Synapse

Volume 15, Issue 1 Winter, 2012
Newsletter of the Spastic Paraplegia Foundation

Monumental Hopes & Dreams for a Cure

SAVE THE DATE

Your registration form is enclosed. Please fill it out and return it before May 18th for Early Registration prices!

Letter from the Editor

Dear Friends,

Planning for the 2012 Conference is in full swing! In addition to hearing about the latest research developments, therapeutic devices, and automobile wonders, we are excited to inform you that a TeamWalk will take place right near the steps of the Capital! What a wonderful opportunity to increase awareness of PLS and HSP. The hotel rate for the SPF Conference will include Thursday, June 7th and Sunday, June 10th, so I hope you will be able to spend a day or two exploring the sights and sounds of our great city. Annette and I are working diligently to provide transportation to and from the TeamWalk as well as providing childcare Friday evening and all day Saturday for children ages five and older. We will also provide detailed information with regards to airport transportation (to and from the hotel) on our web site as soon as details are confirmed.

On a different note - we have several vacancies on the SPF Board of Directors. Please contact one of the Board Members if interested in applying for one of the seats.

Beth Anne Shultz, Editor
Bads.spf@wildblue.net

> *I am still determined to be cheerful and happy, in whatever situation I may be; for I have also learned from experience that the greater part of our happiness or misery depends upon our dispositions, and not upon our circumstances.*
>
> *– Martha Washington*

Synapse

Volume 15, Issue 1 - Winter 2012

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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Beth Anne Shultz......................Senior Editor
Robin Grossbier ....Events
TBD ....Medical Updates

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Letter from the President

Happy New Year!

This year the Spastic Paraplegia Foundation celebrates its 10 year anniversary. The Foundation was established to raise money for research. Over the past 10 years, we have awarded over three million dollars in research grants. Five grants were selected in 2011 to receive funding from the Spastic Paraplegia Foundation for a total of $600,000 (approximately $120,000 each). This is the highest amount awarded in one year thus far. Please see page 8 for the research project details.

Approximately $400,000 was raised through various SPF events in 2011. TeamWalks raised over $100,000 with Sarah Robert-Witt's Magnificent Mile and Linda Gentner's California TeamWalk For Our Cures, contributing significantly to that effort. Other major revenue producers include: Rosella Vigliotta Golf ($20,000), 2011 mailings ($21,000), ExxonMobil Favorite Charities Campaign ($24,200), Drive FORE SPF golf outing ($56,000) and our Millions Rays of Hope campaign ($87,000). The Million Rays of Hope Campaign will continue into 2012 with our goal of raising one million dollars to fund research that will lead to a cure for both HSP and PLS.

The SPF continues to work with the Northeast ALS consortium. Be sure to check out the latest additions to their website- http://www.nealsconsortium.org/index.php. You can search for clinical trials, listen to webinars or contribute to their clinical research blog as Thurza Campbell has (see http://www.nealsconsortium.org/blog.php).

The last day of February is designated as World Rare Disease Day. As 2012 is a leap year, it will be celebrated on February 29. Please help us raise awareness about HSP and PLS by becoming a Friend of Rare Disease Day- http://www.rarediseaseday.org/. Be sure to check out the Rare Disease Communities website jointly established by NORD (National Organization of Rare Disorders) and EURODIS (European Rare Disease Organization): http://www.rarediseasecommunities.org/

Beth Anne and I will be hosting the 2012 Annual Conference which will be held on June 9, 2012. It will be held at the McLean Hilton in McLean, VA and will start with a Welcoming Dinner on Friday, June 8. Plans are also to hold a TeamWalk on the National Mall on Sunday, June 10th. Please see the Events section for additional information.

Ashton Hecker has resigned from the SPF Board of Directors. Our thanks again go to Ashton for organizing the 2011 Annual Conference. Ashton also was the impetus to our Million Rays of Hope Campaign.

My term as President will end in February when elections will be held for the 2012 officers and board members. My sincere thanks for the support and encouragement received in 2011.

Annette Lockwood

Events and TeamWalks

Club House

Vista Ridge – Erie, CO July 10 2011

Submitted by Nina Freda

It was an informal and comfortable get-together where everyone was able to just talk about their experiences, concerns and frustrations. The room was filled with a lot of laughter and all of us were able to make light of ourselves in one way or another. The discussion quickly become personal with stories and questions about bladder control, drugs, falling down, experimental treatments, the government, health care and costs and how we perceive the outside world to be looking at us.

Jennie Lombardi rolled in with her husband Matthew. She had a bunch of supplies that she was willing to give away because she no longer needed them. I was the recipient of a pair of "boots" that might help with the aching in my Achilles heals when I first wake up. Thank you, Jennie.

Maribelle Spellman and her husband Frank drove all the way from Fruita, Colorado (about 200 miles away) to join the meeting. They are a delightful couple. It was interesting to listen and watch Maribelle. She has a lot of the PLS symptoms but walks wonderfully.

Mo and Joe Stroupe came from Colorado Springs. Joe is doing some research on his own about the possible correlation between neck injury and PLS. I was able to talk to Mo about how she transitioned to a walker.

Brian Stolba, a handful in himself, was a delight with his candor and humor. He told several funny stories of how HPS has affected his life and the lives of those around him.

Gene Balzer visited from Arvada. Though somewhat quiet, Gene had stories to tell of his own journey and of the people in his life.

Sue Baucher, also from Arvada, came as well. We asked her to quickly become very rich and very famous so that PLS can have a media "voice" – maybe then, we can get more funding. Ha!

Greg Singer, from Longmont, is a strong, strapping man in a chair. I was telling a story about how I used to water ski and how much I missed it. Greg Singer quickly presented a photo on his cell phone of him skiing on a chair. It was awesome seeing that picture and realizing that I was just making excuses not to be doing something that I love. We all have choices to make and we sure can limit ourselves. **We** are usually the only "ones" in our way. Thank you, Greg!

We talked about how our care givers are essential to our safety, sense of worth and well being. These get-togethers are important for them as well, and we need to recognize this and arm them with the tools that they so desperately need -- because we sure do need them, and we can be a handful.

A special thanks to my husband, Paul, who has signed up with me on this journey. Thanks, too, for scurrying out of the meeting to supply us with food. He knows a lot more about what people need than I do. Thank you, Paul.

Life is not about finding yourself; rather life is about creating yourself. Just because we walk funny or roll, doesn't mean we can't continue to "create" ourselves. We all have the opportunity to teach and learn from this horrible disease.

Final note: If you are one to want more connection to others with PLS or HPS but are waiting around for someone else to put something together…don't. Just find a place, buy some pizza, e-mail the people in your area and just set a date that is convenient for you and that is that. You don't need guest speakers or Doctors or drug reps. You get more than three people in a room with this disease and you will have plenty to talk about, trust me. It's simple, enlightening and fun. Just do it.

I am extremely grateful for all the people I met on this great Sunday afternoon.

Thank you all for coming.

Nina Freda, PLS 2002

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The Magnificent Mile Race

Raleigh North Carolina Sept 18, 2011

Submitted by Sarah Witt

More than 1,200 participants and hundreds of spectators turned out on Sunday, September 18, for The Sixth Annual Magnificent Mile Race (www.magmilerace.com). In addition, more than $50,000 was raised for the research fund of the Spastic Paraplegia Foundation. This race served as the North Carolina-USATF one-mile championship. In the women's division, Addy Bracy, 25, of Carrboro, took first place in a time of 4:54. Addy broke the course record by an impressive 6 seconds and missed breaking the state record by only one second. Joe Moore, 27, of Raleigh, was the men's overall winner in a time of 4:20. In addition, 10 state age-group records were broken during the race. Full results can be found at www.magmilerace.com.

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Drive "Fore" Spastic Paraplegia Golf Outing

Monroe Township, NJ Sept. 19, 2011

Forsgate Country Club

Submitted by James F. Brewi-Chair

With one of the few rain-free days in September we held the third annual Drive "FORE" SPF. I was joined by SPF President Annette Lockwood for the day's events to assist with fund-raising and provide an update on research. With the support of my colleagues at Travelers we transitioned this year's event solely in recognition of the foundation. We had over 100 golfers who enjoyed another beautiful day. My two sisters, Tara Brewi and Tricia Nitz flew in to join me in our fund-raising effort. On the first

tee my daughter Megan took my place as we offered a "Drive with the Honoree." Despite the pressure, she did a wonderful job hitting off with each group. In addition, my sisters offered the *SPF Cookbook* in exchange for a $20 donation, and my wife & I offered to match the donations collected. I'm happy to report we gave away about 100 cookbooks on that day! At the evening reception we were joined by an additional 50 guests. My wife, Maureen Brewi, chaired the evening function and gave a heartfelt thank you to all in attendance. Annette Lockwood followed with an update from the foundation. We closed with the distribution of the golf prizes, the silent auction item winners, as well as the 50/50 raffle which was won by Michele Midwinter who graciously donated the $1,050 back to the foundation! All in all it was a wonderful day and we raised close to $60,000 for research!

Wisconsin Connection

Milwaukee, WI Sept. 22, 2011

Submitted by Annette Lockwood

We had 18 people attend the Milwaukee Connection on September 22nd. The event was held at Fiesta Bravo in Brookfield, Wisconsin. The evening was filled with great food and great discussions regarding life with HSP and PLS along with life as a caregiver. Support and encouragement were shared with those newly diagnosed and old timers shared what has been working for them as far as exercises and therapy.

Front: *Paula McClure, Robin Grossbier*
Middle: *Ann Fletcher, Susan Sauer, Stacy Adams, Annette Lockwood, Tara Brewi*
Back: *Dennis Strangstalien, Glenn Grossbier*

Illinois Connection

Arlington Heights, IL Nov. 11, 2011

Submitted by Sid Clark and Hank Chiuppi

Eighteen of us met for the Illinois Connection at Palm Court Restaurant, Arlington Heights, Il. Besides a good lunch all shared in discussion that include our personal diagnosis story and its progression, drugs like Baclofen and the pump, AFOs and handicap aids, caregiver support, frustrations, and speech problems. We listened, we shared, we enjoyed, and we learned. And we only scratched the surface on these subjects and others that we wanted to discuss. For all in the area "You Are Not Alone", join us for our next Connection. For information on future meetings email us at SPFIllinois@gmail.com.

Picture: Left to right Front row- Paulette Chiuppi, Carol Clark, Steve Beutelspacher; Second Row- Ben Ginther, Ann Flechter, Sid Clark, Hank Chiuppi; Third Row – Cindy Ginther, Krista Boltolina, Karen Oswald, Joan Morris. Pat & Bob Verhoeven, Lynn Staudacher. Not shown are the Sexton family – Larry, Debbie, Dillon, and Chris.

Dallas Fort-Worth Connection

Grapevine, TX Sept. 24, 2011

Submitted by John Staehle

Of the 41 SPF contacts in North Texas with a diagnosis of PLS or HSP, more than 40% of them have PLS. Earlier this year, one of those PLSers, Jeff Smith, suggested having a Connection specifically for the PLSers in our region of the state. The symptoms of PLS, some being similar to HSP, manifest themselves at different times during the progression of the disorder. Some are common in PLSers but rare in HSPers. Past Connections, though not intentional, have focused more on HSP than on PLS. At the SPF Annual Conference in Houston, Jeff met two other PLSers from this part of Texas that were also interested in getting together with other PLSers in the area. So with the assistance of the North Texas Region's SPF Ambassador, the first DFW PLS Connection was held on September 24, 2011.

Seven people enjoyed a casual lunch at Flips Patio Grill in Grapevine. Four PLSers attended as did two spouses and one HSPer. That was the most PLSers attending than either of the two previous HSP/PLS connections. Discussions covered a proposed questionnaire that PLSers could complete anonymously; the Neuro Fitness Foundation, a local fitness facility for neurologically impaired individuals; PLS-related support websites; caregiver comments; and most of all, techniques for coping with the daily tasks made difficult by our conditions. After enjoying each other's company for a large part of the afternoon, we concluded the meeting and agreed to make the DFW PLS Connection a regular event held twice a year.

California TeamWalk Cures & Connection Weekend

Pleasanton, CA Sept. 30- Oct. 1

Submitted by Linda Gentner

On Friday night, the Welcoming Dinner brought about 25 of us together at the restaurant at the Hilton. We had a nice dinner and then adjourned to a separate meeting room for dessert and "Share and Compare" discussion.

People put a lot of thought into asking questions and concerns, especially the people who were joining us for the first time.

Approximately 75-80 people found their way to Pleasanton this year on Saturday for our TeamWalk for Our Cures. After our TW, we met back at the church for a nice luncheon and raffle. New people sought out others and compared symptoms, etc. It seems that people have formed a real bond and were anxiously inquiring about next year.

I was amazed at how many raffle prizes we ended up with -- everything from SF 49er tickets, golf packages, EVERYTHING CHOCOLATE basket, wine baskets, toys and very unique items that brought in well over $1,000 extra. Our CA TeamWalk raised through getting sponsorships over $30,000. Some of our community members included: HSPers: Jean Chambers, Cheryl Schmidt, Sue Stendahl, Kay Brady, Penguin Rudd, Mary Maillioux and Linda Worthington. PLSers: Kris Brocchini, Linda Gentner, Jack Davis, Paul Singer, Jane Mitchell, Sue Dutton, Karina Dreyer and Rick Buchanan

Autumn in Carolina

The Checkered Flag

Rural Hall, NC Oct. 8, 2011

Submitted by Don Wilson

The checkered flag has waved on the SAWCAR 280 and Autumn in Carolina. Our first event was in 2001, but we missed two years along the way, which made this our ninth Autumn in Carolina. Unlike some events over the years, the weather for 2011 could not have been better. Early arrivals gathered for dinner and then moved to the hospitality suite to spend some time catching up with one another.

Saturday morning's topics focused on various types of equipment available to those of us who need some mobility help. *SureHands Lift & Care Systems* gave a great presentation about new developments in 'standing equipment'. *Carolina Seating and Mobility* highlighted the M300 Permobile power chair, and of course, *Dashaway* was also well represented – "the only piece of mobility equipment to make the user better."

Custom box lunches prepared the group for the afternoon program "Early Intervention for the Necessities of Life." These two presentations were filled with informative and useful information with regards to air, nourishment and water -- the three absolutes for life. Connie Paladenech, Manager of the Cardiac and Pulmonary Rehabilitation Programs at Wake Forest health, gave an illuminating talk about breathing problems that can occur within our disease categories, how to identify problems early on, and what steps should be taken to minimize those problems. The following were a few of the options discussed: CPap or BiPap machines, Cannula-delivered oxygen, Ventilator via a tracheostomy, and NeuRx Diaphragm Pacing System.

Dr. P. Wesley Benson, M.D., Gastroenterology Fellow, Center for Digestive Health, Wake Forest Baptist Health, gave an outstanding presentation on the steps that one should take to ensure that the body is adequately hydrated, and what happens to the body when dehydration occurs. Dehydration may be quickly reversed but loss of weight is much harder to overcome and it is almost impossible to fully recover the original body mass. Implanting a PEG (percutaneous endoscopic gastrostomy) tube allows water and nourishment to be taken without having to worry about choking. The process is fairly simple, but it is a surgical which can contribute to other problems. Waiting too long for a PEG tube will drastically reduce the benefit when attempting to replace body mass.

Racing scooters and power chairs were the perfect way end the day. Ronnie Grove and Gary Fisher squared off in the scooter race. Ronnie took the early lead and never looked back. In a rally style race event, Annette Lockwood, the current SPF President, took the lead and easily won her event. Annette and Ronnie then raced for the Grand Champion trophy. Annette won by a mere scooter length!

Over the years, we have welcome folks from 14 states, from coast to coast, and from the south end of Florida to the Great Lakes. We cannot count the number of good friends we have made along the way. They are many and most have visited with us more than once. Two friends who came to that first gathering in 2001 are no longer with us. Lavon Lockwood and Jane McCord have moved on and we miss them. Autumn in Carolina has been a labor of love and the effort is forgotten when that first guest arrives. However, the years are catching up with us. Bettie Jo and I have talked about the last Autumn in Carolina for several years now. This is the time for us to step aside. We are not saying, “Goodbye” just “Until We Meet Again.” Vickie Beauchamp and Beverly Fisher will team up for the 2012 Autumn in Carolina.

**Sadly, Martin Beckner passed away on Thursday, January 19th, 2012**

Tap Room at Vitis Ridge Winery

Silverton, OR **Oct. 8, 2011**

What a fabulous event with an amazing opportunity to meet, share and inspire each other. After a delicious lunch and some time to get to know one another, we were able to share information, stories and resources.

One extremely valuable resource shared was the services of Vocational Rehabilitation. Designed to help disabled workers succeed in their careers, Vocational Rehabilitation was able to help one of our guests with a personal care provider, equipment and van modifications!

The local ALS Association has also been a source of support for some of our guests with PLS as they have an “Equipment Closet” from which they loan adaptive equipment such as walkers, shower chairs and scooters. It is unclear if this is a benefit of the local chapter but may be a resource available from other chapters. The Muscular Dystrophy Association (MDA) has also been a source of support for guests.

Voice “Banking” was also discussed as new software is allowing people to record their own voice when they are facing bulbar spasticity and reduced vocal abilities. The software records your voice now, as you speak predetermined phrases. These phrases and words are then broken down and saved to be used in a bank of data that would be able to speak for you via a computer interface should you lose your ability to communicate vocally.

Even with these great topics and resources, the greatest wish of all is to find a cure for HSP and PLS. The SPF is a fabulous resource and an essential source of funding for research and development. As a result, each guest agreed to contact a minimum of five people and personally ask for their support of the Spastic Paraplegia Foundation.

What a fabulous event with fabulous new friends. We can’t wait to meet again!

Susan Moen, Angela & Dave Irvine, Meryl, Patty Sullivan, Kim & Ryan Doud, Rex Richard, Barb Galloway

Seattle CFC Fundraising Event

October 6, 2011

Submitted by Dave Irvine

Barbara Gross and I attended the Seattle Combined Federal Charities event, (Seattle CFC) at the Seattle Trade and Convention Center downtown. I had no idea what to expect, but Barbara and I "winged it" and had a great time. What these events are is a combined (local, state and federal) charity event where designated government representatives collect information and handouts from attending charities. They then display the information and each employee can choose one or more charities to give to through a payroll deduction. We learned that some representatives came from offices with between 200 to 2,000 employees!

Representatives came from fire districts, police, postal workers, state offices of all sorts, Social Security offices and all of the armed forces including the Coast Guard. The day got rolling, with an MC, Pat Cashman, who handed out awards from the largest givers in 2010 and oversaw the trike races between the fire departments, police, postal workers and whoever entered to race. There were nice prizes and give-aways to those that won.

The SPF was able to distribute around 150 brochures and information that I put together from items sent to me by Jim Sheorn and Linda Gentner. I also printed about twenty "Top SPF Talking Points" and gave them out also. While we were not the flashiest booth, we talked to loads of people and we were both very excited about the event, the potential for raising funds and ideas to make next year even more successful. None of the representatives had heard of the SPF, so just being there was a big win for all of us.

In conclusion, Barbara and I felt this was a great way to get the SPF's message out and it was EASY. Barbara was a natural at getting people to stop and talk. She did a great job of telling our story. We found that you have between 30 seconds and two minutes to capture them and distribute the information. All in all, a great success and I hope it generates funds for the SPF.

Dave Irvine at the Seattle CFC event.

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14th Annual Turkey Run

November 19, 2011

Submitted by Holly Harvey

The 14th Annual VW Turkey Run was held on November 19, 2011 in St. Augustine, Florida. It is a free car show and this year we asked participants to make a donation to SPF. There were almost 100 vintage VWs that contributed $1000 to SPF. The show is hosted by the Old City Oil Drippers, the St. Augustine, FL VW Club. The President of the club is Sean Bielman. His dad, Steve, has PLS. A great time was had by all. Hope to do even better next year!

Sean Bielman with his Dad, Steve, at the 14th Annual VW Turkey Run.

2011 Research Grant Awards

Melissa M. Rolls, Ph.D., *Assistant Professor, Biochemistry and Molecular Biology,* Penn State University, University Park, PA, "Function of spastin in axon regeneration: a new role for the HSP protein Spastin"

Xue-Jun Li, Ph.D., *Assistant Professor, Health Science Center, Department of Neuroscience,* University of Connecticut, Farmington CT, "Elucidating the role of BMP signaling in HSP using patient-specific induced pluripotent stem cells"

Paola Arlotta, PhD, *Assistant Professor of Stem Cell and Regenerative Biology,* Harvard University, "Molecular mechanisms of corticospinal motor neuron dysfunction in HSP and PLS"

John K. Fink, M.D., *Professor, Department of Neurology,* University of Michigan, Ann Arbor, MI, "Natural history of primary lateral sclerosis and hereditary spastic paraplegia: establishing parameters for clinical trials"

Nichole Hein, Ph.D., *Postdoctoral Fellow, Department of Neurology,* University of Michigan, Ann Arbor, MI, "In vitro models of Primary Lateral Sclerosis and Hereditary Spastic Paraplegia"

Up Close and Personal

Submitted by Fran Bray

My lifestyle is somewhat unusual. I am one of thousands who live in an RV and travel to see our wonderful country. Some of us have lived this lifestyle for decades and in fact, many of us do not own a house. Some of us have a "home base" where we stay in our RV when we aren't traveling. Some of us travel continuously, staying at favorite places during certain times of the year. As we age, health issues sometimes arise that can limit our RV activities - mine is Hereditary Spastic Paraplegia. As we all know, having a disease such as HSP often requires a change in living arrangements. For many of us, however, there is an option other than assisted-living, a nursing home, or living with children. What is it? Well, in my case, it is an RV club with a special feature.

I belong to an RV club called Escapees (www.escapees.com). There are thousands of members throughout the United States, Canada, and Mexico. (I know what you are thinking, "I'm not an RV'er and never plan to be!" – BUT please continue reading--you may be surprised). I live in Livingston, Texas, at one of Escapees' campgrounds, Rainbow's End. Nestled up right beside our lovely campground is one of the few state-licensed assisted-living RV parks, Escapees CARE Center.

Many think of the CARE Center as a nursing home, but there are no rooms for living at CARE other than in the residents own RVs. These RVs are parked on sites with paved patios, small storage buildings, and hookups for all utilities, just like a campground. There is no need to move out of the RV. The monthly rate includes three meals a day and a snack, all of which are prepared on-site and served in a large dining room. Meals are delivered to the residents who are ill and unable to make it to the dining area. The monthly fee also includes interior cleaning of the RV every two weeks. The dumping of holding tanks and laundry is provided weekly as well. An on-site registered nurse is available 8:00 to 5:00, Monday through Friday. When the nursing staff is not available, there are other staff to handle emergencies and to answer calls from residents. Transportation to medical appointments is also available for residents.

Many of the residents here are caretakers for a spouse who has some type of physical handicap or dementia. The dedicated and trained personnel provides a wide range of activities, supervision, and assistance with meals and personal needs of these residents five days a week during the eight-hour day. This enables the "caregiver" partner time to do other things that require their attention, allowing them the opportunity for some down time as well.

The center contains a large all-purpose room where a variety of activities take place. Bingo, Wii games, movies, and exercise sessions are some of the favorite pastimes. There is also a large library of books (hard cover, paperback, large print, and audio), movies and documentaries on cassette and DVD; and many games and puzzles. There is also a computer station and a special large-screen reader for those with low vision.

Seating areas include sofas, swivel rockers, and comfy recliners to use while visiting with friends or guests or when just reading or watching a movie.

CARE is a Godsend for me and many others, enabling us to live in a supportive setting without the major adjustments that a complete change of residence would require.

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.sp-foundation.org/donate.htm

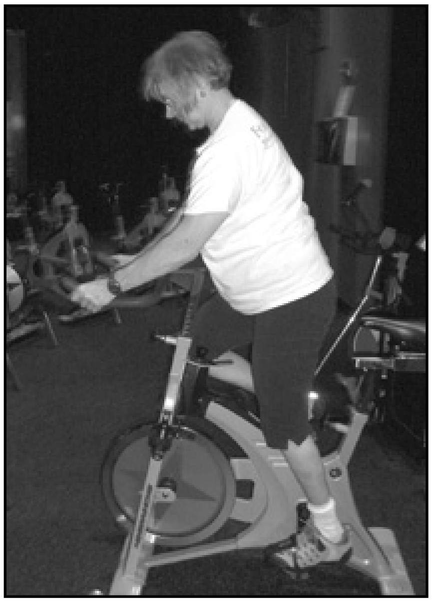
Exercise and You

THINK STATIONERY BIKE!

Contributed by Liz Wrobleski, MPT, PT, HSP

Often times a piece of exercise equipment gets relegated to a corner as a dust collector or clothes hanger. If that applies to your stationery bike, then take a second look at its potential. If you are planning to purchase a stationery bike then this article has some considerations.

Consider having the following on your stationery bike. Outgoing vertically adjustable handlebars or "horns" would allow you to lean forward supported on your arms in sitting or standing. The seat should be adjustable vertically to position yourself with a slightly bent knee at full leg extension. The seat should be adjustable horizontally to allow for a comfortable back position closer or further from the handlebars. Over-the-top foot straps, cages or clips on the pedals allow you to pull up against the resistance engaging your hip flexors and ankle dorsiflexors. Make sure you can get your leg over the middle bar when mounting the bike whether under your own power or with hand assist. Check on the resistance. Make sure it increases smoothly. It should not "grab" as increased resistance is applied. Look for a bike where you can maintain a standing position as you pedal. You may not start there, but you will want to progress to that position if able.



Use the bike to warm up the leg muscles for 3-5 minutes before stretching. While doing a slow cycle you can work on sitting balance by not holding on and turning your trunk/outstretched arms side to side. Perform arm stretches and range of motion exercises including head turns and nods. Repeat the upper extremity and head motions with the eyes closed for an additional balance challenge.

By changing resistance you can pedal lighter and faster or heavier and slower. This will train fast twitch or speed fibers and slow twitch or postural muscle fibers. We need the quick ones to adjust our balance and the slow ones to maintain our balance.

On the pedal down stroke, make the effort to push down with heel and the toes "up." This will provide a stretch to the underlying calf muscle (soleus m.). On the upstroke actively pull up against the strap or cage to facilitate ankle dorsiflexion. The clip-on bike shoe provides the tightest fit to actually pull the pedal up with the dorsiflexors.

Coming to a stand with arm support out at the horns lets you use the end range of hip extension and gives you an opportunity to work on knee control. As you push through the down stroke pushing your heel down first there will be a tendency for the knee to snap back (hyperextend). Now the overlying calf muscle (gastrocnemius m.) whether spastic or shortened exerts its two joint action with the change to extension at the hip. Don't let it happen! Concentrate on maintaining a slightly bent knee. This activates simultaneous contraction (co-contraction) of the quadriceps and hamstring muscles to control the snap back. Make the effort to shift the hips side-to-side so that one leg is forcibly pushing down while the other is free to pull up. This is not unlike the reciprocal activation we see in walking.

My next comments concerning the bike as an aerobic or cardio activity are based on the CDC guidelines updated March 2011. Google http://www.CDC.gov/physicalactivity for complete guidelines. Riding a bike on level ground or with a mix of level and few hills (added resistance on the stationery bike) qualifies as moderate-intensity aerobic activity. One way to tell if you are at this level is being able to talk while biking, but not being able to sing your favorite song. This will raise your heart rate. It is recommended that you do moderate-intensity exercise for at least 10 minutes at a time for 150 minutes a week. That can be broken into 10 minutes 3 times a day over five days or any other combination of time at least 3 days a week for at least 10 minute sessions. Refer to the website for more information. This will at least let you set goals based on recognized standards for health benefits.

There are probably many of you who already own stationery bikes. Make as many changes as you can. For those of you who may purchase in the future shop the sports stores for models you can try. There are many bikes for sale online. Call a local health club and ask if they sell used spin or floor bikes when they purchase replacement equipment. Perhaps emailers to the list serv can share information.

My purpose in this article was to spark interest in the use of a stationery bike as exercise as well as a rehab tool to address common knee and ankle problems in spasticity.

New Class of Stem Cell-Like Cells Discovered Offers Possibility for Spinal Cord Repair

ScienceDaily (Sep. 15, 2011) — The Allen Institute for Brain Science has announced the discovery of a new class of cells in the spinal cord that act like neural stem cells, offering a fresh avenue in the search for therapies to treat spinal cord injury and disease. The research team utilized the Allen Spinal Cord Atlas, a finely detailed genome-wide map of gene expression throughout the mouse spinal cord, to compare the genes expressed, or turned on, in adult spinal cord radial glia with those found in other neural stem cells, revealing a signature set of 122 genes that indicate the likeness of these cells to classic neural stem cells.

The published collaborative study, authored by scientists from the University of British Columbia, the Allen Institute for Brain Science and The Montreal Neurological Institute and Hospital at McGill University, appears in the open access journal PLoS One.

The nervous system has historically been thought to be incapable of repairing itself, as the cells used to create it are exhausted during development. With the identification of these new stem cell-like radial glial cells, it may be possible to activate a certain set of genes in order to encourage those cells to reconstruct a damaged network in the adult spinal cord.

“By using the Allen Spinal Cord Atlas, we were able to discover a brand new cell type that has previously been overlooked and that could be an important player in all manner of spinal cord injury and disease, including multiple sclerosis and ALS,” said Jane Roskams, Ph.D., neuroscientist at the University of British Columbia and senior author of the study.

From disabled veterans to those afflicted with Lou Gehrig’s disease (ALS) or Spinal Muscular Atrophy, spinal cord related diseases and disorders affect people of all ages including nearly one-quarter of a million Americans who have suffered from a spinal cord injury; as many as 30,000 Americans who suffer from ALS at any given time; and approximately 2.5 million people worldwide who suffer from multiple sclerosis.

“This is a tremendous example of how our public atlas resources can lead to critical discoveries that offer promising avenues for developing much needed new clinical therapies,” said Allan Jones, Ph.D., Chief Executive Officer of the Allen Institute.

Dr. Roskams, who led the collaborative research team, has said that it is possible this pool of cells was overlooked because of its unusual location, and because scientists have been working with limited information. With the availability of the public, online Allen Spinal Cord Atlas, the information accessible to researchers has been vastly increased.

In the search for neural stem cells, scientists have been using a few known genes as clues to find candidates deep in the middle of the spinal cord. While some neural stem cells have been discovered there, the newly identified class of spinal cord radial glia run along the edge of the spinal cord, an incredibly convenient location for activating them with minimal secondary damage to help the spinal cord repair during disease or after injury.

“When we first saw known neural stem cell genes appearing in these cells on the edge of the cord, I realized we not only had a brand new cell, but had the capacity to reveal a new gene set that may also guide us to hidden neural stem cells in atypical locations in the brain. I did not expect so many of them to link to human diseases,” Dr. Roskams said.

Identifying these cells and the genes relevant to activate them opens fresh new pathways to explore effective therapies to treat spinal cord injury and several types of neurodegenerative disease.

Story Source: The above story is reprinted from materials provided by Allen Institute for Brain Science.

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ABSTRACT

Cellular Pathways of Hereditary Spastic Paraplegia

Annual Review of Neuroscience Vol. 35 (publication date July 2012)

Craig Blackstone; Cellular Neurology Section, NINDS, National Institutes of Health, Bethesda, MD 20892-3738

Human voluntary movement is controlled by the pyramidal motor system, a long CNS (central nervous system) pathway comprising corticospinal and lower motor neurons. Hereditary spastic paraplegias (HSPs) are a large, genetically diverse group of neurologic disorders characterized by a length-dependent distal axonopathy of the corticospinal tracts, resulting in lower limb spasticity and weakness. Recent work elucidating the pathogenesis underlying HSPs has revealed the importance of basic biological functions, especially membrane traffic and organelle shaping, in axonal development and maintenance. A range of studies are converging on the shaping of organelles, particularly the endoplasmic reticulum, and intracellular membrane trafficking and distribution as primary defects in HSPs, with clear relevance for other “long axonopathies” affecting peripheral nerves and lower motor neurons.

Expected final online publication date for the Annual Review of Neuroscience Volume 35 is June 17, 2012. Please see http://www.annualreviews.org/catalog/pubdates.aspx for revised estimates.

University of Central Florida Lab Creates Cells Used by Brain to Control Muscle Cells

November 2011: University of Central Florida researchers have used stem cells to grow neuromuscular junctions between human muscle cells and human spinal cord cells, the key connectors used by the brain to communicate and control muscles in the body.

The success at UCF is a critical step in developing "human-on-a-chip" systems. The systems are models that recreate how organs or a series of organs function in the body. Their use could accelerate medical research and drug testing, potentially delivering life-saving breakthroughs much more quickly than the typical 10-year trajectory most drugs take now to get through animal and patient trials.

"These types of systems have to be developed if you ever want to get to a human-on-a-chip that recreates human function," said James Hickman, a UCF bioengineer who led the breakthrough research. "It's taken many trials over a number of years to get this to occur using human derived stem cells."

Hickman's work, funded through the National Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health, is described in the December issue of Biomaterials. Hickman is excited about the future of his research because several federal agencies recently launched an ambitious plan to jump-start research in "human-on-a-chip" models by making available at least $140 million in grant funding.

The National Institutes of Health (NIH), the Defense Advanced Research Projects Agency (DARPA), and the Federal Drug Administration (FDA) are leading the research push.

The goal of the call for action is to produce systems that include various miniature organs connected in realistic ways to simulate human body function. This would make it possible, for instance, to test drugs on human cells well before they could safely and ethically be tested on living humans. The techniques could potentially be more effective than testing in mice and other animals currently used to screen promising drug candidates and to develop other medical treatments.

Such conventional animal testing is not only slow and expensive, but often leads to failures that might be overcome with better testing options. The limitations of conventional testing options have dramatically slowed the emergence of new drugs, Hickman said.

The successful UCF technique began with a collaborator, Brown University Professor Emeritus Herman Vandenburgh, who collected muscle stem cells via biopsy from adult volunteers. Stem cells are cells that can, under the right conditions, grow into specific forms. They can be found among normal cells in adults, as well as in developing fetuses.

Nadine Guo, a UCF research professor, conducted a series of experiments and found that numerous conditions had to come together just right to make the muscle and spinal cord cells "happy" enough to join and form working junctions. This meant exploring different concentrations of cells and various timescales, among other parameters, before hitting on the right conditions.

"Right now we rely a lot on animal systems for medical research but this is a pure human system," Guo said. "This work proved that, biologically, this is workable."

Besides being a key requirement for any complete human-on-a-chip model, such nerve-muscle junctions might themselves prove important research tools. These junctions play key roles in ALS, in spinal cord injury, and in other debilitating or life threatening conditions. With further development, the team's techniques could be used to test new drugs or other treatments for these conditions even before more expansive chip-based models are developed.

Reprinted from UCF Today

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Storybook Endings

This is a beautiful story about a boy, a pony, a blind man and a flute. It is written for young adults. My son, the author, James Zdenek, suffers from Primary Lateral Sclerosis. For each purchase of the book, one dollar will be donated to the SPF. Thus far, approximately $100 has been raised due to "Patches"!

Please submit your order to the address listed below. The cost of the book is $10.00 plus $1.50 for postage (per book).

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ELECTRIC SCOOTER TIPS AND IDEAS

HOW TO MAKE THEM WORK FOR YOU AND STAY OUT OF TROUBLE

Your new electric scooter will be a Godsend. It 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. There are 3 wheel and 4-wheel electric scooters.

The three-wheel ones are smaller, lighter, fit better in the car or the trunk, and are easier to travel with / fold up, e.g. airlines. The problem 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 backwards, your body weight may be outside the center of gravity [e.g. outside the wheels] and this may cause you to tip over. It is usually safer to back up an incline than to go forwards, since when going forwards on a level surface, your body weight/ center of gravity is already near the rear wheels, and when you then start to ride up a ramp, your center of gravity might then be behind the rear wheels, causing you to tip over backwards. One advantage of a 3-wheel scooter is that many have a tighter turning radius/ can be used in smaller spaces/ 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 large scooters, e.g. 4-wheels, are difficult and time-consuming to fold up or take apart, and some cannot be disassembled for travel.

Three-wheel scooters have the inherent problem, because they are so light, of the risk of tipping over if you lean sideways, or turn too sharp, or too fast, or on a wet surface [rain or snow], or if you go up or down a grade that is too steep. The standard rules limit the grade to 8%, which means that the incline goes up a foot every 12 feet [or 6 inches for every 6 feet]. 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 of down a ramp that does confirm to these regulations. You need to independently determine whether it is safe for you to go up or down each ramp you encounter.

I have a "3-wheel" scooter that actually has 4 wheels!! The usual front single wheel is replaced by two front wheels, close together. This is a bit more stable, but all the rules about risks and center of gravity still apply.

When you are exiting down a ramp [e.g. 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 put on the brakes. That is NOT what you should usually do! 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 more 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 ramp, that you have at least 6 or 8 feet of clear space, in case you do need to accelerate to regain control, and have room on the ground for the scooter to recover and stop.

Let's move, now, to the 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]. 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.

Some 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 forwards, turn around, and then ride out forwards. Also important for those who take their scooter into their minivan, and thus need to make really tight turns inside the car to maneuver to get into the driver's seat, or in vans without a driver's seat, to move the chair itself behind the wheel. 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, and the 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 unsharp to make turns, so the scooter ends up where you want it to be.

Some adjustments are helpful. If the scooter seat moves forward and backwards, 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 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 on the sides of your scooter, they are very handy, but….it makes it difficult 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. In my case, I sewed them together, with a cloth "spacer" in between, so they sit right on the scooter seat, and 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, secure your personal belongings when you get off the scooter for some reason [e.g. airport security], or raise the arms of the scooter without spilling everything out of the pockets [which are sitting on the seat now and not on the arms. The other night I raised up the left-hand arm, so I could play my guitar sitting on my scooter.

CHARGING: Know how long your charge lasts. That is a slightly incorrect statement, since because you do not ever want to run out of battery [and thus know exactly how long the charge lasted!!], it's better to charge every day, or at the least, every 2 days, depending on your scooter and how many hours it is being used each day.

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. Almost all [?all] scooters have an interlock device which prevents the scooter from being driven when the seat is raised. Why? Because when the seat is raised, now the center of gravity problem 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 move forward with the seat in the raised position creates problems, however, when you're in certain surroundings and situations, for example, you are shopping for items in a store, or are picking food up at a buffet dinner. There's this long table of food, and you need to raise your seat to get to the food. So you are at the beginning, and the following sequence of events occurs:

Seat down to travel--->seat up to get lettuce--->seat down to move 2 feet--->seat up to get salad dressing--->seat down to move--->seat up to get rolls--->seat down to move---> seat up to get main course--->seat down to move scooter, then seat up to look at /select other main courses--->seat down to move--->seat up---> etc.

You get the idea. Same thing happens in an office, a library, while shopping, or at home. Up and down all day. So I had my Hoveround 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, 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 with a raised seat on your scooter. NEVER DO IT!!

An important rule about getting up and sitting down on your scooter - when you get up, e.g. to sit in a seat or to use the toilet, grab something and TURN OFF THE SCOOTER. Then, after you sit back down on the scooter, turn it back on [the main off/on switch]. Why? A catastrophe would 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, and missed the arm, hitting the "go" paddle 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. I turn my scooter off and on maybe 100 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, know you can instantly turn the scooter off. That would prevent a recent episode we heard about, in a retail store, where someone was hit by an uncontrolled scooter left on. Practice this with the scooter stationary.

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 don't have to step off the foot plate to the floor, since it is folded in the up position.

A comment about access to sinks, toilets, and eating tables, where you need to either face forward while sitting [a sink], or get off the scooter [the toilet], and/or not have part of the scooter in the way of whatever device you are trying to use.

Scooters with drive handles in front of you [similar to a bicycle] especially 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. 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 closet is covered with "stuff"--->same problem. The toilet may be too low, so you need to almost "fall" to get onto the toilet, and then getting up again, to your scooter, is another problem. My solution is to learn which part of your scooter is stable and reliable, e.g. the control arm, the seat, the seatback, and park your scooter very close to the toilet [or move it there after you sit down on the toilet], so that when you need to get up, you can grab and support yourself on that part of your scooter.

Be sure the bar on the wall is for handicap people and well-anchored. Each of us has made the one-time mistake of holding onto a towel bar, and having it come loose. If you install grab bars in your home, at key places where you "need a lift" it will be much easier and much safer for you. You will experiment about how to position your scooter so getting into the shower or bathtub is safest. 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.

I am fond of retrofitting my scooters, and have changed all of them. ***Examples:***

1. Make a larger footplate [to fit my feet] and fasten it on top of the small one that is already there.
2. Invent/buy/fasten some carrying bags to the side arms. Don't use duck tape. There is no know solvent that will clean it off, later.
3. Create specialized methods of carrying things, like canes and drinks. These are also sold, and can be used and/or adapted.
4. You may want to get an extra pad for the seat if it is too hard. When we are in chairs for years, our gluteal ["behind"] muscles atrophy and it may be more comfortable with an extra pad, e. g. one that conforms to us, like Soho or Temperpedic.

5. Make instruction cards for airline personnel, and fasten them to the scooter….how to fold the scooter, turn it on and off, and how to find and operate the brake release. Take photos of the scooter, also, in case you need to find a lost scooter or prove something if it gets damaged. Take the photos with you when you travel.
6. Certain items are needed to be with you: scooter keys, car keys, wallet or purse, personal items, medications. Consider buying a small container and fastening it to your scooter. I bought a small tin rectangular baking pan, with lid, about 3 x 5 inches, and screwed it onto the side of my scooter. Into that container goes all my "stuff."

Make sure you tell all your people that you try very hard to be careful not to run into them or bump them, or to run over their toes and 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 our world, these three little words become, "Watch your toes."

Most important, 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, when 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, in an office building, backwards. This 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.

HANDICAP PARKING: The law usually states there is a width requirement for the adjacent blue-hatched areas. 8 feet is often quoted. Most/many are three or four feet, which is barely enough room for the ramp, and sometimes not enough for the scooter exiting the ramp. That's another reason to use a smaller/shorter scooter, when you travel in your car. I've sometimes parked diagonally in two spaces [with a note to the police why I did this] and I also have an orange cone that I place in the adjacent empty space, to discourage parking there. In tight parking situations, it is safer to exit the car with the scooter going forward down the ramp, so you can see not to bump the adjacent [close] car.

Put some white reflective tape on the edges of the car ramp, so 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.

Other thoughts and suggestions: 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 they will not be on both sides of you].

SOME SUGGESTIONS ABOUT RESTAURANTS: Usually a table is better than a booth, particularly if you have trouble getting up and down and changing "seats." There is the problem of matching the scooter seat height with the restaurant table seat height. If you do sit in a booth, position the scooter so the control handle and off/on switches are next to you, and not on the other side, away from you. It is often easier, and simpler, and safer to sit at a table, on your scooter, where a chair has been removed. Avoid the center of the room and near the entrance [people, waiters with food, staff with rolling carts of food will all need to get by you]. If you know you need to transfer to a chair [e.g. your scooter won't work at a table, e.g. the control arms are in front of you and you can't turn to sit sideways on the scooter to face the table], you might bring a fold-up walker or your favorite canes or walking aids with you, to get from the scooter to the table.

Sitting in your scooter to eat at a table also has the advantage of not having the scooter moved somewhere else by the staff, because, "it is in the way."

Lastly, whenever I sit down on my scooter, I have a standard path and sequence of movement. I know where I am going to grab the scooter [with the power off], and I always rotate clockwise to turn and sit down. It doesn't matter what your sitting action plan is, but a standard well-thought out plan and sequence makes your sitting action safer and standard and reliable.

How you handle getting on and off elevators obviously depends on your specific situation. Two-motor scooters can go in forwards, turn around [unless the elevator is full of people], and face outwards to be ready to leave the elevator. Many of us feel safer going forward into an elevator, to be sure not to hit someone already there. That makes is awkward to find the floor buttons, but you ask someone to punch your floor. If there's no one in the elevator to help you, then you don't need help, since it is safe for you to turn around.

MANUAL WHEELCHAIR USERS: If you have read this far, out of interest, you know that many of these principles and guidelines also apply to you. You have your own specific rules, like putting the wheel brakes on whenever you get up or down from the wheelchair and rules about use of the feet supports [which re often adjustable]. You can easily reverse direction in one spot, e.g. an elevator, and you know that in many situations [e.g. going up or down ramps], you may need someone else to be with you, for safety. Opening doors and holding them while you enter and leave [in particular business and commercial building doors with springs, usually does require a helper to hold the door open while you pass through. There are special trays and platforms for manual wheelchairs, to hold things, and these can also be used for electric scooters.

The production of this article has had the benefit of additional input, ideas, and corrections, from a previous version, of which I am very appreciative. If you have any further or additional thoughts, or topics not yet covered, or clever ideas or solutions, please communicate them to me, for the next version.

Malin Dollinger, M.D. November 16, 2011

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