

Synapse

Winter 2006

Serving the Primary Lateral Sclerosis Community since 1997
Welcoming the SP Foundation since 2003



Route 66 Ride Across America - for Benefit of SP Foundation
June 10th - June 24th



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SPF **SPASTIC PARAPLEGIA FOUNDATION, INC.** *Research Education Support*

Lead Sponsor of the Synapse Newsletter

The Spastic Paraplegia Foundation is dedicated to finding the cures for Primary Lateral Sclerosis and Hereditary Spastic Paraplegia through research funding, information and support programs.

<http://www.sp-foundation.org> ~ e-mail: info@sp-foundation.org
Phone (703) 495-9261

EVENTS

The Route 66 Ride Across America, for the benefit of the Spastic Paraplegia Foundation

Ed. Note: Shellie Fischer is the founder of TeamWalks! Many of you may not recall that back in 1999, Shellie birthed the idea, and organized these first fundraisers before the SP Foundation was founded. Now she's organizing another event, which will take place in June. Please read on, and see how you can participate – ride, host or come to a Connection near you, or come watch them ride by.

<http://www.sp-foundation.org/events-Route66Ride.htm>

June 10th - June 24th of 2006. 15 days
3000+ miles, and 12 states!

Join the Fischer's in their fight against motor neuron disorders by requesting your information packet at rt66@elegancencm.com or by calling 505-885-1289. Numerous motorcycle clubs across the ride route are going to be getting participation packets to gain sponsors and contribute to our cause from outside of our patient community. Bikers can participate in the event by filing out a sponsorship form for their ride from start to finish or simply as escort riders as we enter their state. Regardless if it's 3 or 3000 miles all are welcome to participate. We will stop every 300 miles on the route in addition to our scheduled sponsorship packet pick up locations. In the end we will have a huge party in D.C. The prizes will be donated biker gear.

The Travel Route

<http://www.historic66.com/>

We will be on Route 66 from California to Illinois. From there we will cut across on 70 to D.C. We will post restaurant and hotel connections for key cities where we have lunch and stop for the night. Scheduled lunch

stops Barstow CA 10th, Flagstaff AZ, 11th, Gallup NM 12th, Tucumcari NM 13th, Elk City OK 14th, Tulsa OK 15th, Lebanon MO 16th, Terre Haute 17th, Dayton OH 18th, Cumberland WV 19th, Scheduled dinner/bunk for the night stops Needles CA 10th, Holbrook AZ 11th, Albuquerque NM 12th, Amarillo TX 13th, Oklahoma City OK 14th, Joplin MO 15th, St Louis MO 16th, Indianapolis Indiana 17th, Columbus Ohio 18th, Washington D.C. 19th

Bikers who raise \$500 or more will receive a free

US DREAM CLUB SHIRT from Elegance. (Shirt design may vary)
ELEGANCE, P.O. Box 2353 Carlsbad NM 88220 505-885-1289

Colorado Connection, October 1, 2005

Contributed by Greg Singer

jerome.singer@sun.com

Connection organized by Dale

Rutschow dalerutschow@adelphia.net

The meeting was great! We held the meeting at my work, StorageTek at the East Side Café, a large open conference area. We had 12 folks there including the speaker. Our speaker was Dr. Paul Austin (referred to us by Sue Boucher). Dr. Austin is a Chiropractor (http://www.austinchirocenter.com/about_dr.php) focusing on body symmetry, nutrition, exercise, etc... He talked about the nervous system, and then went on to talk about balance in our nerves (homeostasis), and in the rest of our existence. The importance of good nutrition, and making sure we get our share of anti-oxidants, as they help our bodies. He also spoke about slowing down, relaxing, breathing deeply, and how this all helps our bodies. The discussion went on to talk about how opposing muscle groups need to be focused on in our exercise programs. How we in particular due to our spasticity need to insure that we work on the opposing

muscle group to help balance our functional ability. Have a great day, and try to get to a connection if you can, it's great to meet/talk to others. Addendum from Dale: The only thing I can add is that we had 3 new people. They were so happy they came, meeting others with the diseases, the information, and the support they felt. They also hadn't wanted to go, thinking it would be depressing. This is what makes the work to run these worth it!

Nashville TN Connection and TeamWalk Oct. 22, 2005

Contributed by Jim Sheorn
TeamWalkers go to Greece to show their support for the SP Foundation. Just kidding, but they did meet in Nashville on October 22 to attend a Connection Meeting and TeamWalk. During the Connection Meeting, participants listened to Dr. Peter Hedera. Dr. Hedera is a researcher from Vanderbilt Medical Center in Nashville. He discussed symptoms of HSP and PLS and what makes them different. He also gave an update on the research that he and his colleagues are doing. They are currently using worms and trying to identify what causes HSP.
After the Connection Meeting the group went to Centennial Park for the TeamWalk. At Centennial Park there is a life size replica of the Parthenon in Greece. It was a nice fall day to enjoy each other and raise much needed funds for research. Together the group raised almost \$8,000 and we are still waiting on other donations.
Thanks to all who participated and donated.

SW TeamWalk October 23, 2005

Contributed by and organized by Bonnie Guzelf
The SW TeamWalk was held at Kiwanis Park in Tempe, AZ. It was a bright beautiful day. We "walked" the Synapse – Winter 2006

7/8 mile around the lake, feed the ducks and pigeons, met some new friends and had a lovely lakeside lunch.... oh yes....and raised \$1,175.00 for SPF.

Looking ahead-SP Connections in 2006

For more details, contact the person listed:

West Virginia: Contact [Ronnie Grove](#)
Spring Fling March 31, April 1-2.
It's almost time once again for another Spring Fling to get re-connected with both old and new friends. This will be the 6th year running for a WV Connection. This is a mostly social event for those with PLS or HSP to get together and learn from each other. Connections are the one place you can talk funny or walk funny and everyone thinks you are normal. It's a great feeling to be among understanding friends. We learn a lot in a few days and always leave feeling better or so I've been told.

Arrive at your convenience. The first scheduled event will be dinner on Friday, March 31 at 6:30. All day Saturday, April 1st in the conference room at Best Western and any plans you personally make for Sunday. There are no up front expenses such as registration. We "pass the hat" for convention room and incidental expenses. You pay for meals as you go. I will have detailed information on meal reservations and costs a little closer to the event.

Rooms are being held at the Best Western, Berkeley Springs Inn in Berkeley Springs, WV, phone 304-258-9400 for reservations. Mention the Spring Fling and ask about special rates. If you are even thinking about being here I would like to know as soon as possible. I need a rough idea of how many I will have for dinner on Friday.

Connecticut: Contact [Dolores Carron](#)
spring

Colorado: Contact [Dale Rutschow](#)

May in Denver

Texas: Contact [Marlene Doolen](#) The Austin Patient Connection Luncheon is tentatively scheduled for Saturday, September 2, 2006, at the usual location, Brick Oven, noon to 3

Idaho: Contact Pat Bernhard pbernhard@ureach.com support group meeting will be sometime in the vicinity of Sept. 30 in Boise. We always have a GREAT doctor, Dr. Robert Friedman (donates his time), who will explain things and answer questions.

North Carolina: Contact Don Wilson dcwilson@attglobal.net in the fall Other areas may link Connections to the **Ride across America** as plans evolve. Check in at www.sp-foundation.org in the spring. Synapse will post any new information on the Ride across America in the April issue, including phone contacts for those of you without computers.

If your area isn't listed, might you take a turn and plan a Connection? Please contact Linda Gentner, lkgentner@aol.com SP Board member who assists with programming.

SP FOUNDATION AND FUNDRAISING

A Letter from our SP President

Happy New Year! The Spastic Paraplegia Foundation (SPF) continues to grow. Welcome to all who joined us in 2005. We are sorry for the reason that you searched us out but hope that you find both the members and the information helpful. Please accept my sincere thanks to everyone for their efforts in supporting the Foundation. The National Conference and TeamWalk were held in Columbus, OH. DVDs are now available for \$20; please refer to the website, www.sp-foundation.org
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[foundation.org](http://www.sp-foundation.org) to place an order or send a check payable to SPF to: Margie Hegg, 3597 Milton Ave., Columbus, OH 43214.

For 2006, the SPF Board is working with the Nonprofit Center in Nashville to obtain advice on how to energize our fundraising activities. The 2005 Team Walk raised over \$180,000.00 which is an awesome accomplishment. In looking at the results, over 50 new people participated in the event as walkers by proxy. The disappointment is that 94 people who participated in 2004 did not in 2005. Our hope is to structure the 2006 TeamWalk to ensure that everyone has the opportunity and interest in participating and making it a success. Your input is greatly appreciated; please forward any suggestions/comments to Annette.lockwood@sp-foundation.org.

The SPF Board will approve funds soon for the 2006 Research Program. Proposals will need to be received by April 15, 2006. Our Scientific Advisory Board (SAB) will need at least three months to review the proposals and provide their recommendations to the Board. Grant awards will be announced once the SAB recommendations are reviewed and voted on by the Board of Directors. SPF research projects which started with testing mice models, have now progressed to developing neurons in zebra fish embryos. Research is progressing at a quick pace and gives hope that a breakthrough will happen in the near future.

The Board of Directors welcomes Larry Asbury as our newest Board Member. Larry fills the position that was left open when Rick Pallas resigned. There is still one more position that is vacant so if you are interested in joining the board, please refer to the website for information and an application. Applications are

due February 20, 2006 and the applicant needs to be available to attend the 2006 Annual Board Meeting to be held in Nashville, TN on a Saturday in April. Currently April 1 and April 22 are being considered. I wish all of you a prosperous 2006,
Annette Lockwood
President, SPF

One Million Pennies

Collect your pennies and small change and get your family, friends and co-workers to do the same! Ronnie Grove, organizer of the annual Spring Fling weekend in Berkeley Springs, West Virginia, is challenging all of us to collect One Million Pennies by the 2006 Spring Fling event on April 1-2. "Pennies can be collected however it suits the collector. I put a jar in my living room and I can guarantee you no one will leave my home until I have asked if they have any pennies they want to give up for a good cause. I have a jar on my desk when at work. All you have to do is ask. As of the end of December, our total collected is \$8,918.33 reported. We are only 108167 pennies away from goal!" No mailing of pennies at any time, please! Checks should be made out to the Spastic Paraplegia Foundation marked clearly Penny Campaign and send them to SPF Treasurer, David Lewis
PO Box 1208
Fortson, GA 31808.
Contact Ronnie for more information or to report your total sent:
frogrove@pennswoods.net
13 Erin Ln
Berkeley Springs, WV 25411

LIVING WITH HSP/ PLS

Caffeine and Spasticity

Contributed by Dr. John Fink, SPF

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Medical Advisor and leading researcher of HSP and PLS:

I am not aware of any medical publications that show either a worsening of spasticity because of caffeine; or a reduction in spasticity following discontinuation of caffeine. Having said that, there is a link on the Cerebral palsy Information Central website (<http://geocities.com/aneecp/index2.html>) with tips for managing spasticity that recommends avoiding caffeine (in all of its sources, including chocolate) <http://www.geocities.com/aneecp/tips4age.html> There is also anecdotal evidence that caffeine (and particularly stronger stimulants) may be associated with increased reflexes. This does not reach the degree of increased reflexes seen in hereditary spastic paraplegia. It is possible that some individuals with hereditary spastic paraplegia or primary lateral sclerosis may notice increased stiffness (spasticity) due to caffeine. If caffeine is in fact having this effect, I would expect it to be variable between individuals and would depend on such factors as a) individual variation, b) age, c) amount of caffeine, d) concomitant use of other medicines (including spasticity reducing medications), e) timing of caffeine consumption, f) exercise.

On balance, we often recommend a trial (lasting at least a couple of months) of reducing or discontinuing caffeine consumption (particularly for individuals that "drink a pot of coffee throughout the day") to see if this reduces spasticity, tightness, muscle cramps, and improves walking. One caveat: If someone is drinking a lot of coffee/tea/caffeinated beverages, we recommend that they discontinue caffeine gradually (reducing to 50% the first week, 25% the second week, and then switching to de-caf).

Gardening for the Handicapped

By Josh Spece

<http://www.inthecountrygardenandgifts.com/jspece/gardening/accessible.html>

Being in a wheelchair and loving gardening, it seems fitting to include a section on Accessible Gardening in my web site. Millions of people have physical limitations due to aging, injuries, or diseases. That DOES NOT mean we can't enjoy gardening in one form or another! As common as both disabilities and gardening are, you would think there would be more information available on handicap accessible gardening. What follows is a collection of articles I have written and links to other articles and resources on the internet. If you know of other resources that should be listed here, please e-mail me at jspece@sbtek.net.

“Handicap Accessible Gardening”

By Josh Spece - 1998

Many people enjoy gardening as a hobby, or even as a profession. When most people think of gardening, they usually think of someone down on their hands and knees on the ground. This doesn't have to be the case, though. People who have a disability can enjoy gardening just as much as everyone else. Raised gardens can bring the plants up to the people. There are a few things that need to be considered when making a handicap accessible garden.

The first thing to consider, is the construction of the raised garden. It should be a comfortable height to work at. Twenty-eight to thirty inches high is usually good. Second, it should not be too wide. If it is too wide, it will be hard to reach the center of the garden. Generally, it should be no more than two feet to the center, so a bed accessible from all sides could be about four feet across. Length doesn't really matter. It can be as long or as short as you like. The garden can be built with pressure treated two by

eight's with four by four posts in each corner. An easy alternative to building a raised bed is to use large pots. You can grow anything in pots, even cucumbers and tomatoes! An advantage to using pots is that they are portable, and can be easily moved. Once the raised bed is built it should be filled with good top soil or compost.

Next, you need to decide what type of paths to have between and around the raised beds. It can be left as grass, but it may be hard to maneuver a lawnmower down narrow paths. It can also be made of wood chips or mulch. A four to six inch layer will keep the weeds down, but it needs to be replaced every year or two. Wood chips may also be hard for wheelchairs to run on. Another option is pea gravel. This will also keep weeds down, but doesn't have to be replaced as often as wood chips. Once the gravel is compacted, wheelchairs should have no problem getting around on it. A more permanent alternative is a brick or stone patio built around the raised beds. This keeps weeds down, doesn't need to be replaced, and wheelchairs can easily get around on it. A disadvantage to this is that it is more labor intensive and expensive to install.

Once you have the raised garden built and easily accessible, you need to decide what to put in the garden. A good, foolproof choice is annuals. Annuals provide instant color and come in many shapes and sizes in a wide range of colors. Some good choices are petunias, marigolds, snap dragons, pansies, impatiens (if you have shade), and annual salvia. Put the tall plants in the center or back of the bed, and work your way down to the shortest plants in the front. Plants that drape over the side of the bed, such as lobelia and petunias, are good for the edge. Hardy perennials can also be grown in raised beds. Some good

choices are black-eyed-susans, ornamental grasses, hostas (if you have shade), daisies, dwarf iris, and creeping dianthus for the edges. It will take the perennials a year or two to get established, but after that they require very little care, and don't need to be replaced every year like annuals.

When your garden is planted, it will require very little care. When it is dry, or very hot out, give it a good soaking in the morning or evening, never during the hottest part of the day.

About once a month it is a good idea to fertilize your garden so it will keep growing strong and provide lots of flowers and vegetables. Once in a while it is a good idea to dead-head your flowers. This means to take off the old, dead flowers so the plants will continue to make new ones. That's about all there is to maintaining your raised garden

Other Internet Resources

[Enabled Gardening](#) Tending a garden can help your elder in more ways than one. By Donna Stone

[Backyard Habitat](#) Enabling the Disabled to Attract Wildlife at Home. By Michael Lipske

[Accessible Gardening](#) Bring Mother Earth Within Reach. By Lori Hungate

[Enabled Gardening](#) A collection of links by Deborah Simpson.

[I'm not getting older, I'm just getting stiffer](#) by Carol Wallace

[Gardening Tips for People with Arthritis](#) by Jennifer Hollander

[Gardening With the Elderly](#) Ohio State University Extension Fact Sheet by Jack Kerrigan

[Horticultural Therapy](#) Create an Enabled Garden by Joyce Schillen

[Gardening in Raised Beds and Containers for Older Gardeners and Individuals with Physical Disabilities](#)

by Diane Relf

[Recovery in the garden](#) by Filomena Gomes

Living Life with ALS: Motor Neurons as Mailmen

By Aimee Chamernik

Ed. Note: below are excerpts from an article in ALS Today. Aimee's explanation of motor neurons given to her five year old is very understandable.

"Mommy, why did your muscles stop working?" Emily asks, as I spread a glob of jelly on her peanut-butter-and-jelly sandwich. And so begins an impromptu discussion of ALS with a 5-year-old-no-warm-up, no lead-in, no warning this explosive question was on today's agenda. "Wellll. .." I begin, shamelessly exploiting my already-sluggish speech to buy more time. Anything to buy more time. . . How to explain motor neurons to this wide-eyed angel? How do I tell her mine are dying for no apparent reason? . . . As my mind races along I hear a calm voice-is that my voice?-matter-of-factly explaining how motor neurons are like mailmen. And while some of my "mailmen" are still delivering messages from my brain into my muscles, others have parked their mail trucks and are headed off on vacation to Florida without delivering their letters. Nothing scary about Florida, right? Sun, beach, palm trees, Disney World. And just as suddenly as it began, the conversation is over. She got what she needed, and now she's moved on. . .

National Center on Accessibility

<http://ncaonline.org>

NCA is an organization committed to the full participation in parks, recreation and tourism by people with disabilities, technical assistance, courses, information, resources, and maps of accessible trails.

National Center on Accessibility
501 North Morton Street - Suite 109
Bloomington, IN 47404-3732
Voice: (812) 856-4422
TTY: (812) 856-4421

Fax: (812) 856-4480
Comments: nca@indiana.edu
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National Association of Health Underwriters

The National Association of Health Underwriters has created a database that provides information on health insurance options for low-income U.S. residents and people who change jobs or have pre-existing health conditions. The Health Care Coverage Database can be accessed at www.nahu.org/consumer/healthcare (703) 276-0220

It provides a state-by-state list of public health insurance programs for low-income residents, such as Medicaid and SCHIP (the State Children's Health Insurance Program). It also lists 32 states that offer high-risk health insurance pools for those with pre-existing health problems. The database is presented in four parts: Employer-Based Health Insurance Coverage, Individual Health Insurance Coverage, Assistance for Obtaining Health Coverage and Health Care Coverage contacts.

New England Assistive Technology

Contributed by Dolores Carron
They have all kinds of assistive devices and will ship things if you are too far away. They are extremely helpful by phone. Don Hoeman is the person who takes care of the equipment. Their website is www.neatmarketplace.org and phone number is 1-860-243-2869. We held our last CT Connection meeting there and all were very impressed with their resources. They sell their used equipment (what has been donated and what they sell on consignment) for less than half price of new.

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Stages

Written by Thurza Campbell
Learning to live with a disease
takes time and thought and tears.
It's 'specially hard because I'm told
I'll get worse every year.

At first I just felt **disbelief**.

The doctor must be wrong!
"Give me a pill to fix my speech
so I can sing along
with Music Makers who're a part
of each and every week.
Please fix my feet so I don't trip
down many walks I seek."
I exercise and I eat right.
I'm careful what I do
to ward off disabilities.
I ask you, "Wouldn't you?"
But now two famous Boston docs
tell me it's PLS!
"And what the heck is that," I ask.
It surely causes stress.

And next I'm **mad** at everyone
who doesn't understand
that inside there's no change in me.
I do what 'ere I can.
I thought that I'd remain a friend
of folks I'd known so long.
But most folks see me strangely now.
Alone, I must be strong.
There is no time for empathy
in many peoples' lives.
It took me time to learn that life
can take a huge nose dive.
It's bad enough that I can't skate
or ski, or run or dance.
Now sharing times with others do
seem
rare- - I have no chance
to vent to friends and family
about my needs and loss.
Emotions all spin wildly now -
truly tempest tossed.

Then I become **depressed** sometimes
succumb also to **fears**
'bout what my future will be like
in the ensuing years.

I'm told by others I should view
my glass of life half full.
'Tain't easy though. I see their cheer
as just a bunch of bull.
A few folks still stand by me though.
They're treasures of pure gold.
Can I enjoy every day - -
not think 'bout growing old?
I've tried to manage by myself
but lots gets in my way.
I'll be determined not to cry
then I fail many days.

I needed help to move beyond
My fears and "downer" moods.
How to **accept** what I've become?
I guess I've not been good!
Thanks to insightful counseling
I now have useful tools
to slow or stop the spirals down
to help me stay real cool.
The other help for me has been
a Zoloft pill at night.
Now I don't know why that for four
years
I put up such a fight!
I hope I'll be more gracious now –
see me through others' eyes;
be more content with what I do;
change tears to only sighs.
I have been warned that I'll regress
as other losses come.
I may go through these stages more.
Some days I may feel numb.
But knowing that **acceptance** comes
with time, and help, and thought
might help it come more readily
than 'ere I thought it ought.
*Dedicated to Jim, Lissa, and other
loving family and friends.*

The TAO of DI # 32

[<dianamj100@hotmail.com>](mailto:dianamj100@hotmail.com)

Hi friends! Yes, I know I have been slow with the TAOs lately, but this has been the summer of "feel the fear and do it anyway" for me. A person adapts gradually to a disability, especially one that is unpredictable. This summer, however, various situations arose that gave me the opportunity to really push
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the envelope a bit.....to find out what my capabilities really are. I was able to see that, to an extent, I can disable myself more through believing that I am more limited than I really am. First of all, my mother, who lives in a nursing home in Kingston, Ontario, became very ill. It was touch and go. My first thought was "I must get there". My next thought was....."but I am in a wheelchair and disabled.....I don't know what my capabilities are....what if the trip is too fatiguing? What if I fall in an unfamiliar place? What if....what if.....what if? Yup...you guessed it. That creepy little voice of fear had me by the throat. That voice, in years gone by, prevented me from experiencing so much of life. It convinced me that "I can't". It limited my use of the many abilities and gifts that God gave me. In short, it stifled me in fully experiencing what it means to live. However, THIS was different. Mom, I believed, needed me. I have flown many times. I have visited my Mom many times. The difference this time was purely mental. Disabled people travel all the time. What was I afraid of? What was I really afraid of? Sure enough, it turned out to be an old theme: I am 'different.' I walk funny, I use a wheelchair a lot, sometimes I talk funny, sometimes I have to ask for help. Yuck! That was it alright. Her majesty the ego was at it again trying to get me to avoid facing a challenge and thereby, preserve face. Ego is a strange thing. Some say it is good to have a healthy ego, others say we must learn to rise above our ego and act on a higher level. I don't have the answer to the puzzle of whether the ego is helpful or not, but I know what I did; I rose above it and.....asked for help. Within 48 hours, I and my dear friend Sharon were on a plane bound for Ottawa. The ensuing 7 days were one experience after another of ignoring my ego (false pride), and

acting on the quieter, calmer higher self.

The flight attendants were only too happy to accommodate my wheelchair. Heck, they even pushed me right to the luggage claim in the new Ottawa terminal! And, of course, wonderful Sharon, who carried all that luggage, pushed me here there and everywhere and never as much as groaned or complained.

I had to ask for a ground level, 'handicapped' room at the motel.....which they smilingly provided without batting an eyelid. I even got myself behind the wheel of our rented car and drove through the heavy traffic of Kingston!

But, of course, Her Majesty the Ego tried to roar when the big challenge came: seeing, for the first time since I became disabled.....my family.

THAT was a challenge. I don't really know what the fear was rooted in.

Perhaps it was because they thought of me a certain way....so I reasoned.... the Di that burst into rooms at top speed and could do 15 things at once.

Perhaps I was afraid of their reactions.....of 'upsetting' them.

My fears vanished as I hobbled, with Sharon by my side, into Mum's room in the nursing home. She didn't see my disability.....she didn't look pained or scared. Even in her weakened state, her face lit up with a smile. She couldn't believe I had flown all that way

just to see her. I felt humbled. While struggling to breathe, she received me, not as a daughter who was disabled....but.....as "Di"....her daughter.

Later on, I had the wonderful experience of getting together with my sisters, and a dear friend of the family for a family supper at a Kingston buffet. Everyone was only too happy to assist me in filling up my plate. In fact, it made for a few hilarious moments. We laughed the evening

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away together as though nothing about me was different.

So....I did it! Or I should say, with the eager help of friends, family and a few strangers...I did it. Had I listened to my fears...my ego-self, I would have missed what turned out to be an incredibly wonderful experience, for me and for others. I also would have deprived those others of the chance to 'give'....to help another person.....always a growth producing experience.

My Mom began to perk up during our stay.....so thrilled was she that we had come all that way....just for her. Thank God that I listened to the 'quieter' voice inside me and not the loud reverberations of my fear-based ego-self.

Now the door has been opened. I helped my Mom....but my Mom helped me more. Because now I do not feel as 'disabled' as I thought I was. Hmmm, I wonder if maybe all of us are, just a tiny bit, disabled in some area as a result of Her/His Majesty the Ego? I plan to look deeper within myself to discover other areas that my ego-self over-rides my higher-self.....the one who can take wings and fly.

CAREGIVING

Respite Programs: National Organizations, Programs and Referral Sources

Respite care of varied duration can provide much needed breaks for primary caregivers. The organizations below offer services in many states. Query the sites, or call the numbers listed to find something that will mesh with your needs.

Easter Seals

230 West Monroe Street, Suite 1800
Chicago, IL 60606
800-221-6827

Web site: www.easter-seals.org

Easter Seals provides a variety of services at 400 sites nationwide for children and adults with disabilities, including adult day care, in-home care, camps for special needs children and more. Services vary by site.

Faith in Action

Wake Forest University School of Medicine
Medical Center Boulevard
Winston-Salem, NC 27157
877-324-8411

Web site: www.fiavolunteers.org

e-mail: info@fiavolunteers.org

Faith in Action is an interfaith volunteer caregiving program of The Robert Wood Johnson Foundation. Faith in Action makes grants to local groups representing many faiths who volunteer to work together to care for their neighbors who have long-term health needs. There are nearly 1,000 interfaith volunteer caregiving programs across the country.

Family Friends

National Council on the Aging, Inc.
409 Third Street, SW
Washington, DC 20024
202-479-6672

Web site: www.family-friends.org

This group provides respite (and other services) by matching men and women volunteers over the age of 50 with families of children who have disabilities or chronic illness. Programs are located throughout the country.

National Adult Day Services

Association, Inc.

8201 Greensboro Drive, Suite 300
McLean, VA 22102
866-890-7357

Web site: www.nadsa.org

This association provides information about locating adult day care centers in your local area.

National Respite Coalition

4016 Oxford Street
Annandale, VA 22003
703-256-9578

Web site:

www.archrespice.org/NRC.htm

NRC provides a list of states that have respite coalitions. These state coalitions then list respite services available in their state. The majority of the information is focused on helping families of children with special needs, but lately there has been an effort to enlarge their referral base to include lifespan respite information. The NRC is working to gain passage of national lifespan respite legislation.

National Respite Locator Service

800 Eastowne Drive, Suite 105
Chapel Hill, NC 27514
800-473-1727, ext. 222

Web site:

<http://www.respitelocator.org/index.htm>

Access a list of sites nationwide. While the vast majority focus on respite care for families of special needs children, the service now assists programs that provide respite for caregivers of adults and the elderly.

Shepherd's Centers of America

One West Armour Boulevard, Suite 201

Kansas City, MO 64111

800-547-7073

Web site: www.shepherdcenters.org

e-mail: staff@shepherdcenters.org

The organization provides respite care, telephone visitors, in-home visitors, nursing home visitors, home health aides, support groups, adult day care, and information and referrals for accessing other services available in the community. Services vary by center.

**MEDICAL RESEARCH
UPDATES**

**Review of Research published Fall,
2005**

Compiled by Mark Weber

I. More research was done on the effectiveness of treating spasticity in children who have cerebral palsy with botulinum toxin.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=16225811&dopt=Abstract

II. Two Italian teams reported significant progress in treating HSP in animals.

a. Dr. Rugarli used gene therapy to not only stop the progression of the HSP (caused by mutations in the Paraplegin gene), but to actually partially cure the existing degeneration—in mice. View the free PDF of this article at:

<https://www.the-jci.org/article.php?id=26210>

b. Dr. Daga and colleagues in Italy report successful drug treatment of the most common type of HSP (caused by mutations in the SPG4/Spastin gene) in a fruit fly model of the disease.

<http://www.jci.org/cgi/reprint/115/11/3026>

III. Several research teams have reported advances in understanding the role of Spastin in causing the most prevalent form of HSP. Titles of the articles, and link to abstracts follow:

a. Human spastin has multiple microtubule-related functions

http://www.ingentaconnect.com/search/article;jsessionid=188ic1oohbz43.henrietta?title=spastic+paraplegia&title_type=tka&year_from=1998&year_to=2005&database=1&pageSize=20&index=3#avail

b. Spastin mutations in sporadic adult-onset upper motor neuron syndromes.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=16240363&dopt=Abstract

IV.

a. A new review of Infantile-Onset Ascending Hereditary Spastic Paralysis and Juvenile Primary Lateral Sclerosis has been created at the GeneReviews website. These

conditions are very closely aligned and form a continuum.

<http://www.genetests.org/servlet/access?db=geneclinics&site=gt&id=8888891&key=EeRR2zDlzUZpH&gry=&fcny&fw=XEa9&filename=/profiles/iahsp/index.html>

b. New research on this disorder was also reported at:

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=16321985

V. MIT researcher discovers that neurons in the adult brain do grow—contrary to the prevailing belief that they don't. This finding means that it may one day be possible to grow new cells to replace ones damaged by disease or spinal cord injury.

<http://www.sciencedaily.com/releases/2005/12/051227111212.htm>

VI. ALS progression stopped in mice reported by Japanese team.

Our findings clearly prove the principle that siRNA-mediated gene silencing can stop the development of familial ALS with SOD1 mutation.

J Biol Chem. 2005 Oct 12

Full text available for FREE at

<http://www.jbc.org/cgi/reprint/M507685200v1>

Stem Cell News from Project ALS

When most of us think of stem cell therapy, we think of stem cells from other sources being transplanted or implanted. But what about our own stores of stem cells, the ones already residing in our bodies? Can these so-called adult stem cells be recruited for therapeutic purposes?

In conjunction with Project A.L.S., researchers at the Salk Institute and Columbia University have begun to identify stem cell strategies to promote neuronal differentiation from adult stem cells residing within the spinal cord. The Salk's Fred H. Gage and Samuel Pfaff are manipulating gene expression in the spinal cord to

determine if we can control the production of neurons and support cells, and to see if we can direct adult stem cells to acquire motor neuron properties.

In a related set of experiments, Project A.L.S. is funding the Salk's Christopher Kintner and Thomas Jessell, a Howard Hughes Medical Institute investigator at Columbia University, to analyze the frog spinal cord for clues on how to elicit motor neuron generation in humans, and eventually in patients with ALS. What allows the tadpole to develop hind limbs at a later stage of development? Whereas humans develop motor neurons once, during very early stages of embryogenesis, frogs generate motor neurons for a much longer period. Frogs appear to have a sort of "time-release" program for motor neuron generation. The Kintner-Jessell study aims to identify this program in the frog, with an eye toward creating new opportunities for motor neuron regeneration in people with ALS, spinal cord injury, and related neurodegenerative disorders. To date, the Project A.L.S. stem cell team has shown compellingly that an embryonic stem cell can be directed to become a functional motor neuron—the very cell destroyed in ALS—and that these stem cell-derived motor neurons are capable of growing out processes, or motor axons, toward target muscles, connecting with and stimulating them.

Now, through funding by Project A.L.S. and the HHMI, Thomas Jessell and colleagues have cracked the code for motor neuron wiring, deciphering a key part of the regulatory code that governs how motor neurons in the spinal cord connect to specific target muscles in the limbs.

What guides one motor neuron to connect to a leg muscle, rather than to, say, a muscle controlling swallowing? Jessell's groundbreaking paper,

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appearing in the November 4, 2005, issue of the journal *Cell*, suggests that the guidance code—which involves members of the family of transcription factors encoded by the Hox genes—may allow us to develop specialized motor neurons from stem cells.

PLSers Help Needed

Contributed by Mark Weber

If you have been diagnosed with PLS, your help is needed. Because PLS is (almost always) a sporadic condition, research to determine the cause (and then cure) has been a tough road.

(Compare to HSP where the technology exists to discover mutant genes, their protein products and then the chemical cascade in which the protein plays a role.)

That may have changed. Researchers have discovered abnormal substances in the blood plasma and spinal fluid of sporadic ALS patients. (See the recent research in this issue about ALSA funded research using spinal fluid.) The same could be done for PLSers.

Not enough blood and spinal fluid has been collected in the PLS Registry at Northwestern University to allow this type of work to proceed. With your help, this can change. The PLS Registry needs your blood and a tiny amount of your spinal fluid. (If you just can't tolerate another spinal tap, just your blood is OK. But if you can, your spinal fluid would be great.) If you are currently being "worked up" for a diagnosis, and haven't had a spinal tap yet, you'll only need one test. When they do the spinal tap for diagnostic purposes, they'll need to take a small amount more, and send that to the PLS Registry. If you've already had a spinal tap, consider having another. None of this will cost you a cent. Just your time and a two needle sticks.

Please consider donating your blood and spinal fluid to the PLS Registry.

All of the money in the world won't result in a PLS cure unless PLSers help. Without PLSers' blood plasma and spinal fluid, the research can't be done. The answers won't be found. Please contact Nailah Siddique at the PLS Registry at nsiddique@northwestern.edu or (312) 503-2712 to volunteer for this crucial research project. Nailah will send you everything that you need.

Ed. Note: Be sure to allow plenty of time to get agreement from the hospital or clinic drawing your fluid to draw fluid, freeze it and ship it to NWU, as well as the proper original signatures on documents from NWU. Have everything in hand before your spinal tap. The legal protocols are very specific about process.

ALSA-Funded Biomarker Research Shows Promise

Contributed by Lisa Paige

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<http://www.metabolon.com/>

Ed note: In a recent PLS Friends posting Lisa brought this to our attention. I am scheduled to have a spinal tap at MGH on January 23 as part of this study. At the same time, I am having CSF drawn for the PLS registry at NWU.

<http://www.alsa.org/news/article.cfm?id=815>

Roberta Friedman, Ph.D., ALSA Research Department Information Coordinator

The ALS Association (ALSA) announced continued funding to support an ongoing consortium effort to find biomarkers that indicate the presence of amyotrophic lateral sclerosis (ALS, also called Lou Gehrig's disease). The project has already produced a candidate panel of molecules in body fluids that differ between people with the disease and those who do not have ALS.

A predictive panel of biomarkers would allow more rapid and accurate

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diagnosis for patients who often undergo months of tests and uncertainty before finding out whether they have ALS.

Investigators who are part of the consortium recently published initial findings on protein candidate biomarkers and plan to follow up to expand the number of samples tested and identify the marker molecules (see <http://www.alsa.org/news/article.cfm?id=794>.)

Investigators in the consortium include Merit Cudkowicz, M.D. and Robert H. Brown, Jr., M.D., Ph.D. of Massachusetts General Hospital, Lisa Paige, Ph.D. of Metabolon, Inc., Rima Kaddurah-Daouk, Ph.D., now at Duke University, and Robert Bowser, Ph.D., University of Pittsburgh.

Biomarkers include proteins whose levels differ between the healthy and disease state. They also include the products of metabolism, small molecules that differ in the disease state as compared to healthy individuals. Not only would biomarkers serve to diagnose ALS earlier with more certainty, they would allow better clinical trials of new therapies for the disease. "We are hopeful that biomarkers for ALS will also lead to new insights into the mechanisms of disease and help guide development of new drug therapies," said Robert Bowser, Ph.D., University of Pittsburgh, an investigator on the project.

Study investigator Merit Cudkowicz, M.D. said that "finding disease relevant biomarkers for ALS is important for several reasons. It will help us to understand disease mechanisms and also may provide a tool to allow more efficient and rapid testing of new therapies in people with ALS."

The collaborating company, Metabolon, has identified 12 molecules that might serve as

diagnostic markers for ALS. “Data obtained in the first phase of this project demonstrates the power of metabolomics and how metabolomic technology can be used to generate biomarkers for disease diagnosis,” said John Ryals, Ph.D., president and CEO of Metabolon. “These innovative studies will lead to novel diagnostic measures for ALS and identify potential therapeutic targets for drug design.” Metabolon is an industry leader in the discovery of biomarkers through the use of metabolomics. For additional information, visit www.metabolon.com.

Methods now available make it possible to analyze very small amounts of fluid. Charged surfaces of protein binding chips can separate all the different proteins found in the blood or the cerebrospinal fluid (CSF) that bathes the brain and spinal cord. Investigators in the consortium use mass spectrometry to analyze proteins that bind to each chip surface and have determined that certain molecules are decreased in CSF in the disease, and others increase. They found that a set of 19 proteins has potential as a biomarker panel for ALS.

The investigators will continue testing samples with a focus on CSF, since the highest level of biomarkers may occur there. They will focus on biomarkers detected in ALS patients that have not received Riluzole, since a diagnostic for ALS will likely be used for people not yet receiving an ALS medication. Importantly, the researchers will seek the identity of the protein and metabolic biomarkers that appear to be specific to ALS. This will help explain the molecular reasons for the disease and inform the search for potential drug treatments.

Additional study participants, including both ALS patients and those who do not have ALS, are sought. For further information on participating, please contact Robert Bowser at 412-Synapse – Winter 2006

383-7819 or Emily Welsh at 617-726-0563.

PubMed

Link: http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=16191107&query_hl=10

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EVENT PHOTOS

Winner drawn for Turning Leaves Quilt November 15, 2005



The lucky winner is Larry Asbury who lives in NC. Helping Linda Gentner with the raffle drawing are neighbors Sarah & Eveline who are from Ontario, Canada. The lovely quilt, made by the Callico Friends Quilting Club in Canada, raised \$1680 for the SP Foundation.

Colorado SP Connection Louisville, CO October 1, 2005



A group of 11 SPers heard Chiropractor Paul Austin speak on need for body symmetry, nutrition and exercise

Southwest Connection & TeamWalk Tempe, AZ October 23, 2005



TeamWalkers at start of the 7/8 mi. course through Kiwanis Park.

Vancouver TeamWalk Vancouver, BC September 10, 2005



Canadians share experiences after their TeamWalk.

Tennessee Connection & TeamWalk Nashville, TN October 22, 2005



TeamWalkers gather on the Greek Parthenon (replica) steps.



A connection meeting followed the TeamWalk.