

# Synapse

Volume 12, Issue 3 Summer, 2009

## Newsletter of the Spastic Paraplegia Foundation

### EXPLORING NEW FRONTIERS THROUGH RESEARCH

The 7<sup>th</sup> annual National Conference of SPF opened Friday night in St. Louis. It was immediately apparent as participants mingled that Chairperson Tina Croghan had the many helping hands of her students assisting. Students' posters decorated the meeting room. The SPF quilt was on display for the enjoyment of all. Lewis and Clark, dressed in military uniforms were part of the welcoming party.

The featured speaker after dinner was author and columnist with an expertise in accessible travel, **Candy Harrington**. She outlined the worldwide progress in legislation requiring airlines to transport passengers in wheelchairs. She predicted that as the Baby Boomers age, and demand accessibility improvements in both transportation and lodging, that laws will be further refined.

To indicate the range of accessible tourist options, she discussed five wow possibilities:

1. River rafting on both calm water and white water.
2. Exploring a huge Swiss Family Robinson type tree house [www.treehouse.org](http://www.treehouse.org) has built tree houses so far in 37 states.
3. On Lake Powell, above the Glen Canyon Dam, you can rent an accessible house boat. It's even got an elevator.  
[www.globalaccessnews.com/lakepowell07.htm](http://www.globalaccessnews.com/lakepowell07.htm)
4. Eureka makes a wheelchair accessible tent. It can be set up when seated in a wheelchair. The door is large enough to enter through the door in your wheelchair.  
[www.eurekatent.com/p-69-eureka-freedom-tent.aspx](http://www.eurekatent.com/p-69-eureka-freedom-tent.aspx)
5. If you're really adventuresome, try wheelchair bungee jumping. It is to be offered at the 2010 Paralympics in Whistler, BC, north of Vancouver.

Candy concluded her talk by giving the audience five accessible travel tips:

1. For your first trip, go someplace close to home. Plan a simple trip.
2. Ask for the details of what is the accessible room, (e.g. does the room have a roll-in shower?) For 10 tips on finding an accessible room, please read Candy's article in the Living section.
3. Hope for the best but be prepared for challenges.
4. Have a "can do" positive attitude.
5. Know the law. You can't complain about what's wrong if you don't know what's right.



*SPF Quilt on Display*

*Annette Lockwood  
receiving the  
President's Service  
Award from  
Jim Sheorn*



*Linda and Craig  
Gentner with  
Lewis and Clark*

**“Gene Silencing Therapy for Motor Neuron Disease”**

In a pre-recorded interview, **Dr. Robert H. Brown, Jr.**, the chair of the Neurology Department at University of Massachusetts Medical School, explained the process of gene silencing – interrupting the process of creating of specific proteins that are known to be toxic to the motor neurons. The technology, discovered only about 10 years ago, has never been applied to humans.

Dr. Brown’s team recently applied for FDA approval to perform a “human trial” injecting a gene silencing drug into an individual with an aggressive, hereditary form of ALS. If successful the gene silencing therapy would be the first treatment to arrest ALS development – an exciting breakthrough! Dr. Brown noted that specific toxic proteins have been isolated in patients with both hereditary and sporadic forms of Parkinson’s and Alzheimer’s. Therefore, he believes that the gene silencing therapy to turn off the creation of toxic proteins will some day be useful for all motor neuron diseases including HSP and PLS. Dr. Brown concluded the interview by thanking the SP Foundation for it’s contribution of \$25,000 to cover most of the costs associated with the surgery.

**Dr. John Fink** spoke about research advances in understanding both HSP and PLS. Treatment is his ultimate goal. Doctors can do some therapy before they know the complete biochemistry of the cause or causes of each disease. Eventually each disease must be defined. The PLS ‘04 Symposium was a gathering of experts from around the world to determine whether PLS is a separate disease. There appear to be five forms



*Dr. John Fink,  
SPF Medical Advisor Speaking*

*Continued page 15*

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**Editor’s note:** *The National Conference Report summarizes the talks of both Dr. Robert H. Brown, Jr. and Dr. John Fink. Both reported significant medical advances. As a result, we have omitted a separate Medical Reports section this issue.*

# Synapse

**Volume 12, Issue 3 - Summer 2009**

*The Spastic Paraplegia Foundation Inc. (SPF) is a national, not-for-profit, voluntary organization. It is the only organization in the Americas dedicated to Primary Lateral Sclerosis (PLS) and Hereditary Spastic Paraplegia (HSP).*

Synapse Editors  
 Thurza Campbell .....Senior Editor  
 Betsy Baquet .....Medical Research  
 Sarah Roberts-Witt .....Events

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**Corporate Address:**  
 Spastic Paraplegia Foundation  
 212 Farm Rd.  
 Sherborn, MA 01770-1622

**Please Send Donations to:**  
 Spastic Paraplegia Foundation  
 P.O. Box 1208  
 Fortson, GA 31808

**Please direct correspondence to:**  
 Spastic Paraplegia Foundation  
 7700 Leesburg Pike, Ste 123  
 Falls Church, VA 22043  
 (877) 773-4483  
[information@sp-foundation.org](mailto:information@sp-foundation.org)  
[www.sp-foundation.org](http://www.sp-foundation.org)

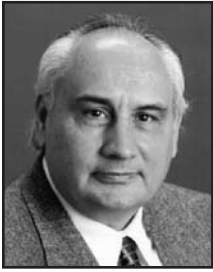
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 John K. Fink, M.D., University of Michigan

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# SP Foundation News

## President's Letter from Mike Podanoffsky



Fall is the time of the year when we hold several local events, usually Connections and TeamWalks. There are Golf fund raisers, Bike rallies and the Magnificent Mile race. Each is an opportunity to meet people who are facing the same challenges you are. Maybe

they are newly diagnosed and have a lot of concerns about the future. It is also an opportunity to see and hear how other people handle their challenges.

You can checkout what events are happening in your local area by going to our web site [www.sp-foundation.org](http://www.sp-foundation.org). If there is no event near you, consider having one. Your bright smile will cheer a lot of people. You will find the instructions on our web site as well, or you can contact us to find out more.

A local activity can be anything you want it to be. Just have any clever get together idea for either a fund raising TeamWalk or a Connection. If it is a TeamWalk, it doesn't have to be far. An alternative to walking yourself is to bring a friend to walk for you or register as a Walker By Proxy to have another community member walk for you. Walker By Proxy is a way to raise funds for research even if you are unable to attend one of the TeamWalks. See [www.sp-foundation.org/walkerbyproxy.htm](http://www.sp-foundation.org/walkerbyproxy.htm).

TeamWalk events have been the life blood of the SP Foundation, representing donations of over \$1 Million since the SP Foundation was created. The research that we've funded with these donations has yielded important insights into our conditions. It has helped researchers to better understand nerve biology and the role of genes as agents for this disease. Exciting new research promises to be able to turn off (or quiet) errant genes.

This year we spent \$25,000 to help fund human trial of a therapy known as gene silencing which interrupts the process of creating proteins that are known to be toxic to the motor neurons. The reality is that research requires money for laboratories, equipment, researcher and their assistants.

Funds for research are not someone else's problem. It is our problem. We need your help to make the next set of breakthroughs. Imagine what \$10 per month from all of us could fund! Consider giving now at [www.sp-foundation.org/donate](http://www.sp-foundation.org/donate).

*Mike Podanoffsky,  
SPF President*

## SPF Board of Directors Welcomes a New Member



Ashton Hecker is a Broker/ Realtor associated with Keller Williams Realty in Houston, Texas. Prior to starting a real estate career in 2000, Ashton was a healthcare executive with hospitals and health maintenance organizations (HMO). He has a

BS degree in Biology from Lamar University and a MS degree in Healthcare Management from Trinity University. He is a member of various professional organizations and a past board member of the Greater Southwest Houston Chamber of Commerce. His granddaughter has HSP.



### SPF Board of Directors:

*(Front Row l. to r.)* Malin Dollinger, Linda Gentner, Mark Weber, David Lewis

*(Back Row l. to r.)* Jim Sheorn, Jim Campbell, Jean Chambers, Larry Asbury, Ashton Hecker, Mike Podanoffsky, Frank Davis and Corey Braastad

# Focus on Fundraising

## Confessions of a Reluctant Fundraiser

Thurza Campbell - June 21, 2009

Way back when I was diagnosed  
I didn't have a clue  
about disease and what it takes  
to help both me and you.

Thanks to the web and SPF  
I learned, to my dismay  
we're 'orphans', and that research funds  
are spent in other ways.

Billions are spent on Parkinson's,  
on cancer, and the heart.  
What can be done for us, I asked?  
How can we make a start?

I can't sit back and just get worse  
while SPF sure tries  
to rally folks to raise the funds  
to help improve our lives.

So then I sat and asked myself,  
"Who's going to raise the dough?  
I cannot talk, can barely walk  
and now I type real slow."

**I hate to ask for money** even  
though I know I should.  
I questioned if I had guts.  
I'd rather others would.

But then I finally realized  
I've got to go ahead  
and work my heart out for us all -  
just put aside my dread.

So here's the secret that I'll share:  
most people wonder why  
you took so long to contact them!  
Surely you can try.

SPF is "us", you guys.  
No "they" will raise the funds.  
Please be a part of helping you  
'til your disease is done.

## Penny Campaign '09

Contributed by Angellina Ikle

Being part of the HSP community, I feel the need/  
desire to help contribute to research and eventually a  
cure, a cure for ALL of us. I have decided to reignite  
the Penny Campaign for 2009-2010. I am asking for  
as many people that can help out as possible. To reach  
my goal, I need a minimum of 15 captains total. This  
is intended to be spread throughout the whole HSP/  
PLS Community, since we are ALL affected by it, so  
please don't feel overwhelmed. Little by little, we can  
make a huge difference. Feel free to contact me for  
further information at [cfrosta@hotmail.com](mailto:cfrosta@hotmail.com).

## The Combined Federal Campaign

Contributed by Jim Sheorn

The CFC is a fund raising opportunity for federal  
employees. Each employee is allowed to pick from  
a large list of nonprofits to make contributions  
throughout the year. Each time the employees are  
paid, a portion that they have chosen goes to the  
nonprofit or nonprofits of their choice.

We would like to see this campaign grow for SPF.  
Please help us do so by informing any federal  
employee that they can help us through the Combined  
Federal Campaign. Mail personal, police, fire fighters  
and many others have an opportunity to help. The  
CFC number is 12554.

## Senior Project is a Class Act - Teens Can Help Us Too

Contributed by: Linda Gentner

Seniors at J.W. Mitchell High School are required  
to engage in a project reflecting long-term career  
goals. Since eighth grade, Stephanie Palazzolo  
expressed interest in physical therapy and thus, chose  
this area for her senior project. During Stephanie's  
research, the SFP website provided her with a wealth  
of valuable information. As part of her project,  
Stephanie organized a local walk-a-thon that netted  
\$320.00. Recently, Flora Brand met Stephanie in  
Clearwater, FL to accept her donation on behalf of  
the Foundation. Says Stephanie, "I know the money  
I raised is not a ton, but I'm happy to be donating it  
to SPF and I hope it helps!" Thanks to her hard work  
and willingness, people like Stephanie Palazzolo put  
us closer to the cure.

## Events

### Spring Forward Seminar Connection -

April 4, 2009

*Submitted by Kathi Geisler*

Sixty people from MA, CT, NH and ME gathered for our annual Spring Forward Seminar Connection at the Sheraton Hotel in Framingham, MA. The event began with Kathi Geisler sharing the story of the development of the HSP and PLS online communities, their merging and the launching of the SPF. She noted that in seven years, the organization (still 100% volunteer managed) has now made some \$2 million available to researchers and helped thousands of people seeking support and information.

Mike Podanoffsky, SPF President, and Jim Campbell, SPF Board Member, echoed Kathi's comments about the remarkable story of SPF, what a difference we've made, and encouraged the audience to get involved with the 2009 New England TeamWalk.

Rob Redden, MD, who is known as "Doc Rob" in the HSP/PLS community, is a primary care physician associated with Midstate Medical Center in Meriden, CT. Rob shared his remarkable story of managing life despite HSP and answered questions submitted by the audience. Questions centered on symptom management and strategies to maintain and improve function.

Mary Cooper is an Adaptive Physical Education teacher certified in Lakshmi Voelker Chair Yoga™. This type of yoga is based on traditional postures and breathing techniques plus other movements that are modified for the chair, making the health and fitness benefits accessible to everyone. Additionally, movements are modified to take into account the fact that everyone has a different level of flexibility (or range of motion) so individuals can adapt them to personal needs. Visit [www.getfitwhereyousit.com](http://www.getfitwhereyousit.com) for more details.



*Windsurfers take  
to the lake*

### Spring Fling - May 1-2, 2009

*Submitted by Annette Lockwood*

The ninth annual Spring Fling organized by Ronnie Grove was held in Berkeley Springs, WV. The group met for dinner at the Francis Asbury Church on Friday where they shared dinner and many stories.

Saturday's meeting was held at the Wesley Chapel UMC. Ronnie kicked off the meeting and thanked everyone for taking the time to attend Spring Fling. Pennies were collected and a small auction was held raising more funds for the cure. Two new couples were welcomed: Virginia and Will Buettner of New Holland, PA and Bill Gibb and his wife, Ellen from York, PA. Annette Lockwood presented an overview of the Spastic Paraplegia Foundation activities. During the afternoon, a group discussion was held about a variety of subjects including caregiver issues, the baclofen pump, mobility aides and current medications.

Ronnie reminded everyone to plan on attending Spring Fling in 2010. A special 10 year reunion is planned for next year's meeting which will be held on May 7-8, 2010.

### Learn to Windsurf Day - May 17, 2009

*Submitted by Marlene Doolen*

The Austin Windsurf Club held its 2009 Learn to Windsurf Day with the SPF as its benefiting charity. The event was scheduled for Saturday but, typical of Austin weather, continuous rain on Saturday moved the event to Sunday with temperatures in the low 70s. Five separate classes were held with four students per class. Students enjoyed the challenge to stay on their boards, not fall into the water, and enjoy the ride.

On another note, \$1415 was raised in the last couple of months from one of the club's Austin Windsurf Club members. Three club members traveled from Texas to Florida for a world-wide windsurfing competition. Much to my surprise, one of the club members thought to put a fund-raiser together with \$1,000 as the goal. When that goal was met, another \$1,000 goal was set. After all was said and done, the total raised was \$1415.

# Upcoming TeamWalks and Connections

## **KENTUCKY CONNECTION**

**July 22, 2009**

The Campbell House, 1375 S. Broadway  
Lexington, KY

Jane Anne King, (gking@rose.net), 229-227-0558

This connection will take place at The Campbell House restaurant. We will meet there for lunch at 11:00 am; the phone number is 859-255-4281. Caregivers, those with HSP or PLS, and family members are welcome.

## **UTAH CONNECTION**

**August 29, 2009**

Jordan River Parkway/Winchester Pavilion  
Murray, UT

Connie Duran, (duran8934@msn.com)

Planning is just starting for this new event. It will be held at the Jordan River Parkway, which is a beautiful recreational and educational resource located minutes away from Salt Lake City. It is fully accessible for the disabled and has barrier-free areas.

## **NC Quest for the Cure and The Magnificent Mile September 12-13, 2009**

Hillsborough St, Raleigh, NC

Sarah Witt, (srwitt@yahoo.com)

Featured speakers on Saturday are Colin Bishop, PhD, and Martin Childers, DO, PhD, of the Wake Forest Institute of Regenerative Medicine; Donald C. Lo, PhD, Associate Professor, Neurobiology Lab, Duke University; and Brian Kramer, MS, L.Ac, Dipl. Ac, CPT, of Kramer Acupuncture. The 4th Annual Magnificent Mile will be held on Sunday afternoon. If you are traveling to Raleigh for the event, discounted rooms (\$79/night) are available for Friday and Saturday nights at the Clarion Hotel. Call 919-832-0501 and ask for a room in the Magnificent Mile block.

## **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.

## **New York TeamWalk - Mount Kisco Sale Days September 12-13, 2009**

Mount Kisco, NY

Ann Lakin, (alakin90@aol.com)

The New York TeamWalk this year will once again be held on the Sunday after Mt. Kisco Sale Days. At sale days, SPF will have a table offering information about HSP and PLS and advertising the TeamWalk. The TeamWalk will be held from 11 am to 1 pm along Main St. People will gather to socialize and enjoy snacks donated by local business. There will also be raffles and around 12:00 we will walk or roll to the end of the street.

## **New England TeamWalk September 20, 2009**

Fenway Park, Boston, MA

Jim Campbell, (jimthurza@comcast.net)

None other than Fenway Park - the home of the Boston Red Sox - is the location for this year's New England TeamWalk. Our day will include lunch in Fenway Park followed by the Fenway tour - even up on the Green Monster! (all accessible) The Red Sox Foundation is donating the tour for up to 100 of us. Covidien is donating Red Sox hats to all participants. It should be a fun day for NE SPF patients, caregivers, and friends and family who support you and SPF. If you live in one of the six New England states and haven't received details in the mail, please contact Jim Campbell.

## **California TeamWalk for our Cures & Connection Weekend**

**September 25-26, 2009**

Pleasanton, CA

Linda Gentner, (lkgentner@aol.com), 510-651-5676,  
A PLS & HSPers Welcoming Dinner will be held Friday night at the Hilton Pleasanton -- pay for your own dinner. There will be discussion time with dessert and coffee following dinner. Get an early start on the weekend and stay at the hotel Friday night with no need to get up early on Saturday morning. The TeamWalk, lunch, and raffle will be at the Valley Community Church

## **Pennsylvania TeamWalk**

**September 26, 2009**

Knoebel's Amusement Park, Elysburg, PA

Sue Meholick, (momofboysonly@yahoo.com),  
814-653-8566

Helen Kienlen, (hmk17@comcast.net), 484-270-8317

We will have a Friday night dinner for those who can attend. We will also have a pavilion set up at Knoebels Amusement Park where we can gather and meet with others before the TeamWalk.

We will have a picnic lunch catered by the Park and then we will take a walk. For those of you who have scooters or wheelchairs you may ride those. There are scooters available for rent at the Park as well. The Park provides us with an escort who will help anyone get a ride back to the pavilion if they get tired and don't want to go any further.

## **DC Metro Area (VA) TeamWalk**

**September or October**

Misty McGlumphy, (mistymcglumphy@gmail.com)

Planning is underway for this event. More details will be available in the coming weeks.

## **Oklahoma Connection**

**October 3, 2009**

Norman, OK

Mark Dvorak, (czechmarkmhd@yahoo.com)

Planning is underway for this event. More details will be available in the coming weeks.

## **Miami Quest for the Cure Seminar and TeamWalk**

**October 16-17, 2009**

Miami, FL

Kathi Geisler, (kathi@kgeisler.com)

We will have a Friday Arrival Dinner featuring Dr. Michael Franklin, who runs an HSP/PLS Support Group in Tampa Bay. Saturday's Quest for the Cure Seminar will feature Dr. Stephan Zuchner, one of our esteemed SPF Researchers. On Sunday, we'll hold our TeamWalk and an optional Miami shopping excursion.

## **Autumn in Carolina**

**October 17, 2009**

Kingswood United Methodist Church, Rural Hall, NC

Don Wilson, (don-wilson@earthlink.net)

Those arriving on Friday may gather for introductions and conversation, and share a meal at a nearby restaurant. We will also have a "hospitality suite" at the Holiday Inn Select on Friday evening for casual conversations after dinner. The gathering on Saturday will be in the Fellowship Hall of Kingswood United Methodist Church, just a few minutes from any of the motels. The program is being formulated. Lunch on Saturday will be custom box lunches from Mrs. Pumpkin's. After the program, everyone will be invited to share a meal at a nearby restaurant Saturday evening. As enjoyed in the past, weather-permitting, there will be wheel chair and scooter races under the sanction from SAWCAR (Scooter and Wheel Chair Association of Racing). For those who are traveling, The Holiday Inn Select (Madison Park, Winston-Salem) has reserved a block of 10 rooms, including five accessible (one with roll-in shower), all under the name of Autumn in Carolina. The rate for the rooms will be \$89.00 plus tax per night. Call 1-800-553-9595 and ask for a room in the Autumn in Carolina block.

## **Tennessee TeamWalk and Connection**

**Early fall** Nashville, TN

Jim Sheorn, (jmsheorn@comcast.net), 615-479-7369

We hope to have Dr. Peter Hedera of Vanderbilt as our guest speaker to present the latest information about his HSP trial.

## **Texas TeamWalk**

**November 6 - 7, 2009**

The Woodlands Bear Branch Park,  
5200 Research Forest Drive, Houston, TX

Ashton Hecker, (ashton@ashtonhecker.com)

Friday dinner will be at la Madeleine in the Woodlands at 7 pm, with a speaker at 7:30 pm. La Madeleine Restaurant is at 9595 Six Pines Dr. #100, The Woodlands; 281-419-5826. The TeamWalk will start at 10:00 am Saturday at The Woodlands Bear Branch Park. For those who are traveling, the best hotel rate is at the Hilton Garden Inn in Houston. The price is \$106; call 281-364-9300. The TeamWalk weekend coincides with the Renaissance Festival, so participants who need a hotel room are encouraged to book early.

# Living with HSP or PLS

## Ten Tips for Finding an Accessible Room

Candy B. Harrington

Although it's been well over a decade since the Americans with Disabilities Act (ADA) was signed into law, wheelchair-users and slow walkers still have problems finding accessible lodging. According to a 2005 Harris Interactive survey, 60% of disabled travelers experienced problems with their overnight lodging choices.

But it doesn't have to be that way. In fact, a little advance planning mixed with a healthy dose of self advocacy goes a long way towards finding an accessible room that meets your needs. Here are a few tips to help you out.

- Never just ask for an "accessible" or an "ADA compliant" room. Instead, describe the access features you need.
- In Europe, if you need a room with an accessible bathroom, ask for an *adapted* room. An *accessible* room only features a barrier-free path of travel; however an *adapted* room also contains an adapted shower and toilet.
- Make sure and ask about the availability of elevators, especially in small European properties. It's not unusual for a property to have an accessible room that can only be accessed by a stairway.
- If you need a roll-in shower, ask for one. This is not a standard feature in all accessible or even adapted rooms. Specify your needs.
- Always call the property directly, rather than calling the central reservation number.
- Bed height is not regulated under the ADA, so make sure and ask for measurements. Many properties are replacing their standard mattresses with high pillow top and luxury models.
- Avoid yes or no questions. For example, ask the clerk to describe the bathroom, rather than just asking if the bathroom is accessible.
- Ask the reservation agent to fax you a floor plan of the accessible room. This will give you the dimensions of the room, but remember that access can vary depending on the placement of furniture.

- If you have difficulty determining if a room will suit your needs, ask to speak to somebody who has recently been in the room. Employees in the housekeeping or engineering departments usually have a good knowledge of access features of the individual rooms.
- Remember to ask the reservation agent if the accessible room can be blocked for you. If the answer is "no" or "sometimes", then find another hotel. Remember, even the most accessible room in the world won't work for you, if that room isn't available when you arrive.

Finally, always trust your instincts. If a reservation agent hems and haws, gives ambiguous answers or sounds inept, call back and talk to another reservation agent or call a different property. When in doubt, always go with your gut.

Candy Harrington is the editor of *Emerging Horizons* and the author of *Barrier Free Travel: A Nuts and Bolts Guide For Wheelers and Slow Walkers*

([www.barrierfreetravel.net](http://www.barrierfreetravel.net)). Visit her blog at [www.BarrierFreeTravels.com](http://www.BarrierFreeTravels.com) for access news, resources and industry updates.

## Nonprofit Helps ALS Patients Communicate

Contributed by: Mark Weber

Imagine if you were trying to solve a crime and the man who could blow the case wide open couldn't speak. Recently, "CSI: NY" broadcasted an episode that included such a man. He communicated with the world by blinking at a computer screen to spell out words and sentences. But for many of the 30,000 people in America living with ALS it's not just a 60-minute cop show. It's real life. With a terminal neuromuscular disease, your muscles atrophy and your world shrinks, but not your mind. It still reaches out. Shirley Fredlund, from New Milford, CT, has seen these eye-gaze systems work miracles. She's seen them throw open the shutters of communication for her clients like a kid racing to the window on Christmas morning. Fredlund is the founder of Voice for Joanie ([www.voiceforjoanie.org](http://www.voiceforjoanie.org)), a nonprofit organization that makes computer-assisted speech machines available for free. In fact, she was a consultant for the recent "CSI" episode.



# 45 Lessons Life Taught Me

*Written By Regina Brett, 90 years old, of The Plain Dealer, Cleveland, Ohio*

*Contributed by Ronnie Grove*

1. Life isn't fair, but it's still good.
2. When in doubt, just take the next small step.
3. Life is too short to waste time hating anyone.
4. Your job won't take care of you when you are sick. Your friends and parents will. Stay in touch.
5. Pay off your credit cards every month.
6. You don't have to win every argument. Agree to disagree.
7. Cry with someone. It's more healing than crying alone.
8. It's OK to get angry with God. He can take it.
9. Save for retirement starting with your first pay check.
10. When it comes to chocolate, resistance is futile.
11. Make peace with your past so it won't screw up the present.
12. It's OK to let your children see you cry.
13. Don't compare your life to others. You have no idea what their journey is all about.
14. If a relationship has to be a secret, you shouldn't be in it.
15. Everything can change in the blink of an eye. But don't worry; God never blinks.
16. Take a deep breath. It calms the mind.
17. Get rid of anything that isn't useful, beautiful or joyful.
18. Whatever doesn't kill you really does make you stronger.
19. It's never too late to have a happy childhood. But the second one is up to you and no one else.
20. When it comes to going after what you love in life, don't take no for an answer.
21. Burn the candles, use the nice sheets, wear the fancy lingerie. Don't save it for a special occasion. Today is special.
22. Over prepare, then go with the flow.
23. Be eccentric now. Don't wait for old age to wear purple.
24. The most important sex organ is the brain.
25. No one is in charge of your happiness but you.
26. Frame every so-called disaster with these words 'In five years, will this matter?'
27. Always choose life.
28. Forgive everyone and everything.
29. What other people think of you is none of your business.
30. Time heals almost everything. Give it time.
31. However good or bad a situation is, it will change.
32. Don't take yourself so seriously. No one else does.
33. Believe in miracles.
34. God loves you because of who God is, not because of anything you did or didn't do.
35. Don't audit life. Show up and make the most of it now.
36. Growing old beats the alternative -- dying young.
37. Your children get only one childhood.
38. All that truly matters in the end is that you loved.
39. Get outside every day. Miracles are waiting everywhere.
40. If we all threw our problems in a pile and saw everyone else's, we'd grab ours back.
41. Envy is a waste of time. You already have all you need.
42. The best is yet to come.
43. No matter how you feel, get up, dress up and show up.
44. Yield.
45. Life isn't tied with a bow, but it's still a gift.

## Mom on Wheels

*Contributed by: Shannon Klann*

I've been diagnosed with a neuromuscular disease and have been confined to a wheelchair for fifteen years. After the proper genetic testing, my amazing husband and I decided to have children. Following an exhaustive search for information and receiving some from women who have endured similar circumstances, we began this chapter of our lives. After my first child, I vowed to write a book or create a website to share tips and information that I've learned. Now that my youngest child has started kindergarten, I have free time to dedicate to this. I'm working on a book and a website, and I'm launching my blog: [www.momsonwheels.net](http://www.momsonwheels.net) OR [www.momsonwheels.typepad.com/mom\\_on\\_wheels](http://www.momsonwheels.typepad.com/mom_on_wheels). I hope my blog will reach people who need this information like I did.

I've also created a community, Mothers in Wheelchairs, on Facebook. To access it go to: Facebook>Applications>Circle of Moms>Communities>Mothers in Wheelchairs

## Neurology Now

*Contributed by Annette Lockwood*

*Neurology Now* [www.neurologynow.com](http://www.neurologynow.com) is the official bimonthly publication of the American Academy of Neurology (AAN). It provides accurate and important new information about advances in the diagnosis and treatment of neurological diseases, such as migraine, Alzheimer's disease, epilepsy, multiple sclerosis, and other disorders.

*Neurology Now* brings expert advice about wellness and disease prevention, new medications and therapies, and strategies for coping with neurological disorders. *Neurology Now* provides balanced coverage of therapies based on the latest developments in laboratory research and clinical trials.

Our goals are to improve communication between patients and their physicians, support disease awareness and self-management, and provide public outreach for the AAN. The AAN is an international professional association of more than 18,000 neurologists and neuroscience professionals dedicated to providing the best possible care for patients with neurological disorders.

If you would like to receive *Neurology Now* (it is free on-line), use the following link -[www.b2bmediaportal.com/register.aspx?fid=NOWF&status=new&key=49TELL](http://www.b2bmediaportal.com/register.aspx?fid=NOWF&status=new&key=49TELL)

## The Rascal is a Great Travel Companion

*Ed. Note: Electric Mobility is a sponsor of Synapse*

There are numerous companies who manufacture scooters which are transportable by airlines when you travel. One such company is The Electric Mobility Company which manufactures the Rascal Fold 'N Go/Rascal AutoGo travel scooters. Scooters are easier to manage when traveling than most power wheelchairs.

- The AutoGo power folds automatically with the push of a button. The Fold 'N Go's seat comes off and is collapsible. The design of these units allow for one-handed disassembly.
- Another advantage of these battery-powered travel scooters is that they weigh only 85-105 pounds. They can carry a person of 250-300 pounds.
- These scooters have a top speed of approximately 4mph.
- The AutoGo travel scooter has an on-board battery charger and the Fold 'N Go has to be charged with a separate charger unit from a standard electric power outlet. The Fold 'N Go/AutoGo are fitted with FAA approved batteries so all airlines must accept them as your luggage without an upcharge according to FAA requirements.

You may contact the Electric Mobility at 1-800-MOBILITY or, visit their website at [www.rascalscooters.com](http://www.rascalscooters.com)

## Life of Scooter and Wheelchair Batteries

There appears to be conflicting information about how to maximize battery life. Some such as [www.batteryuniversity.com](http://www.batteryuniversity.com), recommend, "Charge the batter immediately after use. Lead-acid must always be kept in a charged condition. The battery lasts longer with partial rather than full discharges."

The manufacturer of my scooter, told me to let it run down half way, while the store that sold me the scooter advised me to run it down most of the way before recharging it. I wore out some batteries in a

few months following the store's advice. When I went to the battery manufacturer, they said to charge the battery after every use, as did many other web sources. The "let it run down" advice is valid for NiCd and NiMH batteries, but not for the lead-acid batteries (either gel or liquid) commonly used in scooters. Another tip, don't call the manufacturer or scooter store for replacement batteries. Instead, search online. One source is Interstate Battery 866-842-5368 or go to [www.interstatebatteries.com](http://www.interstatebatteries.com). Their prices were less than half of what the scooter manufacturer wanted for the same battery. If you are covered by Medicare, you only will pay your deductible.

## *Still Walking In My Dreams*

*Contributed by: Malin Dollinger*

*I remember clearly sometimes  
How it feels to walk somewhere, anywhere*

*I can't remember clearly sometimes  
How it felt to walk somewhere, anywhere*

*I've mostly abandoned my dream fantasy  
That I will wake up and walk to the bathroom  
Or anywhere I wish*

*Forgetting is a blessing  
The first line above is the present tense - "feels"  
Part of me has a normal spinal cord  
That sends signals as it should*

*He is my imaginary Siamese twin  
Who remembers dancing, clogging  
Fantasy of walking on the beach  
Or anywhere for that matter  
He can still do these things*

*For peace of mind  
I need to forget that twin  
Concentrate on the here and now  
His twin - me - is on a roll  
Literally*

*Archetype of the microcosm of HSP  
Proving to my people and the world  
That it's no big deal  
When it is a big deal*

*I am a role model for others like me*

*There are two kinds of people  
Those who remember me walking  
Those who don't*

*I instantly classify everyone I meet  
One group or the other*

*I wonder how the second group thinks of me  
Am I first in their thoughts?  
Or is the scooter?*

*I will ask my Siamese twin  
To pretend he is me  
For the rest of my life*



## **Bowler Strikes Past HSP**

*Contributed by: Mike Dyer – The Record*

Frank Goebel, a resident of Troy, NY, has coached dozens of bowlers including youngsters at Olympic Lanes and those in the Troy YABA association. Goebel is an inspiration

to all bowlers, because while helping others, he has suffered from the rare Heredity Spastic Paraparesis for the past ten years. It forced Goebel to use a one-step approach when bowling. He has not let the disease inhibit his game, scoring a 300 in 1999 at Olympic Lanes. "Bowling is my release, my escape from life," Goebel says.

## **The Law of the Garbage Truck**

*Contributed by Ronnie Grove*

One day I hopped in a taxi and we took off for the airport. We were driving in the right lane when suddenly a black car jumped out of a parking space right in front of us. My taxi driver slammed on his brakes, skidded, and missed the other car by just inches! The driver of the other car whipped his head around and started yelling at us. My taxi driver just smiled and waved at the guy. And I mean, he was really friendly.

So I asked, "Why did you just do that? This guy almost caused an accident and sent us to the hospital!" This is when my taxi driver taught me what I now call, "The Law of the Garbage Truck."

*(continued next page)*

(Continued from page 11)

He explained that many people are like garbage trucks. They run around full of garbage, full of frustration, full of anger, full of disappointment and rage. As their garbage piles up, they need a place to dump it and sometimes they'll dump it on you. Don't take it personally. Just smile, wave, wish them well, and move on. Don't pick up their garbage and spread it to other people in your life, whether at work, at home, or to people that you don't even know on the streets.

Always remember that good people do not let garbage trucks take over their day. Life's too short to wake up in the morning with regrets, so... "Love the people who treat you right and forgive and pray for the ones who don't."

### **Meridian Regulatory Acupuncture**

*Contributed by: Annamarie (Dublin, OH)*

Two of my four kids, ages 12 and 7, have been diagnosed with HSP. Over the years our kids have seen various doctors and have done the braces, baclofen, botox, but opted out of the baclofen pump and additional medications.

Our doctor, an anesthesiologist by trade, has his own practice and does Meridian Regulatory Acupuncture (MRA). MRA is only done by trained Medical Doctors, and my understanding is that it balances all the systems in your body (nervous, digestive, skeletal, etc.). Once the systems are balanced, your body can function the way it is supposed to, therefore, healing itself as it does with a cut or scrape on the knee. MRA is a non-invasive procedure – no side effects, etc. Both of my children have had appointments, and we've seen physical changes to their spines, in the office! My son John, who is 12 years old and has been in a wheelchair for 1½ years, said while riding his recumbent bike after one appointment, "I feel my spine uncurling and getting taller. My legs have more energy and feel like they're unlocking."

I encourage everyone to visit the website: [www.drnemeh.com](http://www.drnemeh.com). Watch the videos from Cleveland's Channel 5 and Channel 8.

### **The Mid-America Games**

*Contributed by Mari White*

Here's our son Alex at the Mid-America Games ([www.midamericagames.com](http://www.midamericagames.com)) which is a multi-sport competition. Alex, our 6 year old competed in 7 events and received 7 gold medals. He has HSP. He had a blast and then he danced for over 2 hours with all the cheerleaders and everyone else.



The Games are traditionally held the first weekend in May in Overland Park, Kansas and at Mission Bowl in Mission, Kansas. Events such as track and field, Boccia, Wheelchair Soccer and bowling are offered. There is also an opening ceremony, complimentary lunch and dinner, and an awards ceremony. All events follow the rules published by the National Disability Sports Alliance (NDSA) and Wheel Sports USA (WSUSA). Athletes are classified according to their systems. These Games, while sanctioned by NDSA and WSUSA, welcome anyone with a physical disability over the age of seven and able to perform at a competitive level.

Mid America Games for the Disabled, Inc. is a non-profit organization whose volunteer members are committed to providing competitive modified athletic opportunities for athletes with physical disabilities and to promoting a positive image of ALL individuals with diverse needs and abilities.

They strive, through the annual games, to provide opportunities for individuals to reach and expand their potential within their physical abilities. They promote a spirit of healthy competition for athletes with a variety of physical disabilities including Cerebral Palsy and related head injuries, Muscular Dystrophy, Spina Bifida, spinal cord injuries and many other diagnoses.

One of the professional paralympians from the U.S.A. basketball team was a key note speaker. He has an amputation above the knee. He talked about his struggles as a child where he learned he could do nothing and was no good. At the age of 20 he found out about adaptive sports and started training and believing in himself. Now at age 36 he travels the world, does the ironman triathlons, marathons, rock climbing, and several other things besides motivational speaking and raising two young children. It was a great message of inspiration.

# Caregiving

## CAREGIVER EXERCISES

### *Simple ways to resist injury*

by Christina Medvescek for MDA Quest

It just takes one little wrong move, like leaning over to tie a loved one's shoelace, for something to pop in the lower back and put you out of commission. For a caregiver, this kind of injury can be disastrous.

Good body mechanics (like lifting with the legs, not the back) and assists (like a Hoyer lift or another person) significantly reduce the risk of injury and always should be used. But unless you're also taking care of your body, an injury may be just one wrong move away. Muscles need flexibility and strength to resist injury — and stretching and strengthening exercises are the way to achieve those goals. We're not talking about an hour-long trip to the gym, but exercises that fit neatly into odd moments of the day, like when you're watching TV or sitting at a traffic light.

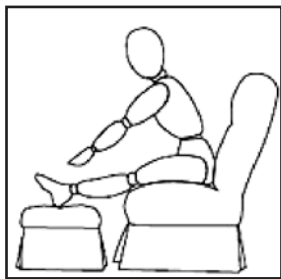
***If you already have painful back, neck or shoulder muscles, check with your doctor before undertaking any of the exercises below***

#### ***Stretch like a cat***

Stretch to the edge of comfort but not beyond, or you may trigger a stretch reflex that actually contracts the muscle and defeats your efforts. Pain isn't the point, nor is distance. Luxuriate in a stretch, the way a cat does.

Hold stretches about 15 to 30 seconds, repeating two or three times. Never bounce to get a greater stretch.

**Lower back stretch:** Tight hamstring muscles can cause back pain, says John Klune, physical therapist at the MDA/ALS Center at the University of Arizona Health Sciences Center in Tucson.



**Lower Back Stretch**

Stretch your hamstrings by sitting in a chair with your feet up on a footrest or coffee table. Keeping your knees

straight, lean forward until you feel an easy, not painful, stretch.

Most adults have bad body habits, like poor posture or only moving in a few routine patterns. The result of these habits is that muscles only stretch within a limited range of motion that works OK for everyday life, but doesn't stand up to stress. Beyond flexibility, leg and hip strength is vitally important for lifting, and strong abdominal and buttocks muscles stabilize the lower back region.

#### ***Opportune moments***

There are dozens of opportunities during the day to fit in quick, gentle exercise. You can perform the exercises listed below basically anytime you have a spare 30 seconds. If you pair an activity with an exercise — for example, always doing partial squats while waiting for your toast to pop or hamstring stretches during TV commercials — you'll improve without even realizing it.

**Shoulder stretch:** Scratch your back. First point your elbow in the air and scratch the top of your spine. Next, curl each arm around the front of your neck and scratch over your opposite shoulder. Finally, hold your elbow down by your side and twist your hand back up between your shoulder blades.

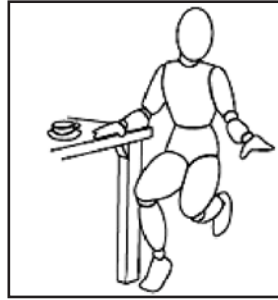
**Chest stretch:** Place your hands at shoulder height on either side of a doorjamb, then step into the doorway so your arms slightly wing out behind you. Feel the stretch through the middle of your chest.

**Neck stretch:** Lower your ear to your shoulder on either side.

#### ***Get strong***

The rule of thumb for strengthening without weights is to tighten your muscles to their maximum, hold for a count of 10, relax for a count of 10 and do 10 repetitions. Be sure you're stable, either by taking a wide stance or by holding on to a secure object.

**Legs and hips:** Whenever possible, climb stairs instead of using an elevator. In addition, try partial squats. Hold on to a stable object like a countertop. Keep your back straight and slowly lower as if you're about to sit down. Go down as far as comfortable, then back up.



**Partial Squat**

For greater effect, use only one leg at time. You also can work on leg strength each time you get up from a desk or table, by rising from the chair using only one leg. Hold on to the table for stability but don't pull yourself up. Alternate legs for an equal workout.

**Lower back:** Here's an exercise nobody will even know you're doing. Whenever you think of it, squeeze your buttocks or your abdominal muscles as tight as you can and hold. "You can't overdo it," says Klune.

A San Diego State University study of abdominal exercises found that they should be done frequently rather than for intense periods. Five minutes a day can make a difference if done regularly.

**Shoulders and arms:** Take a weight like a shoe or soup can and lift it straight up in front and to the side, from your waist all the way over your head.

Hold arms straight out to the sides at shoulder height, then bring one arm across in front of your chest, keeping the elbow straight. Go just to the point where your arm starts to bend, then back.

Force your shoulder blades together in the back, then relax, then push them together again. Do shoulder shrugs that bring your shoulders up toward your ears, as if you're saying, "I don't know."

**Neck:** Place your palm in the middle of your forehead and gently press, resisting the push by holding your head still. Repeat on each side and the back of your head.

## Dr. Fink Answers Your Questions

### Controlling Weight when in a Wheelchair

**Q.** *I am in a motorized wheelchair and I am having a hard time keeping the weight off. I realize the easiest way is to stop eating, but that is hard. I am not interested in taking another pill everyday, but my neurologist said this may become a reality. What should I do? - Steven Stuckey*

**A.** With the caveat that I am not a trained nutritionist, here are my thoughts about weight loss/maintenance in this situation.

- Maintaining "proper" weight is often a challenge, particularly with age, changes in activities, and may be particularly challenging when mobility is compromised.
- Weight maintenance involves food choices (substituting "more filling" foods for "higher caloric foods"); and maintaining sleep-eating-activity-eating-sleep cycles. These cycles contribute to what, how much, and when we eat and how this nutrition is utilized or stored.
- Exercise (daily) is a central part of fitness and weight maintenance. Upper extremity exertion can provide aerobic conditioning. Many (many !) individuals with HSP have told me that exercising in the water (pool exercises) are very effective.
- In this circumstance we have to "think outside the box": figure out what exercises are possible, set up a daily (every single day) exercise plan, consult a nutritionist, maintain a diet log, and look carefully at the factors that contribute to your food choices.

### **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 [www.sp-foundation.org/donate.htm](http://www.sp-foundation.org/donate.htm)

Continued from page 2

of PLS. There are now known to be 40 genetic types of HSP. Even though very diverse presentations of both HSP and PLS are apparent, he and other researchers are trying to find common pathways, since bottom line the nerves involved are the same. A study is in process on 10 PLS people with a fig4 gene mutation now. Go to Pub Med for a complete description of recent HSP research highlights. There are many findings relating to many of the 40 genetic mutations. Complete genetic testing costs \$13K. It is very beneficial however, as it can definitively determine which gene or genes have mutated.

After the genetic portion of his talk, Dr. Fink explained what both embryonic and adult stem cells are, how they can be obtained and the potential of what these undifferentiated cells can eventually do. Currently five phase one clinical trials are under way for various neurological conditions in the US and Great Britain. There are concerns at this time that injections of embryonic derived stem cells might lead to tumors developing, evolving from the donor's genetic material. Dr. Fink is beginning skin biopsy of both PLS and HSP patients here at the Convention to advance his research.

After lunch the first speaker was **Madonna Long**, cofounder and editor of Chloe magazine, for women with disabilities. [www.chloemagazine.com](http://www.chloemagazine.com) 24.4% of women in US are either physically or mentally handicapped. She discovered that no one had been marketing to this segment of the population. Thanks to her efforts, she has gotten designers to design fashionable wheelchair clothes. [www.agapparel.com](http://www.agapparel.com) and [www.legawear.com](http://www.legawear.com). She puts on fashion shows at Ability Expos. She's an energetic spokesperson for how all handicapped can advocate for the handicapped community. For example, she says, "Become an advocate yourself for yourself with your Congressman. Tell your story to them. Take advantage of any opportunity to explain why any upcoming issue is important to you."

**The President's Call to Service Award** was presented to a very surprised and deserving Annette Lockwood.



She was eligible to be nominated for this award since she'd given at least 4000 hours of volunteer service for a non-profit. We know that 4000 hours amount to a fraction of her hours devoted to SPF.

**Dr. David Anderson** discussed the latest advances in intrathecal Baclofen pumps. Reducing muscle tone is the goal of this therapy. An extensive pre-implantation series of tests is required prior to surgery. After surgery the dosage is controlled by a small hand held device. Therapy is advised to help the patient adapt to less spasticity. More study is needed regarding the effectiveness of the pump with HSP. Despite potential problems, most people are pleased with the results.

**Panel discussion: Therapies - Craig Gentner** moderated question and answers with the audience about Botox therapy for spasticity, chiropractic and acupuncture. **Dr. Lizette Alvarez**, a physiatrist has extensive experience with injections of Botox into muscles for temporary spasticity reduction. **Rand Olson, D.C.** is both a chiropractor and acupuncturist. Both are striving to assist patients to optimize all aspects of health. Those five components are: spiritual, structural, emotional, nutritional, and energetic.

The afternoon's agenda concluded with four information-packed **Break-Out** sessions.

Reaching the Media for SPF - Mark Dvorak

Orthosis Designs – Keith Smith

HR 804 – Larry Asbury

Planning a TeamWalk - Kathi Geisler and Jim Campbell



*Breakout Leaders, Mark Dvorak and Larry Asbury*

This information packed event was enjoyed by 170 people. Of those, 94 were first timers. People enjoyed the programs which were planned under the direction of Jim Sheorn, Chair, but many wished for more time to visit. If you missed this one, plan now to join us next year. You're bound to make new friends and be inspired.

7700 Leesburg Pike, Ste 123  
Falls Church, VA 22043

**PEOPLE  
DOING**



*Chair Yoga in Massachusetts*



*The gang was all there at Spring Fling--Virginia Buettner, Sue Meholic, Janet Hawbaker, Jim Spencer, Annette Lockwood, Gene Knicely, Ronnie Grove, Martin Beckner, David Lehman and Dorothy Cockrell*



*Dr. Rob Redden at April 4th Seminar*



*Marlene Doolen at Austin Windsurfing Event*



*Ronnie and Penny at Spring Fling*