

# Synapse

Volume 11, Issue 2 Spring, 2008

*Newsletter of the Spastic Paraplegia Foundation*

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## Letter From The President



**Jim Sheorn**  
President

**T**hanks so much to our supporters!! We had another successful year with fundraising. This year, the SPF will award \$400,000 to research. That, along with funds raised since 2002, amounts to almost \$2 MILLION to find a cure for HSP and PLS. **Thank you.** We hope that you will continue to invest in our future and get one step closer to a cure.

The Annual Letter, which is in the center section, will give you an update on how the SPF did last year. It is also the official beginning of our fundraising effort for 2008. If you have already given, Thank you very much for your support. If you have not made a donation for 2008, we hope that you help with our mission to discover cures for Hereditary Spastic Paraplegia and Primary Lateral Sclerosis by funding research, providing information about these disorders and creating opportunities for mutual support and sharing. We look for another successful year with your help.

**W**e are busy planning the 2008 Spastic Paraplegia National Conference in Valley Forge, PA. So far over 50 people have registered for the conference. If you are planning to attend, please book your hotel reservations with the Crowne Plaza soon. They can be contacted at 1-800-972-2796 or (610) 265-7500. The group rate is \$109 per night. At Friday night's reception dinner, Patricia Leisner Clements will give a talk about disability benefits. Saturday we will have Dr. Bass who will focus on HSP. Dr. Fink, who is the SPF Medical Advisor, talk about Research Advances in understanding HSP and PLS. We are waiting confirmation on a PLS speaker. After a time of learning and fellowship, Dr. Rossatte Biester will give a motivational talk. On Sunday a tour has been set up at the Valley Forge National Park. For the latest update, please log onto the website. To register, either mail in the flyer in this newsletter, or register on-line [www.sp-foundation.org/events-2008conference.htm#Registration](http://www.sp-foundation.org/events-2008conference.htm#Registration).

Just around the corner is TeamWalk, which is the SPF's largest fundraiser. We will be communicating details in upcoming E-News and future editions of *Synapse*. We hope that you will all participate and make this another successful year.

There are many other ways that you can help besides giving a personal donation. Please log onto [www.sp-foundation.org/donate](http://www.sp-foundation.org/donate) for details. Many companies will make a contribution to the SPF based on orders they receive from customers. It makes it very convenient to shop via the internet. If you use this method, please make sure you designate SFP. When searching the internet, please use [www.goodsearch.com](http://www.goodsearch.com). Based on the number of searches conducted, GoodSearch will make a contribution to the SPF. Again, please make sure that you designate SPF. Feel free to share this information with family and friends.

I would like to thank Thurza & Jim Campbell along with all the contributors and volunteers that produce *Synapse*. I hope you will enjoy future editions.

We hope to see you in Valley Forge, PA for the SPF Annual Conference. If you are unable to join us, we will do our best to keep you updated through E-News and *Synapse*.

*Jim Sheorn*  
President  
Spastic Paraplegia Foundation

## LETTER FROM THE EDITOR

I am at least as pleased as anyone else with the new, improved *Synapse*. We've come a long way with several editors, from the 1997 founding of *Synapse* by Joe Alberstadt, followed by Mark Weber, then Jim and me. Last year Sarah Roberts-Witt and Betsy Baquet signed on to help me, but the product was still amateur. Jim and I compiled *Synapse*, always hoping a better layout and distribution would evolve.

Enter Linda Gentner, who inspired the SPF Board to make *Synapse* its official newsletter. This change has created an important vehicle for SPF to fulfill the part of its mission to educate and connect people. SPF Board Member Frank Davis deserves thanks from all readers. Frank enlisted Gulf Business Forms' professional layout staff to convert the 2002-2007 format to the outstanding format you have in your hands. Frank and Annette Lockwood worked tirelessly with the USPS so that *Synapse* could be sent via bulk mail.

Thanks to everyone mentioned above who have helped enable this giant step forward.

Best regards,

*Thurza Campbell*

Editor



*Joe Alberstadt, founder of 'Synapse', with his wife, Carol, on a cruise.*

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**Volume 11, Issue 2 - Spring 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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## UPCOMING EVENTS



### 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.

Call **610-265-7500**

or

**1 (800) 972-2796**

for reservations.

### SPRING FLING - BERKELEY SPRINGS

**MAY 3, 2008**

The 8th annual Spring Fling will be held on May 3 in Berkeley Springs, WV. There will be an Arrival Dinner on Friday, May 2. Please contact Ronnie Grove if you plan to attend. [frogrove@verizon.net](mailto:frogrove@verizon.net) 711-(304)-258-5275 (711 is the Relay prefix)

### KENTUCKY CONNECTION MEETING

**JULY 21, 2008**

The first Kentucky Connection will be held at a local restaurant in Mayfield on Monday, July 21. Check back for more details. Please contact Jane Anne King if you plan to attend. [gking@rose.net](mailto:gking@rose.net) (229) 227-0558

### WARM SPRINGS RETREAT

**WARM SPRINGS, GA**

**AUG 8-10, 2008**

#### *"I Live, I Learn, and I Achieve"*

The first Warm Springs Retreat will be held on Aug 8-10 at the **Roosevelt Warm Springs Institute for Rehabilitation**. The Institute is a state-operated comprehensive rehabilitation center located in Warm Springs, Georgia on a beautiful 950 acre campus. Begun by President Franklin D. Roosevelt in 1927 to treat persons affected by polio, the Institute still remains true to its original mission today *"to empower individuals with disabilities to achieve personal independence"* as a living legacy to FDR. In addition to its continuum of rehabilitation services, the Institute also offers the fully-accessible **Camp Dream**, which is enjoyed by 2,000 disabled campers each year. Cabins for two are available for \$30/person per night and come with a handicap accessible bathroom. Breakfast will be about \$6.00 a person and Lunch \$12.00 per person. The group will go out for dinner on Saturday night for some of that scrumptious Southern cooked food (self-pay). Much more planned but all is **FREE**. Please contact Jane Anne King if you plan to attend. [gking@rose.net](mailto:gking@rose.net) (229) 227-0558

The Conference will begin with an arrival dinner on Friday night. Patricia Leisner Clements, Attorney at Law, will speak after dinner about Medicare and disability benefits.

On Saturday, the keynote speakers will be SPF Grant recipient Dr. Peter Baas of Drexel. Dr. Fink, our SPF Medical Advisor, and Rosette Biester, PhD. We are awaiting confirmation from the speaker who will address PLS. Special breakout sessions will be held for patients and loved ones.

An optional trolley tour is being arranged for Sunday, June 8.

Please register online at [www.spf-foundation.org/events-2008conference.htm](http://www.spf-foundation.org/events-2008conference.htm) or return the enclosed flyer.

Contact: Anna Bonnani [annabonanni@hotmail.com](mailto:annabonanni@hotmail.com) or Jim Sheorn [jimsheorn@comcast.net](mailto:jimsheorn@comcast.net) for more information.

# TeamWalks 2008

## SEATTLE - SEPTEMBER 6

Contact Jackie Bollinger [seattlehspjackie@aol.com](mailto:seattlehspjackie@aol.com) 425-738-1374

## PA - SEPTEMBER 20

The PA TeamWalk will be held, Saturday, September 20 at Knoebel's Amusement Park in Elysburg, PA, which is on the eastern side of the state. Last year we raised around \$13,000 for research and hope to raise more this year and have more attend the walk. We held the first PA TeamWalk here last year and it is a nice clean park and they even had a park attendant go with us on the walk in case anyone needed assistance or a golf cart to take them back to the pavilion. There was time for anyone who wanted to take their families or go themselves on rides.

Come join us for a walk in the park to help raise money for research and to get meet others who you may have talked to on a support list.

Contact Sue Me 814-590-4673 (cell) or e-mail [momofboysonly@yahoo.com](mailto:momofboysonly@yahoo.com)

## RECENT EVENTS

### FEBRUARY 23 – SEATTLE, WA

The first Seattle Connection hosted by Jackie Bollinger was held on February 23. Sandy Efseaff demonstrated the WalkAide for the group. She will also make a presentation at the Seattle TeamWalk on September 6, 2008. Ron Noren is hoping that other PLSers will come to the TeamWalk, he is anxious to meet others with it. Don and Gayle Gould drove up from Oregon and Ron Noren from Tacoma joined the group. Robert Haugland loves to cook and wants to open a bistro. His pastrami recipe is to die for (*his email even starts with pastrami*). Karl is busy raising a family that includes two nieces that they are helping to raise. Also joining the group were Julie and Mark Boyd. Mark commented that thanks to Julie slowing down as a result of HSP, it forced him to slow down which helped him to really enjoy the beauty around him. Thanks to Jackie for putting the Connection together.

*And from Jackie herself, "We had the Seattle Connection today and it was wonderful meeting everyone! One thing I think everyone realized is how important these connections are. The exchange of ideas and realizing you're not alone. There was an immediate connection with everyone, a comfort level you usually don't find when you meet people for the first time."*

### MARCH 8 – CLEARWATER, FL

*Contributed by Kathi Geisler*

Kathi and Ed Geisler, Bruce Maser, Gail and Ernie Leisure and James Scuderi were welcomed by the Tampa Bay Ataxia Foundation Support Group at their March 8 meeting in Clearwater. Crystal, the group's Chairman, organized a picnic at a park shelter for some two dozen people concerned with Ataxia, PLS or HSP.

It was a lovely afternoon to get acquainted and share stories and concerns as well as enjoy lunch in a wonderful setting. There were also two informational programs: one by a physical therapist who spoke about everyday therapies we can do and the other by Dr. Tom Clouse, who presented his "Dancing with Ataxia" program.

Crystal and Kathi will work together to partner on some future events in Florida, as symptoms of the conditions are very similar. The Ataxia Foundation welcomes all people with ataxia (uncoordination) so individuals with HSP or PLS are always welcome to their events. Learn more about Ataxia here: [www.ataxia.org](http://www.ataxia.org)

*The SPF group: Bruce Maser (PLS) on his recumbent bike, Gail Leisure (PLS), James Scuderi (HSP), Kathi Geisler (HSP)*



# SP FOUNDATION NEWS

## HARDY BROWN PLS AWARENESS MONTH UPDATE

In the last issue we told you about US House Resolution 896 to make February Hardy Brown PLS Awareness Month. CA Congressman Joe Baca said, “I introduced this legislation because many Americans are unaware of the severe nature of Primary Lateral Sclerosis. 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.” The awareness month would be named in honor of Hardy Brown – who is afflicted with PLS.

As of April 3rd, 46 Representatives have become co-sponsors, another 54 are needed. The link to the list can be found on the website. Please contact your Congressional Representative if he or she is not on the list yet. 100 co-sponsors are needed before it is brought to the House for a vote! Please go to [www.sp-foundation.org/PLS\\_Awareness\\_Month.htm](http://www.sp-foundation.org/PLS_Awareness_Month.htm) and send the recommended letter to your representative asking him or her to become a co-sponsor of this important bill, **H. RES. 896**. Contact Annette Lockwood if you have any questions or need a hard copy of the letter.

## LIVING WITH HSP/PLS

### M. FRANK LEVY OF LOS GATOS (1925-2008)

*Contributed by Linda Gentner*



*M. Frank Levy (1925-2008)*

Frank was my very first contact with another PLSer. My dental hygienist had read an article in the San Jose Mercury News about a man who had a rare disorder and then about the PLS Newsletter. We did a bit of research and voila there it was. Craig called him and the first words out of his mouth were, “what took you so long?” We then began talking about creating a PLS Foundation -- but then SPF happened. His original diagnosis was PLS and there was nothing to be found on it so he started the PLS Newsletter and made PLS known and his name is still at several universities. He was later diagnosed with HSP and joined the HSP Discussion List and posted occasionally. We communicated about other things than just PLS. We both were season ticket holders for the San Jose Repertory theatre and we would discuss the plays. He added insight because he was an actor in community theater. In his obituary a few of the other things

mentioned were that Frank made tapes for Science for the Blind, manned phones for Suicide and Crisis Service. “For 20 years, Frank edited and published the PLS Newsletter for patients with Primary Lateral sclerosis, which he considered one of his greatest accomplishments”.

Frank received his B.S. from Columbia and a Ph.D from Yale. He will be remembered by many people all over the world as their first contact of learning about PLS and knowing that they were not alone in their struggles.

### SARAH ROBERTS-WITT HONORED AT MDA EVENT IN RALEIGH, NC

*Contributed by Jeff Witt*

On February 29<sup>th</sup> Sarah Roberts-Witt was the Honoree and Spokesperson for the Muscular Dystrophy Association’s, second annual, Imagine Gala, A Celebration of Hope. The event is a fundraiser to benefit their research programs dedicated to the eradication of over 40 neuromuscular diseases. This year’s event nearly doubled the previous efforts; they raised over \$100,000 for the MDA research programs. Sarah attends the MDA sponsored Duke ALS Clinic, where she was diagnosed, receives treatment, and care for PLS.

The evening featured a moving and inspirational video vignette of Sarah, speaking through her computer, about her struggle with her motor-neuron disease and its effect on her and family’s life. Her key messages and plea’s for research funding received thunderous applause from the several hundred in attendance. The evening included dining, entertainment, and quest speakers. To raise contributions, tables were purchased by corporations and both silent and live auctions were held featuring items donated by local businesses. Sarah too under the weather to attend, had her Honoree award presented to her husband Jeff, her two children, Clare age ten, and William age four, on her behalf.

## MANAGING HEALTH CARE

Contributed by Sharon Neumann, Paralegal

It is very important to be the “manager” of your family’s health care --who else can know better than the patient, parent, or adult child of an ailing parent? With over 350 rare disorder and injury clients to track medical history and current medical status, I began using a service to assist. They gather and summarize all your health care info in a HIPAA compliant manner and provide you with a nice personal health journal in hard back and/or on CD. They also update information on an annual basis if you request that service. The physicians appreciate the summary information as a great way to come up to speed on complicated care issues and patients are the final beneficiaries in that care becomes more comprehensive with all the important info being shared as appropriate.

Cost ranges from \$100 on up and depends on a variety of factors. Sometimes insurance companies or local programs (i.e., Kiwanis, Rotary Charities, local health organization non-profits, schools, etc.) will pay for this if they understand the need (a note from your doctor along with the estimate from Rap usually is sufficient to obtain outside funding source.) If you are interested in more info, the company I use is:

**RAP Professional Services**  
**P.O. Box 5233**  
**Traverse City, MI 49686**

In addition, in my own family, we also update our primary care physician and hospital files with a written personal health summary detailing the events of the year and our current questions/concerns. We have found that they appreciate this and our health visits are more efficient and meaningful -- and all our questions/concerns are addressed. The care provider keeps a copy of this summary and their notes in the chart, and we keep a copy with our own notes/journals. We also keep an “emergency card” with us when we travel outside our local community so that our personal physician would be contacted and guide any special care needs.

## Venting Feelings

Contributed by Diana Montague-Jackson  
dianamj\_canuck@yahoo.ca

*“We Cannot Heal What We Cannot Feel and Express.”*  
When someone honestly shares their feelings about something, it helps me a lot. Then I don’t feel so different. One thing about ‘venting’ it DOES NOT have to be logical. In fact, the worst reply to someone who is venting is to try to go logical on them. Venting straightens out the neurotransmitters in the brain, as long as the venting is sincere, full and receives support. Once we have got all that stuff out, and heard someone say, ‘I hear ya. I can tell you feel very angry/sad/etc.’ The logical part of the brain can start to problem-solve. I have studied the research on this at university time and again, it’s a fact.



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## **PATIENT-PHYSICIAN COMMUNICATION: UNDERSTANDING AND ACTING ON HEALTH INFORMATION FROM YOUR DOCTOR**

*From 'WeMove News'*

The ability to understand information provided by healthcare professionals is closely related to *health literacy*, or “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” Many factors affect the ability to understand information, follow instructions, question instructions, finish appropriate treatment, and take medicine at the right time.

### **EDUCATION**

While education level does play a role, adults usually read at a level that is three to five grades below their highest grade completed in school even though their conversation skills may reflect a higher level than the reading level.

### **FAMILIARITY OF MATERIAL**

If you have read about or heard about a subject before, you will have an easier time reading and understanding new information on the topic. It's not too hard to figure out the meaning of new information when it contains only a few unfamiliar words or phrases. When you first read about a new subject, however, understanding the unfamiliar material may be much more difficult.

### **STRESS**

People often receive information about a life-changing medical condition when they are at their doctor's office. It's often hard to put this stressful information to the back of your mind and actually hear and pay attention to what else your doctor is telling you after you receive this information.

### **MEDICAL CONDITIONS**

If you have a medical condition or are taking a medicine that makes it difficult for you to think clearly, you may have more trouble understanding things that you could read easily before you developed the condition.

### **AGE**

People in the United States are living longer. Therefore, we have more people over the age of 65 in this country than ever before. More than 65% of people over the age of 60 have trouble reading and understanding what they've read.

The impacts of low health literacy rates are enormous. People who have trouble understanding the information that their healthcare professional gives them are more likely to make mistakes when taking their medicine, have trouble finding out where to get the healthcare services that they need, when to come in for an appointment, and how to pay their services, and less likely to complete their treatments.



## WHEELCHAIR OPTIONS

by Jim Campbell

Improving mobility is a challenge faced by virtually all PLsers and HSPers and their caregivers. The endless array of products available is confusing. Sources of information include fellow patients, TV ads, on-line literature and the local health aid store – each with a different opinion and perspective. This article seeks to summarize pertinent information and offer sources for more detailed investigation so the selections you make are good ones for you.

In general there are two mobility options – manual and power chairs. A manual wheelchair offers a lower cost way to go longer distances and faster than walking with a cane or walker, provides a convenient and comfortable seat and is low maintenance and reliable because of its simplicity. However, if one no longer has strong shoulders and firm hands, the manual chairs requires the assistance

of a companion to push thus losing some of the independence that a self-propelled patient would have. I know I sometimes unwittingly frustrate my wife when pushing her chair through a store by stopping so I can examine an item on display or talk to a friend with my wife's chair pushed just beyond the object of interest. In contrast power chairs

return independence and freedom to the patient by being self-propelled and steered by the patient. Power chairs are often rugged and powerful enough that they can climb steeper inclines and traverse rough surfaces; however, they are heavier, more expensive, and must be recharged and maintained. As a result of these complementary advantages many patients often have both types of chairs – a manual wheel chair for indoor and light use and a power chair for outdoor use. Table 1 shows the wide array of manual and power chair types available and gives the features of each category. Querying on-line and discussing options with your local rehabilitation facility are good ways to select your category and narrow your selection of the models available in a given category

How best to buy a manual wheelchair? As with many big purchase decisions ideally you should follow a

disciplined selection process: set your goals, explore the options by talking with fellow patients, local dealers and reading articles, investigate the extent of insurance and/or Medicare coverage for the category you selected, set a budget for out-of-pocket cost, be evaluated/measured by a professional and only then make a purchase. Here are some self examination elements for you to consider before meeting with the evaluation professional (*source: [www.wheelchairnet.org](http://www.wheelchairnet.org)*) Your goals, Your needs today and in the near future, Your lifestyle, Your living environment, How you plan to use the chair (*inside only?*) and How you plan to travel (*driver or passenger in a motor vehicles*). As you can see from the manual chair entries on page 9, the expense of a manual chair increases as the weight of the chair drops. Many other sources of information can be found on-line including a detailed list of considerations for selecting both manual and power chairs authored by Stu Porter at [www.geocities.com/stuportner/files/index2.htm](http://www.geocities.com/stuportner/files/index2.htm).

*When it comes to wheelchair options, one thing appears obvious – there's no single perfect answer for all.*

Power chairs come in an even greater range of cost, weight and ruggedness, so deciding on your mobility goals is even more important in the selection process. Power chairs are generally classed as 1) scooters which are either three or four wheel self-propelled vehicles steered by use of a bicycle-type handle bar or 2) power chairs which often have six wheels with

power applied to the mid wheels and are commonly steered through the use of a joystick mounted on the armrest. As can be seen from Table 1 power chairs are typically heavier, can actually turn in place (spin) and are more suitable for outdoor use because of increased power, larger middle wheels and more rugged construction. The self examination elements to consider before buying a manual wheelchair apply here as well with transportability a key factor especially if you expect to use it at locations other than your home. Power scooters often weigh over 150lbs. but can be disassembled and loaded in the car's trunk. This process requires a caregiver who is willing and able to disassemble and reassemble the scooter as well as lift modules up to 35lbs in and out of the trunk. Ideally a power lift or van with a power ramp complements the power chair or power scooter by providing a quick, simple means of transportation. Ramp vans have



door-mounted tie-down straps, but a special module can be purchased for the power chair that allows the patient to drive to the passenger or driver's position and automatically lock in place.

When it comes to wheelchair options, one thing appears obvious – there's no single perfect answer for all. Everyone's environment, interests, physical abilities, degree of adventure, economic circumstance is different and is likely to change with time. But taking time to sort out priorities should lead you to a decision you are comfortable with in both senses of the word.

## MANUAL CHAIRS



### Transport

**Use:** Every day  
On Hard Services  
**Weight:** 30lbs ±  
**Features:** Propelled by caregiver  
Canvas Seat  
Folds for transport  
**Est. Cost:** \$200



### Standard

**Use:** Every day  
On Hard Services  
**Weight:** 40lbs ±  
**Features:** Rugged  
Padded Seat  
Folds for transport  
**Est. Cost:** \$200



### Ultra-Lightweight

**Use:** Every day  
On Hard Services  
Transport in car  
**Weight:** 20lbs ±  
**Features:** High Performance  
Padded Seat  
Folds for transport  
**Est. Cost:** \$1,300



### Beachchair

**Use:** On sand at seashore  
**Weight:** 37lbs ±  
**Features:** Easy to push in sand  
- large balloon tires  
Corrosion resistant materials  
Must disassemble to transport  
**Est. Cost:** \$2,500

## POWER SCOOTERS



### Travel

**Use:** Occasional  
Usually inside  
**Weight:** 110lbs ±  
**Features:** Lightweight for transport  
in auto  
Heaviest model under 35#  
**Est. Cost:** \$1,000



### 3 Wheel

**Use:** Everyday  
Usually inside  
**Weight:** 150lbs ±  
**Features:** Shorter turning radius-3ft.  
**Est. Cost:** \$2,000



### 4 Wheel

**Use:** Everyday  
Usually inside  
**Weight:** 260lbs ±  
**Features:** Stable  
More rugged than 3 wheel  
5ft. turning radius  
**Est. Cost:** \$2,500

## POWER CHAIRS



### Indoor

**Use:** Everyday  
Usually inside  
**Weight:** 130lbs ±  
**Features:** Can be disassembled or  
transport  
Heaviest model under 50#  
Zero turning Radius (spins)  
**Est. Cost:** \$2,500



### Indoor/Outdoor

**Use:** Everyday  
Usable outside as well as  
inside  
**Weight:** 300lbs ±  
**Features:** Larger wheels  
Zero turning Radius (spins)  
More powerful & rugged  
**Est. Cost:** \$5,000

*Don't Forget!!*

We've enclosed an envelope for your Annual Donation. Also, the envelope needs to be returned if you want to receive future issues of *Synapse*.

## ALS ATHELETE CHOSEN TO BE OLYMPIC TORCHBEARER

Lorri Coppola has been selected to be one of those to carry the Olympic Torch April 9. She will be assigned a portion of the route through San Francisco. Her life is ebbing away, but she wants to carry the Olympic torch. She loves the Olympics, and everything it represents, and she has attended three Summer Games — Montreal in 1976, Los Angeles in 1984, and Atlanta in 1996. The torch's only North American stop-over on its way to Beijing for this year's Olympics. Coppola may not be around for the next Olympics.

In December 2005, she was diagnosed ALS or Lou Gehrig's disease. Doctors informed her then that she had two to five years to live. Bulbar ALS, her exact diagnosis, has affected her lung power and her salivary glands. She no longer can speak, eat or drink. "Now I just live each day," she said, typing into a computer.

Coppola always has been athletic, even now as a 67-year-old race-walker. But what makes her so positive in confronting so negative a future? "I was born in Brooklyn," she said, smiling. "You have to be strong just to cross the street." She came to California in 1967. Assertive-

## Joy

*Contributed by Ruth Havener*

Too many people put off something that brings them joy just because they haven't thought about it, don't have it on their schedule, didn't know it was coming or are too rigid to depart from their routine.

How many women out there will eat at home because their husband didn't suggest going out to dinner until after something had been thawed? Does the word 'refrigeration' mean nothing to you?

How often have your kids dropped in to talk and sat in silence while you watched 'Jeopardy' on television?

I cannot count the times I called my sister and said, 'How about going to lunch in a half hour?' She would stammer, 'I can't. I have clothes on the line. My hair is dirty. I wish I had known yesterday, I had a late breakfast, It looks like rain' And my personal favorite: 'It's Monday.' She died a few years ago. We never did have lunch together.

ness training classes then strengthened her resolve. She taught track and gymnastics as a Marin County middle school P.E. teacher for 33 years. Coppola helped win a United States team gold medal at the World Masters 10-kilometer race-walking competition at Buffalo, N.Y., in 1995. And she won individual gold medals in the 10-kilometer and 5-kilometer events at Portland in 1998.

Several hundred people, including Coppola, applied for the chance to carry the Olympic torch. Eighty were chosen. "I'm such a fan," she said. "I appreciate what the athletes have to do to make it to the Olympics. I believe the world comes together in the Olympics. And we need more coming together right now. Bless you all as I catch a dream!!!"



*Background for this article was excerpted from an article in the Oakland Tribune, by Dave Newhouse [www.insidebayarea.com/oaklandtribune/localnews/ci\\_8223634](http://www.insidebayarea.com/oaklandtribune/localnews/ci_8223634)*

We'll go back and visit the grandparents when we get the baby toilet-trained. We'll entertain when we replace the living-room carpet. We'll go on a second honeymoon when we get two more kids out of college.

Life has a way of accelerating as we get older. The days get shorter, and the list of promises to ourselves gets longer. One morning, we awaken, and all we have to show for our lives is a litany of 'I'm going to,' 'I plan on,' and 'Someday, when things have settled down a bit.'

I have a 'seize the moment' friend, she is open to adventure and available for trips. She keeps an open mind on new ideas. Her enthusiasm for life is contagious.

Do something you WANT to...not something on your SHOULD DO list. When you ask, 'How are you?' Do you hear the reply? When you worry and hurry through your day, it is like an unopened gift....thrown away. Life is not a race. Take it slower. Hear the music before the song is over.

# CAREGIVING



[www.carepages.com](http://www.carepages.com)

Use CarePages to connect family and friends and share news, support and encouragement. Whether you are in the hospital, receiving care at home, or recovering, CarePages provides the forum to share stories and get support.

*Ed. Note: I learned about CarePages when a friend was hospitalized recently. Please check out this site, especially if you are homebound.*

*Advice from the site:*

## *What can you say to a sick or handicapped person?*



### **Offer specific help.**

*Saying something like "I made some extra lasagna. When's a good time to bring it over?"; or "Let me drive you to the hospital this week" takes the burden off your friend to ask for help.*

### **Make a statement.**

*Rather than asking "How are you doing?" say something proactive like "It's so good to see you. I've been thinking about you" or "I'm so glad to see you. You have been in my prayers."*

### **Don't beat around the bush.**

*Don't be afraid to talk about your friend's illness and what the progress is --then talk about the daily things you would normally talk about.*

### **Be sincere.**

*Don't say he or she looks great if they really don't (but don't tell them they look awful, either). Instead, stay positive. If they're bald from chemo, for example, try "Your head is such a pretty shape."*

### **Recognize his or her experience as unique.**

*Try not to make assumptions about what your friend is going through. Instead, ask how they're feeling.*

### **Let him or her set the pace.**

*Some days are better than others. Try to gauge your friend's mood and let them know whatever they're feeling is okay. If they want to laugh or vent, go with it.*

### **Encourage his or her strength and courage.**

*Remind your friend to have hope and never let go of it.*

### **Avoid cliches.**

*Instead of "What doesn't kill us makes us stronger", try something simple: "I can't imagine what this is like for you, but I want you to know I am here for you."*

### **Simply listen.**

*Ask how they are doing and if they want to talk. Then listen and resist the urge to offer advice.*

### **Speak up with compassion.**

*Leave a voice message or send a note or email to remind your friend that you love them. Do this regularly.*

## RESPIRE CARE

From "Inspire" magazine, from Mass. ALSA

One way to avoid caregiver burnout is for the caregiver to recognize his or her limits. Many agencies offer respite care. Contact the National Respite Network at 1 (800) 773-8433 or [www.chtop.org/ARCH/National-Respite-Locator.html](http://www.chtop.org/ARCH/National-Respite-Locator.html) for help finding resources in your area.

### CRABBY OLD MAN

*What do you see nurses? ... What do you see?  
What are you thinking... when you're looking at me?*

*A crabby old man... not very wise,  
Uncertain of habit... with faraway eyes?*

*Who dribbles his food,... and makes no reply,  
When you say in a loud voice,... "I do wish you'd  
try!"*

*Who seems not to notice ... the things that you do.  
And forever is losing... A shoe?*

*Who, resisting or not... lets you do as you will,  
With bathing and feeding... The long day to fill?*

*Is that what you're thinking? Is that what you see?  
Then open your eyes, nurse... you're not looking at  
me.*

*I'll tell you who I am... As I sit here so still,  
As I do at your bidding,... as I eat at your will.*

*I'm a small child of Ten... with a father and mother,  
four sisters... who love one another*

*A young boy of Sixteen... with wings on his feet  
Dreaming that soon now... a lover he'll meet.*

*A groom soon at Twenty one... my heart gives a leap.  
Remembering, the vows... that I promised to keep.*

*At Twenty-Five, now... I have two young of my own.  
Who need me to guide... And a secure happy home.*

*A man of Thirty... My young now grown fast,  
Bound to each other... With ties that should last.*

*At Fifty, my young sons... have grown and one gone,  
But my woman's beside me... to see I don't mourn.*

*I look at the future... I shudder with dread.  
And I think of the years... And the love that I've known.*

*I'm now an old man... and nature is cruel.  
Tis' jest to make old age... look like a fool.*

*The body, it crumbles... grace and vigor, depart.  
There is now a stone... where I once had a heart.*

*But inside this old carcass... A young guy still dwells,  
And now and again... my battered heart swells*

*I remember the joys... I remember the pain.  
And I'm loving and living... life over again.*

*I think of the years ..all too few... gone too fast.  
And accept the stark fact... that nothing can last.*

*So open your eyes, people... open and see.  
Not a crabby old man. Look closer...see...ME!!*

Contributed by Joseph Alberstadt,  
age 70, PLS since age 41

### AND ALWAYS REMEMBER:

*Life is not measured by the number of breaths we take, but by the moments that take our breath away.*

## MEDICAL RESEARCH

Renewed hope blossoms this spring as we enter a season of exciting discoveries, groundbreaking research and budding new therapies. Scientists continue to unearth critical factors causing motor neuron disease, planting the seeds for effective treatments and cures. Molecular discoveries have enabled experts to better understand the effects of proteins on motor neurons and the role of the surrounding cellular environment. SPF scientists continue to solve the mysteries of brain development and function, while ongoing case studies have broadened overall knowledge of disease progression and diagnosis. Stem cell research continues to evolve as a new dawn of promise appears on the horizon.

*Betsy Baquet, Medical Editor*

### PROPOSED POTENTIAL THERAPIES FOR ALS - NOVEMBER, 2007

Great progress has been made over the past few years in the understanding of why motor neurons die. This is critical to developing effective treatments to slow the progression of ALS, as well as other motor neuron diseases, and preventing their onset.

Scientists have determined that different parts of motor neurons degenerate at different times and for different reasons. More and more evidence suggests that in ALS, the axon, which is the long extension of the cell that branches off and attaches to the muscles, starts to degenerate before the cell body—the bulbous portion of the cell containing the nucleus. Studies have shown that protecting the cell body alone does not work, reinforcing the idea that different parts of the motor neuron are dying by different molecular processes. Protecting both the axon and cell body, as well as surrounding glial cells, has become the focus for many scientists developing therapies for clinical trials.

Riluzole is currently the only FDA approved therapy, which typically extends survival by several months. This works by curbing the release of harmful chemicals that damage motor neurons. Encouraging research has increased the number of prospective therapies for ALS, and possibly other motor neuron diseases. Scientists have already identified certain molecules that aid in the protection of axons, cell bodies and other important cell types. Employing different drug therapy techniques, such as viral introduction or injection into cerebrospinal fluid, scientists have seen positive results in animal models. When increased amounts of cell-protective molecules, such as NAD, VEGF and IGF-1 are introduced into the targeted cells, disease onset was delayed and progression was slowed. Another therapy under research is the use of RNA interference, or RNAi. A clinical trial is in the planning stages for patients with familial ALS.

Recent breakthroughs in stem cell research have led scientists down new roads for treating ALS and other neurological disorders. Originally, stem cells were being used to replace damaged nerve cells. However, research shows grafted stem cells can act as a biological pump delivering vital growth factors to protect and regenerate injured nerve cells in the spinal cord.

Surprisingly, research has also proven that regular exercise can stimulate the growth of new neurons and increase the level of growth factors in the nervous system. Animal studies have also shown physical exercise can protect neurons following trauma or disease onset. Remarkably, when mice received both exercise and IGF-1 therapies, their survival rate went from 120-202 days. Lifestyle, eating habits, as well as genetics, are also being researched as defenses against ALS and other motor neuron diseases.

SOURCE: “Playing Defense Against Lou Gehrig’s Disease,” Scientific American, 2007, November, p. 86-93.

### RESEARCH: SPF FUNDED HARVARD RESEARCHERS PUBLISH NEW FINDINGS - JANUARY 28, 2008

A team led by Jeffrey Macklis at Harvard has discovered a protein, and its associated gene, that regulates the sequence of events that occur during in-utero brain development. This protein, SOX5, is critical in preventing the premature emergence of normally later-born neurons in the brain. Deficiency, loss-of-function or overexpression of this protein disrupts the proper order of events necessary for normal brain development. Dr. Macklis and his colleague, Dr. Paola Arlotta, are both SPF funded scientists.

SOURCE: Neuron, Volume 57, Issue 2, 24 January, 2008, p. 232-247  
[www.tinyurl.com/yuzuwy](http://www.tinyurl.com/yuzuwy)

### ITALY: LITHIUM SLOWS ALS PROGRESSION IN 44 PATIENTS - FEBRUARY 4, 2008

Daily doses of Lithium, along with Riluzole, delayed progression of ALS in an Italian study of 44 patients. No treatment to date has shown such a dramatic effect on this disease. At the end of a 15-month trial, about 30 percent of the 28 patients that took Riluzole only had died, while all 16 patients receiving Riluzole plus Lithium had survived. The disease progressed rapidly in those patients on Riluzole only, but progressed very slowly in the Riluzole-plus-Lithium group. “MDA has already had conversations with researchers in the U.S. to follow up on these results with a larger, confirmatory study” according to Dr. Valerie Cwik, MDA Medical Director and V.P. of Research.

SOURCE: [www.als-mda.org/research/news/080204Lithium\\_slows\\_ALS.html](http://www.als-mda.org/research/news/080204Lithium_slows_ALS.html)

## **PLS CASE REPORTS—POLAND - FEBRUARY 15, 2008**

The debate continues whether PLS is a distinct disease or whether it represents one end of a spectrum of motor neuron diseases. A study was conducted in Poland where four PLS patients were observed. Slow progression was common among them, as well as only upper motor neuron signs during the time of observation, which covered a period from 1990 to 2007. The findings support other studies suggesting the pure PLS cases have a prolonged course of disease with a high level of independence when compared to other motor neuron diseases.

SOURCE: Clin Neurol Neurosurg. 2008 Feb. 7  
[www.ncbi.nlm.nih.gov/pubmed/18262342?dopt=Abstract](http://www.ncbi.nlm.nih.gov/pubmed/18262342?dopt=Abstract)

## **RESEARCH: JIP1 PROTEIN REGULATES AXONAL DEVELOPMENT AND CORRECT BRAIN FUNCTION - FEBRUARY 15, 2008**

The JIP1 Scaffold Protein regulates axonal development in cortical neurons. Although its functional significance is not fully understood, its role for axonal transport is important. JIP1 is necessary for normal axonal development and promotes axonal growth dependent on its interaction with the motor protein kinesin-1 and c-Abl tyrosine kinase. JIP1 is therefore an important regulator of axonal development.

SOURCE: Curr. Biol. 2008 Feb. 6  
[www.ncbi.nlm.nih.gov/pubmed/18261906?dopt=Abstract](http://www.ncbi.nlm.nih.gov/pubmed/18261906?dopt=Abstract)

## **SCIENTISTS FIND NERVE-MUSCLE SIGNS GO BOTH WAYS - FEBRUARY 19, 2008**

Researchers have found that muscle fibers do more than passively receive signals from nerve fibers that tell them to contract or relax. Instead, signals traveling from muscle fibers to nerve fibers profoundly influence nerve-fiber location and function. In mice bred with a lack of the protein beta-catenin in the muscles, there was a malformation of neuromuscular junctions, the place where nerve and muscle fibers meet. However, lack of the same protein in the nerve cell did not cause this type of neurological problem. It can be concluded by this experiment that muscle beta-catenin is key for neuromuscular junction formation, and the findings could also provide leads to elusive nutritional factors produced by muscles that are critical to nerve cell survival and development. This research could also have implications for a variety of neuromuscular diseases.

SOURCE: [www.als-mda.org/research/news/080219nerve\\_nerve\\_muscle\\_signals\\_ALS.html](http://www.als-mda.org/research/news/080219nerve_nerve_muscle_signals_ALS.html)

## **PRIMEGEN BIOTECH RESEARCHERS ANNOUNCE NON-VIRAL REPROGRAMMING OF HUMAN CELLS INTO STEM CELLS**

**February 28, 2008**

Scientists from PrimeGen Biotech have derived stem cells from non-embryonic human cells, such as skin, without using viral methods. Unlike non-embryonic stem cells produced in the U.S. and Japan (as reported in the last issue of *Synapse*), PrimeGen researchers are the first to use methods that do not involve potentially tumor-causing viruses or genetic manipulations.

SOURCE: [www.medicalnewstoday.com/articles/98869.php](http://www.medicalnewstoday.com/articles/98869.php)

## **EXPERIMENTS SUPPORT LOOKING OUTSIDE NERVE CELLS IN ALS - MARCH 6, 2008**

Researchers have further extended the role of astrocytes, a nervous system support cell, in ALS. The teams found that diminishing production of a toxic protein in astrocytes, sharply slowed disease progression ALS mice. When the toxic protein was high, disease progression was faster, and surrounding cells produced more toxic compounds.

This evidence, along with other studies supporting these findings, makes a good case for looking beyond motor neurons alone for causes and treatment targets in ALS.

SOURCE: [www.als-mda.org/research/news/080306nerve\\_cells.html](http://www.als-mda.org/research/news/080306nerve_cells.html)

## **GERMAN COMPANY DEVELOPS GROUNDBREAKING ALTERNATIVE TO STEM CELL THERAPY -**

**MARCH 6, 2008**

Blasticon, a German biotech company, has a patented technology based on which white blood cells extracted from veins can be turned into cells with programmable properties comparable to those of stem cells and can be differentiated into different functional cells for diverse applications. The reprogrammed cells can be used both as diagnostic agents or for therapeutic purposes.

SOURCE: [www.medicalnewstoday.com/printerfriendlynews.php?newsid=99645](http://www.medicalnewstoday.com/printerfriendlynews.php?newsid=99645)

# YOUR SPF STATE AMBASSADORS

## VOLUNTEER OPPORTUNITY – JOIN OUR COMMUNICATIONS COMMITTEE

### AND BE PART OF THE SPF TEAM!

The people listed below have offered to be the SPF contact person for many of our states. We need an ambassador in each state where there are members of our patient community living. Even if your state has an Ambassador, please consider “adopting” one of our “orphan” states or offer to help your state ambassador. You don’t need to live in the state to help spread the word, welcome new people with PLS, SP and HSP. Help is also needed in larger states and especially in Canada. Please contact Linda Gentner, [Linda@gentner.com](mailto:Linda@gentner.com) - 510-651-5676

- AL** Elwanda Olander, [Lakehousetwo@aol.com](mailto:Lakehousetwo@aol.com)
- AZ** Erika Annis, [ArizonaMommyOf3@aol.com](mailto:ArizonaMommyOf3@aol.com) - 520-822-1936
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- NH** Judy Johnson, [juddbun@comcast.net](mailto:juddbun@comcast.net) (effective 7/1/08) (HSP)
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- WA** Jackie Bollinger, [seattlehspjackie@aol.com](mailto:seattlehspjackie@aol.com) - 425-738-1374
- WV** Ronnie Grove, [frogrove@verizon.net](mailto:frogrove@verizon.net) - 304-258-5275
- CANADA** Jean Chambers, [jeanchambers@SHAW.CA](mailto:jeanchambers@SHAW.CA) - 604-990-1060
- CANADA** -- need more hands to help

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7700 Leesburg Pike, Ste 123  
Falls Church, VA 22043

*People Doings*



*A Winning foursome at the RGM Golf Classic*



*The putting contest is underway*



*Jane Anne King enjoys being able to stand again*



*Bruce Maser, Kathi Geisler, and James Scuderi*



*Craig from the Ataxia Foundation Support Group and Ed Geisler cooking*



*Karen Johnson attended HSP Meeting in Madrid.*