acquires conspicuous financial rewards from its use of the copyrighted material … Conversely, courts are more willing to find a secondary use fair when it produces a value that benefits the broader public interest…The greater the private economic rewards reaped by the secondary user (to the exclusion of broader public benefits), the more likely the first factor will favor the copyright holder and less likely the use will be considered fair.

Id.

Whether making a single copy of an article appearing in a scientific journal, made and archived for personal use, or even shared with another person also suffering from HSP or PLS, remains an open legal issue. The court's analysis in the Texaco case might arguably support the fair use of articles copied and distributed among members of SPF suffering from HSP or PLS. However, I recommend a conservative approach. Either obtain permission for such use, or refer to a web site for an electronic view of a relevant article.

Mary Schultz is a partner is the law firm of Schultz &Associates LLP, www.sl-lawyers.com , 640 Cepi Drive, Suite A; Chesterfield (St. Louis), Missouri 63005, (636) 537-4645. Mary B. Schultz graduated from Northwestern University Law School more than 30 years ago, in 1985, and has been practicing primarily in Missouri ever since. Mary B. Schultz is admitted to practice in Missouri and Illinois.

Mary Schultz was diagnosed with HSP in 2012, and through genetic testing has learned that her gene mutation is in SPG7. Mary has been a member of SPF, and has benefited from friendships and support she has received through SPF.

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North East ALS Meeting in Clearwater Beach, FL, October 4-7, 2016

By Frank Davis, President, SPF

NEALS is an organization whose mission is to rapidly translate scientific advances into clinical research and new treatments for people with Amyotrophic Lateral Sclerosis (ALS) and motor neuron disease. They were founded in the northeastern part of the United States in the mid- 1990s, but have since expanded all over the country. They have a national meeting in October of every year. This was my first time to attend.

The Upper Motor Neuron Disease Committee met the morning of October 5th. HSP and PLS are "upper motor" neurological diseases. The room contained about 45 scientists and the topic of conversation was PLS. This was exciting to me as I had never been anywhere where PLS was such a focus of attention among some of the top neurological scientists in the country. Scientists that I recognized were Dr. Hiroshi Mitsumoto with Columbia University Neurological Institute, Dr. Sabrina Paganoni, and Dr. Nazem Atassi, both with Massachusetts General Hospital. Speakers were Mitsumoto, Paganoni and Dr. Dale Lange with the Hospital for Special Care in New York, NY. Dr. Lange talked about the study of a drug called Dalfampridine (Ampyra) that they have proven helpful for people with PLS.

The main topic of conversation was a PLS registry that Dr. Mitsumoto is spearheading along with the help or partnership of Dr. Sabrina Paganoni and Dr. Nazem Atassi. Dr. Atassi was the meeting facilitator as he is the head of this committee. He and Hiroshi were friendly and welcoming to me. Everyone in the room was excited about this PLS patient registry. The amazing thing is that everyone was excited about it, not because there was money behind it as there is none (until SPF sponsored it this winter), but because of the good it will do for people with PLS.

They have enlisted the assistance of all 25 NEALS sites and have enlisted in 4 countries to do this PLS registry. They already have 79 patient records enlisted in the registry before it has really begun. Dr. Mitsumoto had asked the MDA for funding and was surprised that MDA does not cover PLS. It is not one of their diseases. Another project that Mitsumoto has worked on is a PLS Clinical Trial Readiness Workshop which has the objective of being ready for a clinical trial once the registry has begun. They have a PLS functioning scale test-retest reliability in 20 centers.

I talked with Dr. Atassi after the meeting. I mentioned to him that they could get in a last minute appeal for funding from SPF. I said that we could get information to our membership with PLS, if they will just keep in touch. I mentioned that I was open to helping promote their PLS registry. He asked about HSP as well. I said that he could send a proposal to us any time. Nazem later emailed Mitsumoto to let him know that we were open for some communication from them about funding for this project. Mitsumoto emailed me when I was at the airport on Friday, to which I replied promptly. He has since contacted Mark Weber, Esq. who, as we all know, manages our Scientific Advisory Board.

Dr. Teepu Siddique spoke at the General Session about CRISPR and ALS. He largely spoke about how CRISPR could be used to create rats or mice with the motor neuron disease of their choice. He did not really speak about CRISPR as a tool to cure any disease.

The last day, I asked Dr. Nazem Atassi if he could spare a moment. He was in a hurry to get somewhere so could only give me a moment. He said their registry will be longitudinal, in depth, detailed questions and tests. There isn't yet anything else like it.

I attended the general sessions and met a lot of other scientists. The Spastic Paraplegia Foundation was mentioned many times as we have worked with them through many projects including the Virginia Freer Sweeney Foundation Grant which has made such a huge difference. By the way, Dr. Atassi said if we wanted to sponsor another person similar to what we have done with Dr. Fournier and Dr. Paganoni, we should start looking for the best candidate now. He said that he would help work with us on this.

Some scientists were very familiar with HSP, but to show you how rare we are, one even asked me, "What is HSP?" I think it is important that we have a presence in NEALS, particularly since they have an Upper Motor Neurological Disease Committee. I have asked to be a member of that committee and think I will be allowed to be a member even though I am not a neurologist. One neurologist, who introduced several of the speakers at the general session, came up to me the last day to say that she was opening a special clinic for HSP and wanted to know if we could help her let people know about it. I said yes.

I flew out of Tampa on Friday afternoon with Hurricane Matthew raring in northern Florida. The palm trees outside the airport were bent over in the wind, but the flights were barely delayed.

YOUR WHEELS ARE YOUR LEGS – Part I

Electric Scooters and Wheelchairs: How To Be "On A Roll" Safely And Efficiently

By Malin Dollinger, MD, SPG4

Introduction

Over the past 25 years I've had some 15 different scooters and other mobility devices, including wheelchairs, walkers, crutches, and lately the TEK standing device. I have made major handicap modifications and unique devices in my home (a separate article will appear soon). I've taken these scooters via car, train, and plane to most states, as well as cruises and to hotels, and I am about to regale you with descriptions and discussions of what goes right and what goes wrong, and how to make your own experiences simple, successful, safe, and satisfying.

The beginning of the "wheels experience," whether a wheelchair or a scooter, represents a compromise you finally realized was necessary for your lifestyle and well-being. I respect your previous repeated decisions to remain "walking" as long as possible. Perhaps you've used a scooter only for long or difficult trips, and now it's needed most or all of the time. In my own case, my need to conduct the "ordinary" practice of medicine required me to begin full-time use of a scooter much earlier than would have been desirable.

Standing and walking, even with assistance or of limited extent, is important for bone and muscle health, the compelling reason why I now use the new TEK standing mobility device. So….even if your life now revolves around a scooter, find some way to be standing every day, even if it's just holding onto handrails, with someone there to protect you from falling. All of us paraplegics need to stand every day, even for a few moments during necessary life activities such as getting on/off the toilet or shower seat, getting in and out of bed, in and out of our cars, and transfers from our scooter back and forth to a seat, e.g. in a restaurant or a movie. Whenever I do these daily transfers, I linger in the standing position for an extra minute, to remind my bones that humans --homo sapiens-- learned to stand and walk a long time ago, and that just standing has health benefits.

Wheels in Your Life

Now, all about "wheels." The general subject of wheeled transportation aids includes self-powered walkers, useful for folks with mild or early leg weakness. They are light-weight, often fold up, and are easy to carry. They are especially useful for shorter distances, and often have a seat, for resting mid-way, and a storage compartment. Walkers and scooters and wheelchairs often have attachments to hold drinks, crutches, spare parts/keys, and may have lights and horns, so you will be more self-sufficient when using them. My daughter has a home-made crutch holder on her electric scooter, where she keeps her walking sticks, handy for shorter distances. Here is her scooter mounted on a platform at the back of her SUV. This location is very handy, since it does not take up space inside the car, and she can park in a regular parking space if need be, since the scooter is mounted on a foldable platform behind her car. Later I will discuss the ins and outs of using side-entry handicap vans, which require special handicap parking places with a blue-hatched non-parking space adjacent to the car, to allow space for the ramp to come out, and for you to drive your scooter up and down the ramp.

The term "electric scooter" is usually synonymous with "scooter," terms often used interchangeably, and "electric wheelchair" is similarly often used as a general description of what we are riding in, for example telling people how we get from place to place. Technically, an "electric wheelchair" is in fact a larger and more complicated piece of mobility equipment, compared to an electric scooter, and is much more expensive. "Electric wheelchairs" are often the mobility devices

Continued on next page

of choice for those who are quadriplegic, and may use special, e.g. mouth-operated, control devices, or alternatively, mounted computer equipment, joysticks, or other specialized gear to permit control of mobility and function, as well as to provide very important varieties of position change for the occupant.

An "electric scooter," or simply a "scooter," is a *wheeled mobility device*. Your doctor may need to use those exact words on the prescription to get insurance reimbursement. A "scooter" is generally smaller and lighter than an electric wheelchair, and probably 95% of us handicap folks use what we call electric scooters, or simply scooters. They come in two different styles: those with steering handles with built-in controls in front of you (like a bicycle), and those with nothing in front of you while sitting in the scooter, the driving and steering being controlled with a hand-operated joystick. The definition of "joy" here is the joy in being able to easily go somewhere. Using your scooter preserves your strength, enables you to do things and to go places you could not otherwise do, increases your degree of independence, and lessens your chance of injury from falling or other mishaps. Persons with major shoulder or hand problems may prefer an electric scooter compared with a hand-operated wheelchair. However, there are new clever hand-lever operated manual wheelchairs, which are much more efficient and easier to operate than the conventional wheelchair, where the occupant runs the wheelchair with their hands holding onto a metal rim next to the tires. There is also a light-weight chair called a companion chair, with no metal propulsion rim, that requires an attendant to push the chair.

Scooter Driving Precautions

The **3-wheel scooters** are smaller, lighter, fit better in the car or the trunk, and are easier to travel with/ fold up, e.g. airlines. You can purchase a "hoist" that will lift your small three-wheel scooter in and out of the trunk of your car. One difficulty with the 3-wheel scooters is that they are smaller (wheelbase is smaller) and are lighter, so the weight of the person riding the scooter begins to approach and, in fact, usually exceeds the weight of the scooter. Also when you lean sideways, or backward, your body weight may be outside the center of gravity (e.g. outside the wheels) and this may cause you to tip over. So you need to be careful and drive slowly and carefully when turning, or on wet ground, or going uphill or downhill. On an incline, it is safer to back up than to go forward, since when going forward on a level surface, your body weight/ center of gravity is inside the wheelbase, but when you start to ride up a ramp, your center of gravity might be behind the rear wheels, causing you to tip over backward. One advantage of a 3-wheel scooter is that many have a tighter turning radius and can be used in smaller spaces and require fewer "back and forth" turns to go in a different direction. Also, they are usually easier to take apart/fold up than are larger scooters, especially if you are the only one there to do the folding. Many larger scooters, e.g. 4-wheel, are difficult and time-consuming to fold up or take apart, and some cannot be disassembled for travel. My travel scooter is a three-wheel scooter, and quickly and easily comes apart into small, light-weight pieces.

Three-wheel scooters, being light-weight, have the inherent problem of stalling if you go up a grade or ramp that is too steep. Often you can prevent a stall by going up a ramp or grade backwards, so your weight is right over the drive mechanism/wheels. The standard rules limit the grade to 8%, which means that the incline goes up a foot every 12 feet (or 1 inch per foot). However, just because there are "rules and regulations" about standard ramp inclines, that doesn't mean that you, in your scooter, on your ramp, under your weather conditions, can safely go up or down a ramp that conforms to these regulations. You need to independently determine whether it is safe for you to go up or down each ramp or grade you encounter.

When you are exiting down a ramp (e.g. from your car), and you are going forwards, what should be your action if you get into trouble, or the scooter begins to slip or get out of control? The usual response to such sudden situations (like when driving a car) is to quickly jam on the brakes. That is NOT what you should usually do going downhill on a ramp! That simply brakes the rear wheels, which because of the established momentum, going down the ramp, causes the braked rear wheels to swing around (your weight is now on the front wheels, not the back ones, and now you are sitting in a moving scooter, sideways, and the scooter tips over, going sideways down the ramp with you on it. So when going down that ramp, and you feel things slipping, PUT ON THE "GAS" NOT THE BRAKE. That gains control again. Just always be sure that when you are going down that inclined ramp you have at least 6 or 8 feet of clear space ahead of you., If you do need to accelerate to regain control you will have room on the ground for the scooter to recover and stop. At my home I have a raised concrete "sidewalk" leading from my car to the house door; thus the extended ramp is level when I am on it.

Now **4-wheel scooters**. These come in various sizes and weights, and are often customized for the user. Some can come apart for travel, but with more difficulty. I have a big 4-wheel scooter for inside the house (Hoveround) and a smaller 4-wheel to put in the car when I go somewhere (Jazzy). It fits in the car a lot easier. One consideration when going to a public gathering, or even a restaurant, is the ability to move a larger scooter through/around crowds of people. I thus take my small "travel – 3-wheel scooter" to things like cocktail parties. However, my wife precedes me through the mass of people, running interference.

Many 4-wheel scooters have 2 motors, one for each wheel, so with practice you can "turn on a dime" and stay in the same spot while turning. This is really neat in elevators, for example, when you can ride in going forward, turn around, and then ride out forward as well. It's also important for those who take their scooter into their minivan, and thus need to make really tight turns inside the car to place the scooter in the mid-car empty space, so you can maneuver to get off the scooter and into the driver's seat or in vans without a driver's seat, to move the scooter or wheelchair itself behind the wheel. When you get your first scooter, you need a few weeks of practice with either type of scooter, especially those with two motors. It is common and expected to have a few mishaps while learning. Door jambs, for example, get damaged when you bump into them. Pick the same area to practice, so you mess up only one door jamb. You will learn how sharp or un-sharp to make turns, so the scooter ends up where you want it to be. This is the same need for practicing a new skill that is needed when you first have hand controls installed in your car. I spent the first month practicing on back streets and parking lots.

Practical Scooter Use

Some adjustments are helpful. If the scooter seat moves forward and backward, and you need the scooter to be "short" or small, in a tight space, move the seat forward. Sometimes, however, in a tight space, you still will need to go "back and forth" several times to turn around or to get through a doorway. When I'm away from home, and I go "uphill" up the ramp into my car, I move the seat forward first, so the center of gravity is still inside the wheels. Going down the ramp, exiting from my car, I move the seat backwards, for the same reason, so my body / center of gravity is still inside the wheelbase.

If you have pockets and bags on the sides of your scooter, they are very handy, but….they make it awkward to raise the arms - things will fall out, and the scooter becomes effectively wider, so it may have a problem passing through otherwise wide-enough spaces/doorways. I created "saddlebags" which are a pair of commercial wheelchair/scooter bags, which are usually placed over the arm supports. I sewed them together, with a cloth "spacer" in between, so the spacer sits right on the scooter seat, and the bags project out both sides. I have a seat cushion on top of the spacer, to keep the saddlebags in place. This is very handy, if you need to change scooters, or secure your personal belongings when you get off the scooter for some reason (e.g. airport security), or raise the arms of the scooter (to play your guitar!) without spilling everything out of the pockets (which are sitting on the seat now and not on the arms), you simply remove the entire contraption: the two saddlebags and the connecting spacer.

Charging: Know how long your charge lasts. That is a slightly incorrect statement because you do not ever want to have a dead battery, even though you'll learn exactly how long the charge lasted!! It's better

Continued on next page

to charge every day, or at the least, every other day, depending on your scooter and how many hours it is being used each day. The control panel of your scooter should have some type of indicator showing your battery charge status.

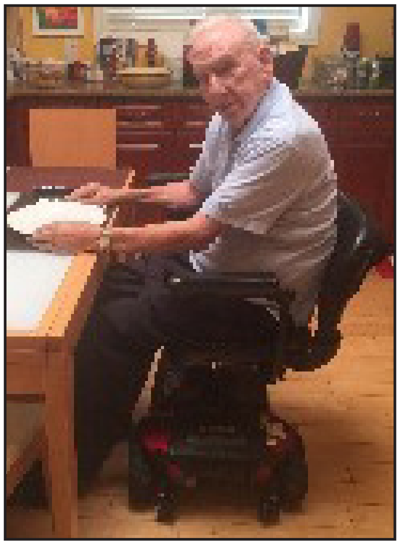
Seats that raise and lower: Some scooters have this feature, which is really neat for buffet dinners, libraries, and other places where you need to reach higher things, and move forward over and over, between the reaching. Most scooters with "liftable" or rising/lowering seats have an interlock device which prevents the scooter from being driven when the seat is raised. Why? Because when the seat is raised, the center of gravity is higher making the scooter less stable (the lower the center of gravity, the more stable the scooter). Now the center of gravity problem on inclines is really serious and risky. When the seat is up high, and you are going up a ramp, you are now much more likely to be sitting with the center of gravity behind the rear wheels, and to tip over backwards.

Being unable to drive forward with the seat in the raised position creates problems when you're in certain level surroundings and situations. For example, when you are shopping for items in a store, or are picking food up at a buffet dinner or taking things off shelves in your kitchen or office. There's this long food table, and you need to raise your seat to get to the food, then lower it to move a few feet, then raise it again, over and over.

You get the idea. Same thing happens in an office, a library, while shopping, or at home. Up and down all day. I had my Hoveround factory-modified to disable that feature so I could move the scooter while the seat is raised. The manufacturer had me read dozens of pages of technical specifications and sign a release form taking full responsibility. There is a rumor that a similar modification by the manufacturer or owner, with permission, would be possible in other brands of scooters, but I can't comment on something that is only a rumor. However, I want you to understand the risks of riding up or down ramps or inclines with a raised seat on your scooter. NEVER DO IT!!

I offer an important rule about standing up and sitting back down, from sitting on your scooter. When you get up to transfer to another seat, to use the toilet or grab something, TURN OFF THE SCOOTER POWER. After you transfer back to the scooter, then you may turn it back on (the main off/on switch). Why? A catastrophe could occur if you left your scooter on, stood up to get something, then in the act of sitting down, slipped a little, naturally reached back to grab the scooter arm to prevent falling, and missed the arm, instead pushing the control joystick backwards, causing the scooter to go backwards (empty), not to be where you left it a moment ago, and then you fall backwards on the floor in front of the scooter. I turn my scooter off and on maybe 30 to 50 times a day, specifically to avoid this risk.

Always keep in mind exactly where the off/on switch is, so in the event of a crisis, you can instantly turn the scooter off. That would prevent a recent episode we heard about that occurred in a retail store where someone was hit by an uncontrolled scooter that was left on. Practice this with the scooter stationary. I've gone through doorways too close to one side and the joystick hit the door jamb and jammed "on" with the scooter also wedged in the doorway. If this happens to you, the first critical act is to turn off the scooter (know instantly where/how to do this) and then you can figure out how to move the joystick assembly back where it belongs, so you can now control the scooter when you turn it on again.

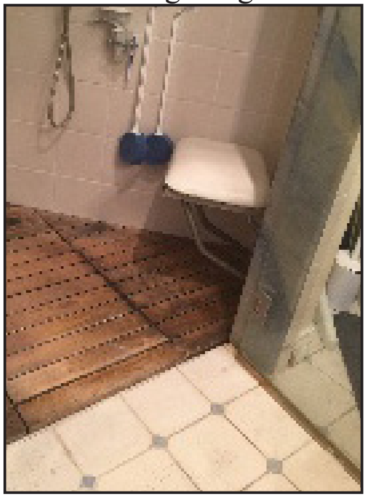


For those scooters with a foot plate that folds up and down, it is usually safer to fold the foot plate up when you are getting off the scooter. Your feet are thus closer to you and you are more stable and less likely to fall. You also do not have to step off the foot plate to the floor, since it is folded in the up position. Same action with a movable seat (forward and backward); move it forward when you get off or on the scooter.

A comment about access to sinks, toilets, and tables, where you need to either face forward while sitting (at sinks or tables) or to get off the scooter (for toileting), and not have part of the scooter, the control handles in particular, in the way of the table setting/food, the sink, or whatever device you are trying to use. Scooters with drive handles in front of you (similar to a bicycle) have this problem, since you can't park in front of a sink or toilet and use them. You need to park next to the sink or toilet, or if you have enough room, make a right or left-hand turn and park sideways in front of the sink of toilet. Scooters that are controlled with a joystick, with nothing "in front" of you, can simply be rolled up to the sink, the toilet, or the dinner table. My travel scooter has a seat that rotates sideways, making it easy to drive next to the food table, then rotate the seat to face the table.

Here's a neat and important safety use of your scooter, when you use a toilet. Toilets in commercial buildings have varying degrees of conformity to ADA regulations. I have seen a host of different kinds of wrong installations: the bar behind the toilet is so close to the toilet that you can't get your hands around it or the water tank is covered with "stuff," usually extra rolls of toilet paper, and you can't even access the grab bar. The toilet may be too low, so you need to almost "fall" to get onto the toilet; then getting up again, to your scooter, is another problem: little to hold onto with both hands. My solution is to learn which part of your scooter is stable and reliable - the armrest, the seat, the seatback - and park your scooter very close to the toilet or move it there after you transfer to the toilet. When you need to get up, you can grab and support yourself on that part of your scooter with one hand and the single grab bar on the wall with your other hand. The illustration shows a bathroom with a large space next to the toilet, where you can park your scooter next to the toilet, and then use the scooter armrest to hold onto, as well as the wall grab bar. Most commercial handicap toilets have only one handrail on the side of the toilet (usually the toilet is in a corner of the room), and thus you do not have another bar to hold onto with the other hand. A few public bathrooms have a second side-handrail, that folds up against the back wall when not in use. You ride to the toilet with that handrail up, then lower it after you're sitting on the toilet.

Be sure the bar on the wall of the bathroom of a commercial building or hotel is for handicap people and well-anchored. Most of us have made the one-time mistake of holding onto a <u>*towel*</u> bar, and having it come loose. Installing grab bars in your home at key places where you "need a lift," will make it much easier and much safer for you. You will have to experiment with how to position your scooter so getting into the shower or bathtub is safe. In my case, I had a wood floor built inside my shower, same level as the bathroom, so I simply drive my scooter into the shower, transfer onto a shower seat, and then "drive" my empty scooter out of the shower so it won't get wet. I reverse this process when I am done.



More Helpful Hints for Scooter Use

Make sure you tell all your family and people around you that you try very hard to be careful not to bump them or run over their toes. Thus they need to keep a "respectful" distance from your scooter. Every successful marriage has a magic "three little words." Although commonly quoted as, "I love you," in my world, these three little words become, "Watch your toes." My dog has a unique command, "Beep-Beep," which tells him to get out of my way, when I am going in his direction.

Most importantly, people do not appreciate the damage that can be done if a scooter runs into them or hits them. They are not used to scooters, and often people don't seem to notice I am traveling in my scooter near them. Sometimes my scooter seems to be invisible. I do a lot of horn honking, especially at airports, where

Continued on next page

people are walking right at me staring into thin air. You can also put a tall flag on the scooter – yellow is noticed more easily than red, or even use both colors.

It is often easier to go through a large doorway backwards, in an office building, in particular if your scooter has two motors. It sometimes gets tricky, going through forwards, depending on which hand you use to control your scooter, and which side of the door has the handle. You need to instantly identify whether the sides "match." A right-hand scooter control and a right-sided door handle is easy: you reach out with your left hand to open the door (or the reverse idea for left-sided scooter controls).

Sometimes there is no "match," for example you drive your scooter with your right hand, and the door handle is on the left side of the door. Thus, when you use your left hand to open the door, the door is in your way. If that is the case, or especially if it is a heavy door with strong springs, try grabbing the door with your free hand, opening it halfway, the reverse the direction of your scooter so you appear to be exiting, then back through the doorway while your free hand opens the door the rest of the way. Of course this is a lot easier with a 4-wheel scooter with 2 motors.

Put some white reflective tape on the edges of the car ramp, so especially at night you can more easily see where the edge is. If you have a three-wheel scooter, put another strip of reflective tape in the center of the ramp, so you know where to point the front wheel, to stay in the middle of the ramp.

If you have someone with you, have them walk in front of you. They can anticipate obstacles and run interference. If you can travel close to the walls of a room, rather than the center, the space you need is much less likely to be used by others and if it is, they will be on one side of you.

Many scooters have a basket, which is very useful for carrying goods with you. If it is detachable, put a name and address label on it in case it gets separated when travelling. For that matter, put labels on your scooter with your name, address, contact information, as well as a label showing how to release and lock the brakes. Some scooters have an adjustment allowing the handrails/arm rests to be moved closer or farther away from the center of the scooter. This is especially useful when travelling, for example getting through narrow doorways. Cable ties and Velcro are very useful for fastening your basket and other things to your scooter. I once had to have an airline search the airplane baggage compartment for my missing scooter basket.

[Look for Part II of Malin's article, "YOUR WHEELS ARE YOUR LEGS," in the Spring issue of Synapse. Ed.]

SPF 2017 ANNUAL CONFERENCE

June 23 - 25

Save the Date

ATLANTA AIRPORT MARRIOTT GATEWAY
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Hotel Registration: Mention "SPF" for discounted room rate of $119 and $8 self-parking, Call (404) 763-1544 Atlanta Airport Marriott Gateway. Conference Registration: Pay Online or Make Check Payable: SP-Foundation Mail to: 1605 Goularte Place, Fremont, CA 94539. Questions, please email SPFKentucky@gmail.com

Tentative Agenda

June 23, Friday
1:pm Welcome
1:30pm - Breakout Sessions
5:30pm – Welcome Reception (cash bar)
6:30pm – Dinner, plated

June 24, Saturday
7:30am – Breakfast, plated
8:30am – General Session, Panel
9:00am - Kid's Day Excursion to Atlanta Zoo
12:Noon – Lunch, plated
1:45 pm – General Session, Breakout Sessions
5:00pm Social Mingle (on your own)
6:pm – Dinner (on your own)

June 25, Sunday (Add-on Cost)
Excursion to Georgia Aquarium (must prepay, preregister, para- transportation provided by MARTA)

Registrant Name#1:____ **Disorder: N/A___ HSP____ PLS ____SP____ ALS____ Other___**

Registrant Name #2: ____ **Disorder: N/A___ HSP____ PLS ____SP____ ALS____ Other___**

Child Name #1: ____________________________________ **Age:** _____ **Disorder: N/A___ HSP____ PLS ____SP____ ALS____ Other___**

Child Name #2: ____________________________________ **Age:** _____ **Disorder: N/A___ HSP____ PLS ____SP____ ALS____ Other___**

Address:____

Mobile Phone while in ATL: (____)___________ Text?: Y / N 2ND:Mobile: (____)______________ Text?: Y / N

E-mail: ____

(1) Are you registered in your home state with para-transportation services? _____ If yes, ask your local paratransit services to fax "Visitor's Status" information to ATL MARTA Mobility at 404-848-6900 if you are attending the Zoo (child) _____ (y/n) or Aquarium (Adult/Child) ______(y/n). (2) If not previously registered with para-transit services, while in Atlanta, are you attending the Zoo (child) _____ (y/n) or Aquarium (Adult/Child) ______(y/n). (3) Will a companion join you? ______ , If yes, please attach a registration form for the companion. (4) What aids are you likely to use in ATL? Check all that apply: Cane_____ Crutches ____ Walker____ Scooter____ Wheelchair ____ Powerchair _____ Animal ____ Other _____ (5) Meal Requirement: Regular ________ Vegetarian____ Food Allergies______________ (6) Are you driving or flying to ATL? _________

Registration Fees: SPF Donation .... $_______
QTY:____ @$100 per adult ($110 after 5/20/17) (1-day rate $80)...$_______
QTY:____ @$70 per child (age <18-yrs old) ($80 after 5/20/17)...$_______
(Conference Fee includes: Friday Dinner; Saturday breakfast, lunch, and snacks during breaks)

Saturday Kid's Day Excursion to Atlanta Zoo includes lunch & para-transit (must pre-register)
QTY _____ @$0 Child (3-11) / QTY _____ @$21 Adult (12+)……..………………………………..……..…$_______

Sunday Optional Excursion: Georgia Aquarium includes para-transit
Adult QTY____ @$32 /Children(3-12)QTY____ @$27 /Seniors(65+)QTY____ @$29 ……………………..$_______

Total Fees Enclosed ....$_______

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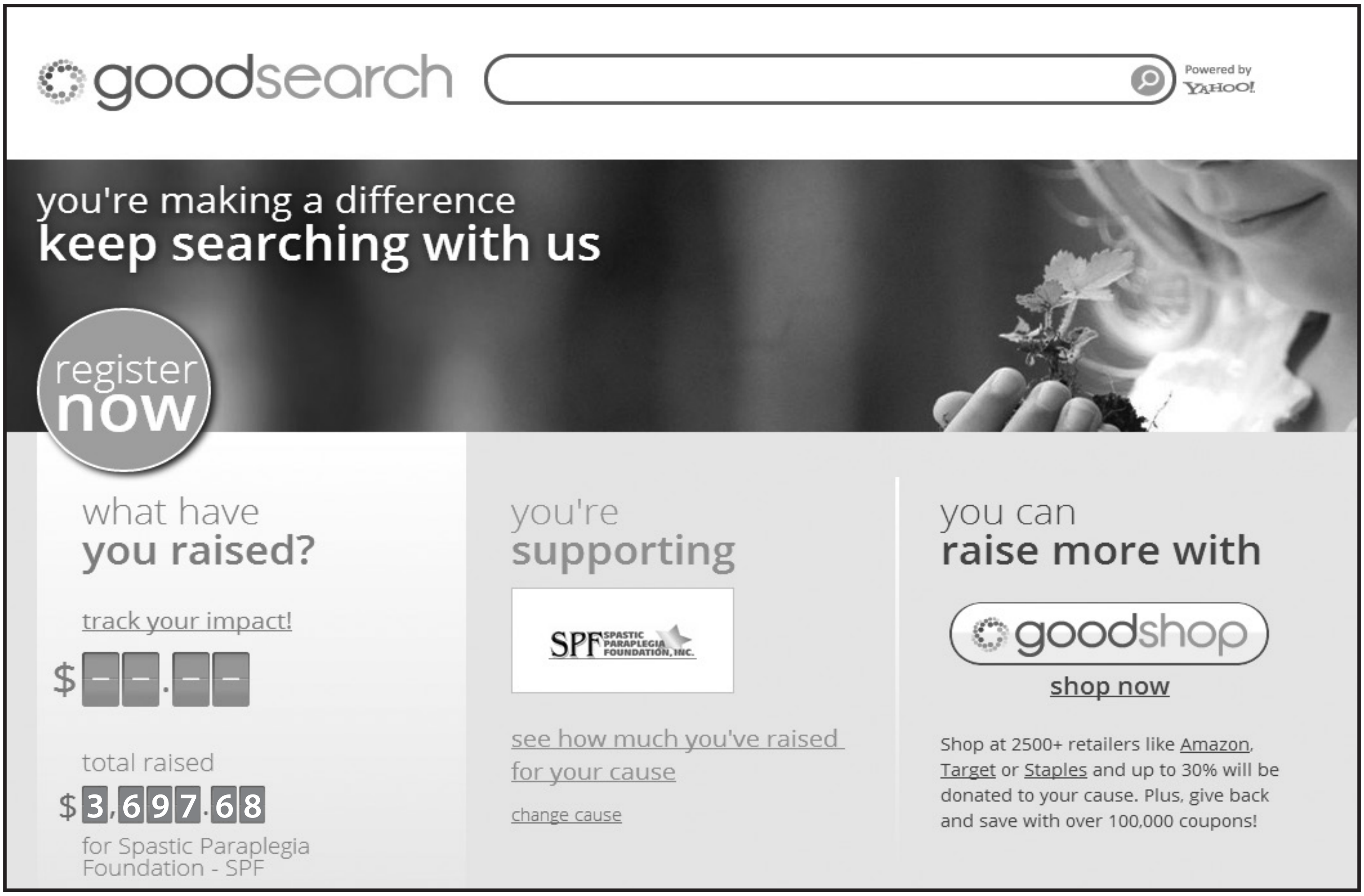

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