

# Synapse

Volume 11, Issue 1 January, 2008

*Newsletter of the Spastic Paraplegia Foundation*



## **SPF National Conference Valley Forge, PA**

**Date:** June 6-7, 2008

**Hotel:** Valley Forge Crowne Plaza. The group rate for SPF is \$109/room. 9 h/c rooms are reserved for SPF. Reserve online at <http://www.cpvalleyforge.com/reservations.asp> or call 610-265-7500.

**Program:** The Conference will begin with an arrival dinner on Friday night. One of the  
Synapse, Winter 2008

keynote speaker will be SPF Grant recipient Dr. Peter Baas of Drexel. Dr. Fink, our SPF Medical Advisor, will be at the meeting. The website will be updated as other conference speakers and programs are confirmed. The first 20 people to register for the Conference will receive a video prepared by the German HSP group at their 2007 meeting. The video features a Physiotherapist working with 3 HSP patients demonstrating different therapy modalities.  
**Contact:** Anna Bonnani [annabonanni@hotmail.com](mailto:annabonanni@hotmail.com) or Jim Sheorn [jimsheorn@comcast.net](mailto:jimsheorn@comcast.net) for more information.

### **Nearby tourist options:**

Valley Forge National Park

<http://www.nps.gov/vafo/> has wheelchair accessible trolley tours of the park.

Independence Hall and the Liberty Bell

<http://www.nps.gov/archive/inde/indep-hall.html>

### **President's Letter**

Happy New Year!

We are proud to announce that our sixth year brings *Synapse* as the official Spastic Paraplegia Foundation (SPF) Newsletter. It will provide information on Connections, Research and human events in our community. *Synapse* will continue to be available online. You will find the subscription form to receive the print version included in this issue. *Synapse* is published quarterly. Please return the form included with the envelope to receive future issues.

Plans are underway for the 2008 SPF National Conference that will be held on June 6-7 in Valley Forge, PA. Dr. Peter Baas of Drexel, one of our most recent grant recipients, has agreed to speak at the meeting. Dr. Fink, our Medical Advisor, will also be at the meeting.

In 2007, approximately \$420,000 was raised through various SPF events. TeamWalks

raised about \$168,000. Other major revenue generators were: 2007 mailings (\$70,000), Loop for Life (\$33,000) and ExxonMobil Charities Campaign (\$28,000). Donations received during 2007 that were not associated with an event brought in another \$64,000. Watch for the 2007 Annual Report which will contain additional details.

On [Page X](#), you can read about the introduction in Congress of a resolution to establish February as PLS Awareness Month. For this to be brought to a vote, 100 Congressman are needed to co-sponsor this. We need your help to make this happen. Please contact your Congressman and ask him to co-sponsor **H.Res.896**.

On January 11<sup>th</sup>, the Request for Proposal for 2008 research grants was sent to researchers. On [Page X](#), you can read the details, submitted by the SPF Research Grant Committee, chaired by Mark Weber.

In February, the SPF Board of Directors will hold elections for officers and members. Please welcome Mike Podanoffsky who will be joining the board. Mike, a Principal System Architect, brings a wealth of computer networking experience to the board. Jim Sheorn as the President Elect will become the new President. Currently we have two openings on the board so if you are interested please contact me.

Our sincere thanks go to Thurza and Jim Campbell for their remarkable efforts on *Synapse* as well as the sometimes tedious work of maintaining the website designed by Frank Reyerse.

Since the start of the foundation in 2002, I have had the pleasure of meeting and speaking to so many of you. I want to thank everyone for their help and support over the past three years. Although I am stepping down as President, I plan to remain active on the board and continue to raise monies for research as I am convinced that a cure is within reach.

*Annette Lockwood*

## **Synapse** **Volume 11, Issue 1 January, 2008**

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

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Published quarterly for the HSP/PLS community  
Available online at [www.synapsePLS.org](http://www.synapsePLS.org)

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SPF Board of Directors: Annette Lockwood, President; Linda Gentner, Vice President; David Lewis, Treasurer; Frank Davis, Secretary; Members: Larry Asbury, Kris Brocchini, Jean Chambers, RN, Malin Dollinger, M.D., Jim Sheorn and Mark Weber, Esq.  
SPF Medical Advisor: John F. Fink, M.D., University of Michigan

### **Disclaimer**

The Spastic Paraplegia Foundation does not endorse products, services or manufacturers. Those that are mentioned in *Synapse* are included for your information. The SPF assumes not liability whatsoever for the use or contents of any product or service mentioned in the newsletter.

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## SP FOUNDATION NEWS

### SPF Request for Proposals, 2008

During 2008 the Spastic Paraplegia Foundation (<http://www.spfoundation.org>) will be awarding research grants searching for causes, therapies and cures of Primary Lateral Sclerosis (PLS) and Hereditary Spastic Paraplegia (HSP). A listing of the \$1.5 million in previously funded grants is available at (<http://www.spfoundation.org/assets/pdf/SPFGrantSummary.pdf>)

Individual grants up to \$60,000 per year will be awarded for one and two year proposals. Proposals on any aspect of Hereditary Spastic Paraplegia (HSP) or Primary Lateral Sclerosis (PLS) will be considered. We have changed some elements of both the scope and the timing of our grant process this year:

1. Our goal is to provide half of the award funding to each of the disease targets. To achieve this goal, the Board of Directors has voted to create dual evaluation tracks. PLS proposals will not compete against HSP proposals. As in previous years, proposals benefiting both diseases will also be considered. Make clear in your proposal into which track your proposal fits: HSP, PLS, both.
2. A new category of applications being considered is Starter Grants. Starter Grants are one-year awards for new investigators entering the field proposing innovative and novel

projects. Alternatively, Starter Grants can be pilot studies by established investigators. These applications do not require strong preliminary data but must emphasize novelty, feasibility, innovation and relevance to HSP or PLS.

3. The deadline for applications is March 31, 2008.

The application process is outlined in a PDF document titled “2008 Research Grant Guidelines”. It may be found at our website, (<http://www.sp-foundation.org>) We hope that readers will consider forwarding this RFP information to their neurologist, and any others who you think might apply.

Research Grant Committee  
 Mark Weber, Chairman  
 Jim and Thurza Campbell  
 Jean Chambers  
 Malin Dollinger  
 Jeff and Sarah Rogers-Witt  
 Don Wilson

### Congressional Legislation Introduced for Hardy Brown – PLS Awareness Month: your help is needed now

Congressman Joe Baca (D-Rialto, CA) introduced legislation to bring greater awareness to the neuromuscular disease Primary Lateral Sclerosis, or PLS. The resolution encourages Americans to recognize February, in conjunction with Black History Month, as Hardy Brown – Primary Lateral Sclerosis Awareness Month. The awareness month would be named in honor of Inland Resident and co-publisher of the *Black Voice News*, Hardy Brown – who is afflicted with PLS. “I introduced this legislation because many Americans are unaware of the severe nature of PLS,” said Rep. Baca. “We need to recognize the courage of the brave men and women who endure through this condition, while at the same time work to encourage greater awareness and better funding for research and treatments.”

Please contact your Congressional Representative. Ask him or her to become a

co-sponsor this important bill, **H. RES. 896**. To find your Representative go to, <http://www.congress.org/congressorg/directory/congdir.tt> then type in your Zip Code.

## EVENTS

*Compiled by Sarah Rogers-Witt, Events Editor*

### TEAMWALKS STEPPED IT UP IN 2007

The 2007 SPF TeamWalk season officially closed on Sunday, October 21<sup>st</sup> in Nashville, TN, and what a season it was. Between mid-August and late October, 11 TeamWalks were held across the United States. Those events added nearly \$160,000 to the Foundation's coffers.

#### October 19-20 - Houston, TX

The Texas Two Step TeamWalk in Houston, which was organized by Brad Hendricks, was an enjoyable weekend. We started with dinner Friday evening. About 15 people attended. On Saturday morning, 32 participants met at the park for the TeamWalk. A granddaughter of one participant had TeamWalkers sign their names on the back of her t-shirt. She proudly wore it as she walked with her grandfather and other family members. Two families had a reunion of sorts, with many relatives in attendance. It was good to see the family support. One couple drove from the Dallas area to Houston, which is at least a seven-hour drive one-way. They made the round trip in one day!! This was their first contact with others going through the same changes in life.

To me, this is an important part of TeamWalks and lunch connections. I remember my first time meeting others, and it changed my approach in dealing with a rare disorder. - *Marlene Doolen*

#### October 21 - Nashville, TN

We completed the 3rd Annual Nashville TeamWalk and 1st Annual 2 Steppin' to a Cure on Sunday, Oct 21st. We had a small group for the TeamWalk Connection;

however, three families were attending for the first time. One was dealing with PLS and two with HSP. More than 150 people came out for 2 Steppin' to a Cure. We hope to find a location next year that has Friday or Saturday night available so more people will be able to attend. Thanks to Terri McDonough for helping to make this event happen. - *Jim Sheorn*

### UPCOMING EVENTS

#### 2008 SPF National Conference

June 6-7, Crowne Plaza, Valley Forge, PA  
Hear from leading experts about cutting edge research and meet others dealing with similar challenges. Details in the SPF section

#### Colorado Connection

January 26, 10 am, Saint James Parish Hall, Denver

Dale Rutschow: [dalerutschow@comcast.net](mailto:dalerutschow@comcast.net);  
Deacon Dennis Morales: [dipnote@msn.com](mailto:dipnote@msn.com)

#### Seattle Connection

February 23

Details pending.\*

Jackie Bollinger: [seattlehspjackie@aol.com](mailto:seattlehspjackie@aol.com)

#### Florida Spring Connection

March 8 or 9, Tampa Bay Area

Details pending.\*

Kathi Geisler: [kathi@kgeisler.com](mailto:kathi@kgeisler.com) or 978-256-2673

#### New England Spring Seminar

March 29, 9 am to 3 pm

Best Western Hotel, 380 Winter Street, Waltham, MA, 781-890-7800

Registration: \$25 per person

Featured speaker: Jeffrey D. Macklis, MD, D.HST; Director of the Harvard Stem Cell Institute, Mass General Hospital/Harvard Medical School Center for Nervous System Repair and recipient of a 2006 SPF Research Award. Dr. Macklis' talk is entitled:

“Growing, Protecting, or Repairing Corticospinal Neurons is Complex: Assembly Instructions Required; Molecular Development and Repair of Corticospinal Motor Neuron Circuitry”



A Friday Arrival Dinner will be organized for those who are interested.

Kathi Geisler: [kathi@kgeisler.com](mailto:kathi@kgeisler.com) or 978-256-2673

Though we have just entered 2008, it's never too early to start planning your own fund-raiser. Linda Gentner will once again be the TeamWalk Coordinator. She can provide guidance and put those who are interested in touch with veteran TeamWalk leaders. Linda can be reached at [Linda@Gentner.com](mailto:Linda@Gentner.com) or at 510-651-5676. Let's put even more feet (and wheels) on the street this year.

#### **Abilities Expo**

March 28-30 New York Metro

May 30-June 1 Southern CA

September 12-14 Minnesota

[Abilities Expo](#) showcases the latest products and services to enhance the lives of people with disabilities

#### **Medtronic Movement for Living**

##### **Teleconferences:**

##### **Spasticity Management**

February 12, March 11, and April 8 (pediatric focus), 7 pm EST

Registration: 1-888-743-8348 or

[https://www.medtroniceducation.com/kma/www/itb\\_mfl/3.listing.html](https://www.medtroniceducation.com/kma/www/itb_mfl/3.listing.html)

Medtronic officers free educational teleconferences during which a doctor will discuss severe spasticity, explain how the intrathecal baclofen pump works, and answer patient questions.

\*Check <http://www.sp-foundation.org/calendar.htm> for details as they become available or contact event organizer.

## **LIVING WITH HSP/PLS**

### **Timely Tips to Help Limit your Tax Liability**

*Excerpted from an article by Bill Norman in MDA/ALS Newsmagazine, Vol 13, No. 1*

[www.irs.gov](http://www.irs.gov) contains a wealth of information. You can search for current publications by topic or keyword; download tax forms (including Form 1040), publications and instructions; research your tax questions; and electronically file your return.

If you don't have Internet access or prefer to speak to a living person at IRS, you can order forms, publications and instructions by calling toll-free (800) 829-3676. To ask questions about your particular tax situation, call (800) 829-1040. If you use TTY/TDD equipment, call (800) 829-4059 to both order forms and ask questions. The IRS Web site also contains contact information for IRS offices in your state. Below are explained some publications for the disabled.

***Publication 501: Exemptions, Standard Deduction, and Filing Information*** for definitions of "qualifying." Age restrictions apply in some cases, but not for a child of any age who is permanently and totally disabled, and who lived with you for more than half the year.

***Publication 502: Medical and Dental Expenses***, In addition to medications and professional care, you may be able to deduct the cost of transportation to medical care; medically connected improvements to your home; and the cost and maintenance of a wheelchair. Health insurance premiums, nursing care and dental treatment are other possibilities.

***Publication 503: Child and Dependent Care Expenses***. If you provided care for more than half the year to a spouse, you may be able to exclude from your income up to \$5,000.

***Publication 524: Credit for the Elderly or Disabled*** If you're under age 65, you must have retired on permanent and total

disability; have received taxable disability income; and not reached the mandatory retirement age established by your former employer.

**Publication 525: Taxable and Nontaxable Income**, No benefits you receive from the Veterans Administration — including disability, education and grants for homes designed for wheelchair living — need to be counted as income.

**Publication 529: Miscellaneous Deductions.** If you're still working (even at home), you may be able to deduct the cost of attendant care at your workplace, plus other expenses necessary for you to work, such as speech recognition programs, adapted keyboards, special telephone equipment, etc. Some have had success deducting the cost of attendant care needed to get *ready* for their workday, arguing that they can't work without it. These expenses are not subject to the cap imposed on normal work-related expenses.

**Publication 596: Earned Income Credit**, This tax credit, designed to benefit low-income families, is for qualified people who work and have earned income less than an annual amount determined by the IRS

**Publication 907: Tax Highlights for Persons with Disabilities.**

**Publication 910: Guide to Free Tax Services**, contains a list of such tax assistance and education programs.

**Publication 3966: Living and Working with Disabilities/Tax Benefits and Credits.**

## Small World Stories

*Aussie Maureen*

In the early 70's, there was a very popular cartoon show in Australia, that was hosted by a guy called "Skeeter". Everyone my age used to watch it after school. He was the entertainment director on the cruise I went on when I was twenty. He went on to some fame and fortune by writing many books and taking over the drawing and writing of a very popular Aussie comic strip called "Ginger Meggs", which is printed worldwide. Last August I got the shock of

my life when he registered at an ALS site called OZPALS for Aussie and New Zealanders. He has ALS! I wrote to him. His ALS started with bulbar palsy and he was unable to speak anymore. Recently he went to India for stem cell treatment but had to cut the trip short as he developed breathing and swallowing problems. He now has a peg and constantly on a breathing machine and not doing well at all.

*Dolores Carron*

Back in the summer of 2000 I was at the pool where I had been going to exercise and saw a man who walked with a spastic gait. When I inquired about his condition and was really surprised to find he also had Primary Lateral Sclerosis. It was Frank C. He already had the preliminary plans made for that first 'Connection', so he asked me to co-chair it with him and the first CT Connection was held in October 2000.

*Kathi Geisler*

A HSP/PLSer flew into Regan Airport on his way to NIH. In the men's restroom he bumped into my husband Ed. They recognized one another from Connections and Conferences, and said hello.

## Gary Pinkel- His Story

*Excerpted from*

[http://www.attcottonbowl.com/news\\_room/releases.php?uid=183](http://www.attcottonbowl.com/news_room/releases.php?uid=183) and <http://www.columbiatribune.com/2007/CottonBowl/>

The nation's football fans all know about Missouri Coach, Gary Pinkel. Gary Pinkel is now 122-74-3 (.621) overall at the conclusion of his 17th year as a college head coach and 49-37 (.570) at Mizzou. His latest win was the New Year's Day Sugar Bowl. Pinkel is more than a successful coach. He's a part of the HSP community. Here's the story of how he draws on family values as he deals with his siblings' HSP. Gary Pinkel was born and raised in Ohio with an older sister, Kathy, and a younger brother, Greg. "We were a middle-class home. My mom and dad were very value-oriented. You

always got verbal lessons like, 'If you've got nothing nice to say, keep your mouth shut.'

The relationships that perhaps define Pinkel's character best are those with his siblings. When Kathy was in high school, she began having trouble walking, experiencing the first signs of hereditary spastic paraplegia. Eventually, Kathy required a wheelchair. When Pinkel was just starting high school, he remembered walking with Kathy, whose symptoms had just started to develop. "She walked with her feet in, and I remember people staring at her," he said. "I loved her to death, so I'd stare them down. I'd flat-out stare them down until they wouldn't look at her anymore." The disorder never afflicted Pinkel. Instead, he was anything but crippled. He blossomed into a star athlete in college.

Pinkel's senior year in college, he married. The same year he learned that Greg was also suffering from HSP. Soon after the diagnosis, his parents filed for divorce. He assumes the pain of Greg's diagnosis was too much to bear. "I just don't think they could handle the pressure of that happening," Pinkel said. "... First they had my sister, and they worked through that. Then there was me, and everything was fine and dandy. Then all of a sudden, bam, here we go again. That's what I really think it was, because they're both great people. Unfortunately, it happened."

Pinkel dealt with the diagnosis differently. He internalized the pain, questioning what he had done to avoid the disease. "That was just emotionally very difficult for me personally," he said. "I felt like the chosen one. So I went through a lot with that."

"He's always been very supportive and helpful," Kathy said. "But how he feels deep down in his gut? I'm sure there are moments when he wonders, 'Why did I escape? Why didn't they?' I think he's chosen to go on with his life and still be a part of my life and my family's life."

Disease and divorce didn't cripple the family, though. Both parents remarried soon after, and both sides reunited around their common cause: football. "Football kind of brought us all back together," Pinkel said. "They all came to games, and we kind of had a rule that it's all about the family and none of those other issues."

His brother, Greg, died in 2005, a day before he would have turned 47. Brother and sister remain extremely close. "She's always been remarkably inspiring to me, because how she's graduated college, she's got kids and she's never complained about anything once in her life," he said. "I get players that come in here and tell me how tough it is getting up to go to a class, you know. That doesn't go over very well. 'Don't tell me about your problems. Those aren't problems.' "

As Pinkel reflected on his past, he was asked why is loyalty the one word that seems to define his character and career. "I don't know," he said. "As a friend, I try to be very considerate and loyal. I guess in relationships, it's all about trust. ... Now I'm wondering why I am so loyal? I guess it's just the makeup of who you are. Sometimes you can look back and ask, 'Why do you try to be respectful?' Well, I do because of my mom. It's what I was taught. I'd like to think that I'm not a whole lot different from when I was in college as far as being around people."

## **Turn your Toilet into a "Bidet"**

*Contributed by Don Wilson*

There are many models of bidets that basically replace the seat on a standard toilet. There is a range of features and also a wide price range. Some have remote control. I found a number that were comparable. Each offered a heated seat and heated air for drying. Two of the three had two wands for washing, the other only one, and in all cases the wands are self-cleaning. I learned that "high end" was best for us. After trying another brand, we now have a Tres Bien made by Takagi.

Installation was very easy. The seat of the toilet is removed and a docking plate is attached in its place. Then the bidet unit locks in place. It is easily removed for cleaning if necessary. The water supply valve is installed in the line feeding the toilet tank. While some models suggest installation to a standard grounded 110-120 volt circuit, others (and I) strongly suggest that a GFCI (ground fault circuit interrupter).

The temperature of the seat, the cleansing water and the drying air is adjustable at three levels. The seat has a sensor to insure that the bidet works only when someone is sitting on the seat. There is even an alarm that can be sounded in the event of problems.

Here is Bettie Jo's testament, a few days after I installed hers: "Morrie Schwartz (Tuesdays with Morrie) made the memorable statement that the thing he hated most about having ALS was that someday someone was going to have to wipe his ass, and it would be soon! I shared that fear. I was using a variety of products for personal hygiene, all with less than satisfactory results. At the risk of sharing "too much information" by day's end I was afraid that I smelled like a diaper pail. "Don had talked about getting a bidet for years but I always resisted. I was hesitant about the expense. I also had my doubts about effectiveness. I did not think that a stream of water without any sort of cleaning solution would be effective. I was wrong! My bidet, affectionately known as my "butt washer", surpasses my wildest expectations. "My bidet uses a gentle stream of warm water to wash. It has a warm air dryer as well. It does such a thorough job that I don't know how I functioned without it."

<http://www.juscuzz.com/handicapped.asp>

\$289.00 with a water heater

<http://www.biffy.com/> \$99.95 + \$59. for a water heater adapter; uses no electricity

<http://www.sanicare.com/> carries several brands, range of prices

<http://www.sandman.com/intimst.html>

\$449.95

<http://www.lubidet.com/> \$ 420. no specs at site

<http://www.totousa.com/> free standing bidet, as well as adapted toilet seat

<http://www.biobidet.com/> various models, up to \$499.

<http://www.fresh-seat.com/tresbien.html> various models up to \$697.

### Access Adventure

<http://www.access-adventure.org/>

For Michael Muir contact: 707.432.0150

Imagine the boundaries of your life defined by a wheelchair...Now think what it means to gain access back into nature, to go places you once thought out of your reach. Access Adventure is a unique program that uses wheelchair accessible horsedrawn carriages to provide open space recreation and wilderness access for people living with the challenges of disability. The program is open to people of all ages with compromised mobility, not just wheelchair users, and there is no charge to participate.

Access Adventure is about freedom. When we are not limited by the challenges we face, we are free to challenge our limits. February 16 and March 15 Carriage Rides, 4-H, & Blacksmithing demonstrations, Rush Ranch, 10 am - 1 pm

April 9-13 "[Wildflower Wingding](#) (and Four-In Hand Frolic)", [Ft. Hunter-Liggett](#), Los Padres National Forest

April 19 [Earthday/Birthday](#), John Muir Historic Site, Martinez

April 26 "[Rush Ranch Days](#)" and The Horse Show, Rush Ranch, Suisun City

"We focus on what is possible, not on what we have lost. The worst disability is a bad attitude."

Michael Muir, Director Access Adventure

### PLSer to Donate Proceeds of his Novel to MDA

*Contributed by the author, Marvin Wiebener*  
[marvinwiebener@yahoo.com](mailto:marvinwiebener@yahoo.com)

I recently published a novel titled The Margin. It is a contemporary mystery set on a ranch in northwest Oklahoma. The Margin



has had a decent run on Amazon, but I'm not yet satisfied with its sales. Here is the reason why. I was finally diagnosed with PLS in 2001, after a few years of going to one specialist after another. Many of you can identify with that, I'm sure. I retired shortly after the diagnosis--I could still walk then--to pursue my life-long desire of becoming an archaeologist (amateur). It wasn't long after my retirement that I realized I'd never be able to master the physical requirements of such an avocation.

About that time I began seeing a neuro-muscular physician at the MDA/ALS Division clinic in Oklahoma City. The doctor and staff were, and still are, very, very helpful in ways I never imagined. I had always thought that the Muscular Dystrophy Association dedicated their services to children only, but that isn't the case. My wife and I make yearly contributions to MDA, a few dollars here and a few more there, but knowing now what all they do prompted me to dedicate the proceeds from my novel, The Margin, for the first year it is in production, to the MDA. To that end I'm enclosing my website for you to look at it. If you are interested in a good mystery go to <http://outskirtspress.com/TheMargin>

Synopsis: Just after the Korean War, Fred Gray, a veteran and third-generation Oklahoma rancher, headed to the county courthouse to perform a land-record search on his property. In an old journal recording official events as far back as 1893, Fred found a handwritten drawing next to an entry made by his grandfather around the turn of the 20th century. He was curious about the drawings, but then marriage came, children were born and raised, and a living had to be made.

Fifty years later, Fred asks the county clerk to make a copy of that journal page so he can study it more closely. He remembered a story his grandfather told him when he was a child, and although the years dulled the specifics of his grandfather's tale, he recalled it involved a family heirloom, a single gold candle stick. The candle stick,

his grandfather Jeremiah's story and the drawing come together to reveal a 400 year old secret that pulls the rancher and his family into a succession of mysterious and terrifying events.

The Margin is available from Amazon. Please access Amazon via the SPF shopping mall, so that SPF will also benefit from the sale. <http://www.spf-foundation.org/shopping.htm>

### **My Aha Moment**

*By Thurza Campbell*

'Twas just a simple question that  
My friend had posed to "T".  
She asked if "T" remembered how  
her grandma used to be.

Now Taylor's not a little kid  
She's in her 18<sup>th</sup> year.  
She was around when I could talk,  
ski fast and without fear.

Yet her reply when asked the past  
which was relayed to me,  
was, "I really don't remember much  
....she's really what I see."

Thank goodness that my friend told me  
about zero recall.  
It jolted me; it blew my mind.  
On me, it cast a pall.

But then I paused and pondered some -  
realized this is a gift.  
A teenager is teaching me!  
I feel my spirits lift.

It matters not, all that I was  
to anyone on earth.  
So now that I have PLS  
how can I feel some worth?

I'll use The Little Engine's line  
"I think I can..." each day.  
And if a legacy evolves,  
OK, I've got no say.

## CAREGIVING

### Wheelchair Manners

*Contributed by Liz Henry*

- 1) Please ask before touching!
- 2) That goes for pushing the chair especially.
- 3) My lap is not your shelf.
- 4) I'll ask if I need direct help.
- 5) "Would you like help" is fine, good manners; "Here let me do that for you" while doing it already -- is not. I value my abilities.
- 6) Walking beside me is nicer than walking behind me; then I can see you.
- 7) Coming down to my level for conversation is extra polite, thanks! Looming over me especially from behind... not so much.
- 8) Think of the chair as an extension of my body or personal space, treat it as such.
- 9) Thanks for unblocking my path so I don't get trapped, much appreciated. Move your backpack out of the aisle.
- 10) Really, please don't move the chair! I wouldn't pick you up and move you, would I?
- 11) Please don't bump it either, it's annoying and often it hurts me.
- 12) Let's talk about science fiction and feminism instead of wheelchairs and disability and pain, once we get past introductory chit chat.
- 13) No I don't really want to listen to your process your feelings and fears about disability unless we're already friends.
- 14) No I don't want your medical advice unless I ask for it.
- 15) If I ran over your toes, my bad, I'm so sorry.

### Help for Caregivers

[www.helpstartshere.org](http://www.helpstartshere.org) In thousands of ways, social workers help people help themselves. Welcome to your source for professional advice, inspiring stories - even a social worker directory to help you find a social worker near you.

*...from the site:*

*By Bette J. Freedson, LCSW*

### What Makes Situations Stressful?

Stress is a normal part of life. It can come from any situation or thought that makes you feel frustrated, angry or anxious. And what is stressful to one person is not necessarily stressful to another.

In small doses, stress can be good because it may motivate you to be more productive. However too much stress is bad. Prolonged stress can leave you vulnerable to physical and psychological [illnesses](#). Persistent and unrelenting stress may lead to anxiety (a feeling of apprehension or fear and unhealthy behaviors, like overeating and abuse of alcohol or drugs. What follows is a more detailed description of the "ABCs" of stress and how social workers help their clients deal effectively with stress.

### A —The Activating Event

The activating event is whatever happens that gets your stress going. It could be called the AGGRAVATING event because it almost always is something that disturbs you in some way. The activating/aggravating event can be something that happens in your life, something that you worry might happen.

Activating/aggravating events lead you to think and feel uncomfortable, and can cause you to have negative thoughts and feelings. If you do not deal with these negative thoughts and feelings, you are unlikely to resolve them, and as a result may end up feeling bad about yourself.

### B —The Beliefs

When an activating/aggravating event occurs, you will have reactive thoughts and feelings, even if you do not think you do. There is a possibility that during difficult situations your thoughts will be negative, bringing up unpleasant emotions, such as frustration, disappointment, anger, rage, or fear. If you are unaware of having these feelings, you may act out your feelings in negative ways, rather than dealing with them effectively and solving problems that they may cause.

Our thoughts and feelings operate in a circular way, in which feelings lead to thoughts and thoughts lead to feelings. The thoughts we have about a situation will be based on the beliefs we carry from our families and other life experiences we have had.

### **C—The Consequences and D —The Decisions**

Thoughts and feelings lead you to make decisions about how to behave and cope in situations. When decisions are made from frustration, anger, resentment, or fear, the decisions may lead to undesirable consequences (for the situation or for yourself.) Awareness of what you are thinking and feeling based on conscious knowledge of your beliefs is your best friend for making good coping decisions that will bring positive consequences for all concerned, including increased self esteem for you.

### **How Social Workers Help**

Social workers help their clients to deal with stress by:

1. Helping people identify internal and external sources of stress
2. Helping people identify the coping resources they usually use in stressful situations, and evaluating the effectiveness of their existing methods
3. Helping people understand how stress affects the body and the mind, and what the results of untreated long-term stress can be on both mental and physical health.
4. Teaching people relaxation and meditation techniques that help to reduce stress.
5. Teaching people the role of thinking and emotions in stress reduction, and helping them think through coping with stressful situations in a more productive way.
6. Helping people develop more effective and healthy coping mechanisms, which then can become automatic parts of their response patterns to stress.

### **Helping Hands:Caring for others comes with a price — and a reward**

*Excerpted from an article by Amy Labbe in the MDA/ALS Newsmagazine Vol. 12 No. 10.*

*"It is one of the most beautiful compensations of life that no man can sincerely try to help another without helping himself." — Ralph Waldo Emerson*

The physical and emotional demands caregivers face can be brutal, and often may seem insurmountable. An idea slowly gaining favor is that caregivers can actually benefit from the act of caregiving. Although the toll on those providing long-term care can't be denied, evidence shows positive emotional and physical benefits are correlated with helping behavior, says Stephanie Brown, health research scientist specialist at Ann Arbor (Mich.) VA Medical Center and assistant professor of internal medicine in the Center for Behavioral and Decision Sciences in Medicine at the University of Michigan.

In one study, Brown and colleagues examined the effects of helping behavior on mortality, looking at 423 older married adults over a five-year period and controlling for demographic, personality, health, mental health and marital relationship variables. They noted "individuals who reported providing instrumental support to friends, relatives and neighbors, and individuals who reported providing emotional support to their spouse had a 30 percent to 60 percent decreased chance of dying over the course of the study" compared to their non-helping counterparts.

### The emotional-physical connection

How the act of helping positively affects the body remains a matter of speculation, but Brown and others suggest that the positive emotions generated by helping behavior may bolster caregivers' overall sense of well-being, affecting such things as life satisfaction and the ability to cope with stress.

Positive emotions also have been shown (in various other studies) to lead to physical effects such as increased longevity

and faster recovery from cardiovascular stress.

### Finding the joy

Despite the obvious burdens involved, “when provided with proper respite and support, caregiving is often a joyful and beneficial experience for the one who gives,” says Stephen Post in his paper “Stumbling on Joy.”

The benefits to be gained, he says, are the moments of joy, the positive emotions and their associated effects. A professor of bioethics at the School of Medicine, Case Western Reserve University in Cleveland, Post says joy can be found in little moments; it can be as simple as a smile shared between the caregiver and loved one, or a few quiet moments spent watching the sunset at the end of a hectic day. Some may find joy in the pride they feel over overcoming the difficulties involved in caregiving, or in the reassurance that comes with knowing a loved one is receiving the best care possible.

Caregivers can experience the positive emotions or “helper’s high,” Post explains, even in caring for someone with ALS who may not be able to offer a smile or reassuring touch “because there is still a person before them, and because the joy is not dependent on reciprocity.” Post stresses the importance of *respite and support* as crucial variables in a caregiver’s ability to find joy in the caregiving experience.

“The benefits of caring and giving do not occur when people are overwhelmed,” he says. “So it’s important to provide support for carers so that they can find meaning and enjoyment in what they do.”

### A sense of peace

Jimmy Adams, 55, of Tyrone, Ga., cared for his wife, Barbara, from the time she received her ALS diagnosis in November 2004 until she died on Aug. 26 at the age of 54. He says he wouldn’t take anything for the last five years with Barbara, and that he knows exactly the sort of joy Post describes. “The pleasure I got, and the

comfort knowing she was taken care of and she was in my arms and God was with us, took all the pain away,” he says.

Adams recalls many joy-filled moments that occurred during the time he took care of Barbara, such as how he’d scratch her nose for her when it itched, and how when he’d hit the right spot, “she’d just *smile* — she had the prettiest smile.” One particular moment of joy that Adams remembers well happened before Barbara lost her speech, when he helped her reposition herself one day. “She said, ‘I’ve never ever felt scared when you’re around,’” Adams says. “She made me feel like a king. A caregiver’s just like everybody else,” he says. “They’re going to get aggravated and upset. Barbara’s parents coming over to give me a break — well, it took the stress off me. It charged my battery.”

### Treasuring moments

Brown notes that additional studies are needed to determine the breadth and depth of benefits associated with the act of caregiving. But even absent knowledge of all the how’s and why’s, it surely can’t hurt to recognize and treasure the moments of joy found in everyday caregiving.

The ways in which those joys benefit the body may be shrouded in mystery, but the warmth they bring the heart is immediate and sustaining, a gift worth holding onto and treasuring for its own sake.

## **MEDICAL RESEARCH**

*Compiled by Betsy Baquet, Medical Editor*

The beginning of this year brings with it many hopeful advances in research and increased understanding of motor neuron disease causes, diagnosis and treatment. Stem cell research has reached significant milestones that have diffused the ethical debate concerning embryonic stem cells. Numerous case studies, along with genetic and molecular research, have helped scientists to gain significant insights into the genesis and differentiation between motor



neuron diseases. Pharmaceutical trials continue on the ALS population, lending essential data to apply to the full spectrum of motor neuron diseases. Experts across the globe continue to share their independent findings, strengthening the scientific community, as a whole, in its understanding and potential for finding treatments and cures.

### **SCIENTISTS BYPASS NEED FOR EMBRYO TO GET STEM CELLS**

Two teams of scientists reported on November 20, 2007 that they had been successful in turning human skin cells into embryonic stem cells. Both teams used a process of adding four genes to skin cells, which reprogrammed their chromosomes, converting them into blank slates that should be able to turn into any of the 220 cell types of the human body. This incredible breakthrough could essentially negate the ethically-debated need for the creation or destruction of an embryo for the extraction of stem cells. Although both teams, one in Wisconsin and the other in Japan, agree that there are still potential risks using this new method, stem cell researchers say they are confident that it will not take long to perfect the method and that current drawbacks are temporary. In addition to sidestepping ethical issues, this new work could also allow scientists to vault significant research problems, including the shortage of human embryonic stem cells and restrictions on federal funding for such research. Both scientists and ethicists agree, this new method should reshape the stem cell field, overcome barriers and accelerate the movement towards cures and therapeutic discoveries.

SOURCE: Gina Kolata New York Times November 21, 2007

### **ACT ANNOUNCES CREATION OF HUMAN EMBRYONIC STEM CELL LINES WITHOUT THE DESTRUCTION OF EMBRYOS**

On January 10, 2008 Advanced Cell Technology, Inc. together with colleagues announced the development of five human embryonic stem cell (hESC) lines without the destruction of embryos. The new method has been published in the journal Cell Stem Cells. These new results have the potential to end the ethical debate surrounding the use of embryos to derive stem cells. In fact, the NIH report to the President refers to this technology as one of the viable alternatives to the destruction of embryos.

The peer-reviewed technique was initially carried out by ACT scientists under the direction of Robert Lanza, M.D., and then independently replicated by scientists on the West Coast. Single cells were removed from the embryos using a technique similar to preimplantation genetic diagnosis (PGD). The biopsied embryos continued to develop normally and were then frozen. The cells that were removed were cultured utilizing a proprietary methodology that recreates the optimal developmental environment, which substantially improved the efficiency of deriving stem cells to rates comparable to using the traditional approach of deriving stem cells from the inner cell mass of a whole blastocyst stage embryo. The stem cells were genetically normal and differentiated into cell types of all three germ layers of the body, including blood cells, neurons, heart cells, cartilage, and other cell types of potentially therapeutic significance.

“This is a working technology that exists here and now,” said Robert Lanza, M.D., Chief Scientific Officer at Advanced Cell Technology and senior author of the paper. “It could be used to increase the number of stem cell lines available to federal researchers immediately. We could send these cells out to researchers tomorrow. If the White House approves this new methodology, researchers could effectively double or triple the number of stem cell lines available within a few months.”

SOURCE:

<http://www.advancedcell.com/press-release/advanced-cell-technology-announces-creation-of-human-embryonic-stem-cell-lines-without-the-destruction-of-embryos>

### **SOME “PARTIALLY PROTECTED” FROM HSP EFFECTS—BRAZILIAN HSP STUDY SHOWS GENDER DIFFERENCES**

A Brazilian HSP study shows an earlier age of onset and more severe symptoms in men than women within one extended Brazilian family. The most frequent cause of autosomal-dominant HSP are SPG4 mutations. The analysis of 30 individuals who carry the SPG4 mutation showed that males have, on average, an earlier age at onset and are more severely affected. Understanding why some individuals, particularly women, are “partially protected” from the effects of this and other pathogenic mutations is of utmost importance.

SOURCE: Eur J Hum Genet. 2007 Dec;15(12):1276-9. Epub 2007 Sep 26. <http://www.hspersunite.org.au/news.aspx?nid=107>

### **ADVANCES IN HSP RESEARCH**

Recent advances have greatly improved genetic diagnosis of the group of diseases known as Hereditary Spastic Paraplegias. Identification of SPG4, the gene most frequently involved in HSP, allows for detection of an increased number of cases. Mutations in SPG11 account for a majority of the autosomal recessive complex forms of the disease with atrophy of the corpus collosum. In addition, the SACS gene has been implicated in an increasing number of various origins. However, the identification of new genes and variations has become more complex, and clinical and other information concerning the disease is now crucial for choosing an appropriate genetic testing procedure for each patient.

SOURCE: Curr Opin Neurol. 2007

Dec;20(6):674-80.

<http://health.groups.yahoo.com/group/PLSeries-NEWS/message/4412>

### **UNDERSTANDING DISEASE PATHWAY IN Primary Lateral Sclerosis**

Autosomal recessive mutations in the ALS2 gene lead to a clinical spectrum of motor dysfunction including juvenile onset ALS, PLS and HSP. Four ALS2-deficient mouse models have been generated by different groups and used to study the behavioral and pathological impact of alsin deficiency...subtle deficits that are observed in behavior and pathology have aided in our understanding of the relationship between Alsin and motor dysfunction.

SOURCE: Mol Neurobiol. 2007 Dec;36(3):224-31. Epub 2007 Jul 10 <http://tinyurl.com/2tdkol> <http://health.groups.yahoo.com/group/PLSeries-NEWS/message/4413>

### **ALS SPECIALISTS GATHER IN TORONTO**

The 18<sup>th</sup> International Symposium on ALS/Motor Neuron Disease (MND) took place in Toronto December 1 – 3, 2007. 750 attendees gathered, most of whom are clinical and scientific experts in ALS. Discussions of critical issues included compelling evidence that ALS is not one disease but many. The evidence includes the wide range of survival time, variability in the parts of the brain affected, and the lack of a single genetic factor leading to ALS in a large percentage of patients. Although ALS patients can be segregated by familial or sporadic, site of onset symptoms and rate of disease progression, these categories still fail to reflect the wide variation in the disease or as guidance for selecting potential responders to different treatments. Further, the failure of mouse studies to predict human responses to experimental treatments may be due to the lack of uniform cause of ALS in humans compared to the uniform cause of the

disease in rodents, which is usually the introduction of SOD1 gene mutation.

There was also much discussion of drug trials, including better selection prior to conducting large, expensive and time-consuming trials. Some results of specific trials were presented:

**Minocycline** (anti-biotic) showed harmful in ALS—accelerated deterioration with no effect on survival rate.

**Celecoxib (Celebrex) and Creatine combination**—selected for further study due to score on ALS Function Rating Scale.

**TRO19622 compound** from Trophos (France)—This cholesterol-like compound is designed to prevent cell death, and was well tolerated and warrants further study.

**Ritonavir**—eliminated due to poor respiratory effects, weight loss and weakness.

Hydroxyurea—considering phase 2 trials; trials showed slightly improved ALSFRS scores, strength and respiratory scores.

Currently being used for Leukemia.

Additional important issues discussed included:

**Dutch study warns against Chinese stem-cell treatments**—12 patients followed to China; seven had short term improvement that lasted less than a day; three saw no change and two said they deteriorated.

**Strenuous lifestyle may increase ALS susceptibility**—preliminary results of a scientific team from an ALS center in Montpellier, France, suggest that consistent strenuous activity over decades from heavy work or exercise may increase one's risk of developing ALS.

SOURCE: [http://www.als-mda.org/research/news/071218als\\_toronto\\_conf.html](http://www.als-mda.org/research/news/071218als_toronto_conf.html)

## **SCIENTISTS USE IMMUNE SYSTEM TO TARGET ALS PROTEIN**

Mice affected with familial ALS from SOD1 mutation showed improved survival and slowed gait deterioration after targeting misfolded SOD1 protein molecules

with immunologic strategies. Scientists created “monoclonal antibodies” (immune system proteins), and used them to target abnormal parts of the SOD1 molecule. Dr. Neil Cashman of Amorfix Life Sciences of Toronto states, “We’re optimistic that we’re on a good path to specifically destroy misfolded SOD1 in all types of ALS, while sparing the normally folded molecules.” In contrast to some in the ALS research community, Cashman has long believed that abnormally formed SOD1 protein molecules underlie not only the type of ALS that results from mutated SOD1 genes but also other types of ALS, such as nonfamilial (sporadic) ALS and non-SOD1 familial ALS.

SOURCE: [http://www.als-mda.org/research/news/071105ALS\\_protein.html](http://www.als-mda.org/research/news/071105ALS_protein.html)

## **ALS MICE LACK NORMAL BLOOD-SPINAL CORD BARRIER**

Florida scientists say a barrier that normally exists between the spinal cord and the bloodstream is disrupted in mice with ALS, and that its loss could play an important role in causing or exacerbating nerve-cell death in this disease. The researchers say that the damage to motor neurons could be accelerated if leaky blood vessels are allowing large molecules, such as immune-system proteins, to enter the nervous system. If future studies demonstrate that disruption of the blood-spinal cord barrier occurs before any disease symptoms or other signs of ALS appear, it would indicate that such disruption plays a primary role in ALS pathogenesis.

SOURCE: [http://www.als-mda.org/research/news/071213spinal\\_cord\\_barrier.html](http://www.als-mda.org/research/news/071213spinal_cord_barrier.html)

**PHOTO GALLERY**

**Texas TeamWalk**

**Tennessee TeamWalk**



Participant set out on TeamWalk in Houston, TX.



Glenn Smith giving a ride to granddaughter Reagan



Jim Sheorn and horsing around at start of a TeamWalk in Nashville.

**People Doings**



John & Rita DiClemente at granddaughter Holly's National Guard induction



Jim & Thurza Campbell with Doug & Flora Brand in St. Petersburg, FL



Editor in beachchair with son Bill and grandson Connor

**2008 National Conference Site**



Washington's HQ. at Valley Forge



Independence Hall, Philadelphia



Valley Forge Crowne Plaza



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