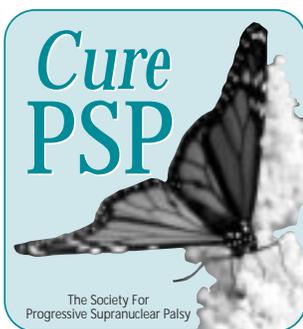


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website:
www.psp.org

INSIDE:

**THE LATEST IN
PSP RESEARCH**

**SPECIAL EVENTS:
VOLUNTEERS
RAISE MONEY
FOR THE
SOCIETY'S
PROGRAMS**



The San Francisco PSP Conference For Families



San Francisco, California, home of North Beach, Fisherman's Wharf, Union Station, Alcatraz, a historic car system and The Golden Gate Bridge. Did you know that cable cars have been a signature of San Francisco since 1873? Did you know that the nearly two-mile Golden Gate Bridge, completed in 1937, sways 27 feet to withstand winds of up to 100 miles per hour? San Francisco's Laurel Heights Conference Center at UCSF was the setting for the Society's "PSP Conference for Families" on Saturday, April 24, 2004. Over sixty-five people attended to learn about progressive supranuclear palsy and ways to better manage daily activities of life.

Nancy Brittingham, Editor of *The PSP Advocate*/Director of Special Projects, and Carol Marchi, former Society board member and current member of the Outreach and Education Committee, welcomed the guests and were pleased to introduce an excellent panel of speakers.



James Tetrud, MD, Director of the Movement Disorders Treatment Center, The Parkinson's Institute, Sunnyvale, California presented "An Overview of Progressive Supranuclear Palsy." Dr. Tetrud discussed many topics including atypical parkinsonisms, the clinical features of PSP, its epidemiology and pathology. Environmental risk

factors and future therapy were also included in his program. Dr. Tetrud presented these therapeutic issues for PSP patients and families to discuss with their neurologist.

DRUG TREATMENT OF PSP:

- Carbidopa/levodopa (Sinemet)
- Dopamine agonists (Requip, Mirapex and Permax)
- Anticholinergic drugs (Artane, Cogentin)
- Cholinergic (Aricept, Exalon, Reminyl)
- Tricyclics (Elavil, Tofranil)

VISUAL DISTURBANCES IN PSP:

- Decreased blink rate-artificial tears
- Blepharospasm-Botox
- Inability to open eyes-talking books
- Double vision-prisms
- Inability to look down-prisms

FALLS :

- Caused by impaired postural reflexes
- Often in the home
- Physical therapy gait evaluation
- A major reason for hospitalization
- Cane, walker, wheelchair may be necessary
- Upright walker

COGNITIVE CHANGES:

- Memory difficulties: 11-29% of PSP patients
- Range from benign forgetfulness to dementia
- May lower threshold for developing hallucinations.
- May be mimicked by moderate to severe depression
- May be associated with agitation or behavioral change

The Society for Progressive Supranuclear Palsy

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Reba and David Saks

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**In 1963, Dr. J. C. Steele, together with Dr. J. C. Richardson and Dr. J. Olszewski, identified PSP as a distinct neurological disorder.*

VISION

A world free of PSP

MISSION

The Society for PSP is dedicated to increasing awareness of this under-recognized disorder, advancing research toward a cure, and providing support and education for persons with PSP, their families and healthcare professionals.

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(In memory of Henry and Jane Ogiba)

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(In memory of Lois Croft Davis)

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It's a Girl!!



Society Director of Outreach & Education, Jessica Quintilian, and her husband, Sean, welcome with love their new little angel...

Juliana Grace
Born March 1, 2004
12:59 p.m.
6 pounds, 14 ounces
20 inches

Congratulations to Jessica and Sean on the birth of their first child!



A Special Thanks

For the fifth year, Mr. Jay Troxel continues to support the publication of The PSP Advocate in memory of his beloved wife, Eloise H. Troxel.

"I didn't ask for it to be over, but then again, I never asked for it to begin. For that's the way it is with life, as some of the most beautiful days come completely by change. But even the most beautiful days eventually have their sunsets."

Unknown.



These words are profound as I reflect on my journey with the Society. It is interesting to me how certain events take you down a path you might not otherwise have traveled and the experience can be quite amazing. Because of this tragic disease, it has brought all of us together to share one vision, one mission and the chance to meet extraordinary individuals who have become my friends. For me, it has been priceless. I have grown in many ways both personally and professionally and many lessons have been learned. It was Eleanor Roosevelt who said, "you gain strength, courage and confidence by every experience in which you really stop to look fear in the face. You must do the thing you think you cannot do." Those words resonate with me as you can well imagine serving as the President for the Society, it has been very fulfilling but time for me to move on and travel new paths. What I hope I leave behind is the conviction to carry on what was started many years ago by my predecessors and throughout my tenure. As I pass the gavel on to the incoming President, Stephen Hamer, I am confident that his leadership, the strength of the Board and the guidance of the Executive Director will move the organization forward. I know I leave it in good hands. My philosophy on life is that with every ending there is a new beginning and I look forward to a beautiful sunrise. Thank you for your trust and for the opportunity to serve as your Board President over these last three years.

Sincerely,
Liz Brisson
President



Liz honoring John Steele, MD/FRCP and Society guardian angel, Jay Troxel



Liz with her husband Roger

PSP Research Update



Laurel Bolin, PhD., Assistant Research Scientist, The Parkinson's Institute, Sunnyvale, California, presented "The Latest PSP Research" at the San Francisco Family Conference. PSP research has finally gained international momentum. Exciting and hopeful work is being done to find the cause and cure of PSP. Laurel is one of the Society's research grant recipients.

The Society for PSP supports strategic areas of research that will contribute to our understanding of the disease and, hopefully, identify therapeutic possibilities. Research focus includes (1) the genetics of PSP, (2) new therapeutic approaches to PSP, (3) development of animal models for PSP and (4) biomarkers of PSP.

With the sequencing of the human genome, much interest has focused on the genetic links to human disease. We know that the pathological hallmark of PSP is aggregations or "tangles" of the structural protein, tau. Therefore, the gene that encodes the tau protein continues to be analyzed. It has previously been shown that PSP patients express the H1 haplotype of the tau gene. Dr. Matt Farrer of the Mayo Clinic is examining this area of the gene to identify differences between PSP and control DNA. Dr. Allison Goate of Washington University in St. Louis is examining the H1 haplotype by individually sequencing that portion of the tau gene in PSP patients. Data from these studies may reveal characteristics of the tau H1 haplotype that are unique to PSP and potentially causal in the disease.

New therapeutic approaches are, of course, of great interest. Two studies supported by the Society for PSP are exploiting biochemical analysis of tau protein modifications in very different ways. Dr. Nancy Muma of Loyola University has shown that PSP brain tissue contains high levels of an enzyme, transglutaminase, which links tau proteins in tangles. She has identified an inhibitor of transglutaminase, cystamine, which protects brain cells in culture. She will now test its ability to prevent tau tangle formation in a mouse model. Professor Kenneth Kosik at Brigham and Women's Hospital in Boston has studied the enzyme, Cdk5, which modifies tau and makes it more likely to aggregate and become toxic. He used a biochemical screen to test 60,000 chemicals for Cdk5 inhibitory activity. He will now test six candidates in a model system to determine how effective they are in limiting tau aggregation and cell death. In a different approach, Dr. David Brooks of University College London is using diagnostic information and imaging techniques to characterize brain inflammation and PSP. He will correlate brain PET scans that reveal the extent of inflammation with MRI data indicating brain cell activity and compare these data with the PSP patient's clinical progression. Taken together, this information will determine if anti-inflammatory therapeutics are warranted. The hope is that these diverse studies may converge in the development of effective therapeutic intervention(s) in PSP.

To understand the PSP disease process, animal models are necessary. Dr. Parvoneh Navas of the University of Washington is developing a double mutant mouse model. She

has previously identified mutations in the tau and parkin genes of a PSP patient. This is interesting because parkin mutations cause an early onset form of Parkinson's disease. The mutant forms of these genes will be incorporated in the mouse genome. The resultant transgenic mice will be analyzed for the effects of mutant tau and parkin proteins on brain function. Professor Etienne Hirsch of INSERM is examining a chemically induced model of neurodegeneration. He has injected rats with annonacin, a plant extract that interferes with cellular energy metabolism and could be the cause of the PSP-like parkinsonism on the Island of Guadeloupe. In these animals, the neurons that die are those in areas of the brain associated with PSP pathology. This research continues with a focus on tau protein aggregation in the dying neurons. These models may help define distinct mechanisms that contribute to neurodegeneration in PSP.

The identification of a biomarker for PSP would permit accurate diagnosis. Today a diagnosis of PSP relies on clinical symptoms assessed by a movement disorders specialist. There is also considerable interest in a biomarker for what it might reveal about the disease. Most disease biomarkers are present in the circulating system i.e. blood. In neurodegenerative disease, the fluid that bathes the brain tissue, cerebral spinal fluid, is also a potential source of a biomarker. We have analyzed blood sera from Dr. James Tetrud's PSP patients. We reasoned that the abnormal accumulation of tau in brain cells could trigger an auto-antibody response which could be measured in the circulatory system. Assays indicate that indeed, 65% of PSP patients tested make antibodies against tau. Increasing the numbers of patient sera analyzed will determine the significance of these results. This evidence of an immune response to abnormal tau may reflect immune system activity that damages brain cells and we are investigating that possibility.

This update covers only a few of many ongoing research projects that are funded by the Society for PSP. This grant support will produce a body of scientific data from diverse investigative approaches that taken together could lead us to the cause and cure of PSP.

Research Grants Program

The Society for PSP provides grant support for basic and clinical research <http://www.psp.org/research_center/research_grant_recipients.asp> in progressive supranuclear palsy. Application deadlines are April 1 and October 1 of each year.

Proposals designed to collect pilot data in preparation for a Federal or other large grant application are encouraged. In 2002-2003, 15 of 36 submissions were funded.

PIs will be expected to present their results at the Society for PSP's annual research symposium held as a satellite to the meeting of the Society for Neuroscience. Travel and lodging expenses for this one-day meeting should be included in the budget. The presentation would be made at the first symposium occurring after the expiration of the term of the grant.

To learn more about the details of past PSP research grants <http://www.psp.org/research_center/research_grant_recipients.asp> please refer to back issues of our newsletter, *The PSP Advocate* <http://www.psp.org/press_room/newsletter.asp>

PSP Families Unite! This is something we all can do.

*Become a Member of the 2004 "Research for the Cure" Honor Roll
Support the critical and dedicated work of our PSP researchers.*

Dear PSP Advocate Friends,

Progressive supranuclear palsy (PSP), one of the "tauopathies" is one of the traditionally inscrutable, untreatable neurodegenerative disorders. The Society for PSP was founded in 1990, in part, to remedy this situation. It has been remarkably successful in helping to make this relatively rare disease known to the neurological and neuroscientific community. The Society for PSP has for the past seven years maintained a grant program funding some of the most interesting and promising avenues of research in PSP. The 2004 International PSP Research Symposium, in San Diego, California, on October 28-29, 2004, will bring together the Society's grantees since 2002 to present their work and benefit from the criticism and inspiration of their colleagues.

As you read in the past issue of *The PSP Advocate*, our research funds are dwindling. We must find a way to keep fostering and supporting PSP research which has now gained international momentum. The Society must continue to accelerate the pace of this research. Research is expensive but think of the results-finding the cause of PSP and then its cure. The Society's vision- "A world free of PSP." We need your help.

This Symposium will truly be an exciting and educational event. Researchers from all over the world will provide presentations on the progress they have made today with the hope for tomorrow in finding a cure for PSP. You can be a part of this exciting event as well as future research. Please join The Society for PSP by becoming a "Research for the Cure" sponsor and join the Honor Roll for the 2004 International PSP Research Symposium. The Honor Roll will be published in the 2004 Research Symposium program as well as *The PSP Advocate*. Show our researchers around the world that you support their critical and dedicated work.

I traveled the PSP journey with my dad as many of you have with your loved ones. But, the Society had not yet been founded. There was little information about the disease and absolutely no PSP research. Fortunately, great strides have been made and must continue to be made in the future. So, when you are asking yourself what you can do to fight this disease, support the Society's research program. Send in your valuable gift today. Join me and become a member of the 2004 "Research for the Cure" Honor Roll. When the cause and the cure is found, you will be a part of this life-saving discovery.



My father on vacation at the beach with the family

Thank you,
Nancy Brittingham
Editor, *The PSP Advocate*



The 2002 International PSP Research Symposium

"RESEARCH FOR THE CURE" HONOR ROLL

*Support the 2004 International PSP Symposium in San Diego.
You will be recognized in the Symposium Program and *The PSP Advocate*.
Give you gift online at www.psp.org or use the enclosed envelope*

Your gift is TAX-DEDUCTIBLE. A copy of the Society's financial statement is available upon request.

Research - San Francisco

San Francisco PSP Conference

Continued from Page 1

Evaluation:

- Brain imaging (MRI, CT)
- Psychological testing (e.g. MMSE)
- EEG
- Blood work (e.g. thyroid profile, vitamin B12, serology, chemistry panel)

COGNITIVE DECLINE TREATMENT:

Consider eliminating or reducing:

- Anticholinergics (e.g. Artane, Cogentin, Pro-Banthine, Kemadrin, Atrovent, Detrol, Ditropan)
- Amantadine
- Levodopa or dopamine agonist dose

Trial of cholinesterase inhibitors

- Aricept (5 to 10 mg per day)
- Exelon (1.5 to 6 mg twice daily)
- Reminyl (4 to 16 mg twice daily)

Memantine (Namenda) 5 mg/day to 10 mg twice/day

SLEEP DISORDERS

- Insomnia

Sleep fragmentation and difficulty with sleep initiation: tricyclic agents, benzodiazepines, Benadryl or "IPM" OTCs
Treat depression

REM-behavioral disorder: clonazepam

Consider sleep apnea (Sleep study may suggest CPAP)

- Excessive daytime sleepiness

Correct poor sleep at night

Reduce anticholinergics, amantadine

Reduce dopamine agonist, levodopa dosages if possible

May use selegiline; caffeine; Provigil

Susan Langmore, PhD Speech and Language Pathologist, Assistant Clinical Professor of Speech Pathology Department of Neurology, UCSF, presented "Speech and Swallowing Problems in PSP" Listed below are some of the topics covered in her presentation.



COMMON TERMINOLOGY:

- Dysphagia: any difficulty swallowing and usually occurs following onset of speech disturbance
- Aspiration: foreign material entering the airway below the level of the vocal folds
- Dysarthria: speech disorder due to neurologic damage and is an early symptom that usually begins within 24 months.

LANGUAGE & COGNITIVE PROBLEMS

- Occur in most patients eventually
- Language and cognitive problems can make speaking more difficult
- Trouble getting a sentence started; slow to process and respond; difficulty shifting topics quickly
- Reading and writing problems may appear

NATURE OF SWALLOWING PROBLEM

- Slower to initiate and to complete the swallow
- Food and liquid may fall into throat before swallow is triggered - can fall into airway (aspiration) - coughing

- Slow, weak tongue movements
- Incomplete food clearance through the throat

TREATMENT OF THE SWALLOWING PROBLEM

- Swallowing therapy - exercise, strategies
- Supervision and cueing may be needed if person can't self-monitor well
- Repeat swallow ("dry" swallow)
- Alternating solids and liquids
- Take one sip at a time
- Decrease bolus size (smaller bites / sips)
- Decrease rate of eating
- Sit upright / keep neutral head posture
- Minimize distractions
- Diet texture modification
- Soft-cooking foods, grinding meats, pureeing
- Moistening dry-textures
- Thickening liquids

Many questions were asked by the guests and the speakers answered as many of them that time would allow. One guest stated "The most useful information came from asking presenters specific questions both in the presentations and after in the question and answer session."

PSP families were very appreciative that the Society planned this conference. Families came from Pasadena, Los Angeles, Nevada and Texas. Most PSP families had never seen another PSP family. "It was comforting, in a way, to be in a room with folks who are experiencing PSP firsthand." "This was a rare chance to get together with other families." "We no longer feel alone because we have met others in our same situation." The conference ran over time and there still was not enough time! Soon though, each attendee that indicated interest, will receive the names and contacts of the people that were there. Use this list to call each other, share with each other and support each other. And ... perhaps a support group will grow from this meeting.

Society for Progressive Supranuclear Palsy Brain Donation Program

For Diagnosis of and Research on PSP

Society for PSP Brain Bank

Supported by the Eloise H. Troxel Memorial Fund
Mayo Clinic Jacksonville • Jacksonville, FL 32224

The purposes of the Society for PSP Brain Donation Program are:

1. To provide families with postmortem diagnostic evaluation for relatives suffering from PSP and related disorders.
2. To provide tissue for PSP research to scientists at medical institutions or other research centers.

To obtain informational packets about brain tissue donations, please contact the Society for PSP.

Phone: (800) 457-4777, (410) 486-3330 / E-mail: SPSP@psp.org

The Society for PSP, Woodholme Medical Building, Suite 515
1838 Greene Tree Road, Baltimore, MD 21208

If you are considering brain donation, it involves a great deal of preparation - So the time to plan is NOW!

PSP Advocate, Second Issue 2004

Outreach

The 56th Annual American Academy of Neurology

April 24th - May 1, 2004
San Francisco, California



The American Academy of Neurology (AAN) provides valuable resources for medical specialists worldwide who are committed to improving the care of patients with neurological diseases. The AAN's more than 18,000 members look to the AAN for the most comprehensive professional development, career enhancement, and practice improvement opportunities available.

The 56th Annual Meeting Scientific Program in San Francisco highlighted leading research on the most critical issues facing neurologists. More than 1,000 poster and platform presentations covered the spectrum of neurology - from updates on the latest diagnostic and treatment techniques to prevention and practice management strategies. The Society for PSP was represented by Nancy Brittingham, *The PSP Advocate* editor, at an educational exhibit at this year's meeting which continued the tradition of cutting-edge neuroscientific research and top-quality education programs. "The Diagnosis of PSP" (CD-Rom) by Lawrence Golbe, MD, Chair of the Society Medical Advisory Board, was distributed at the Society booth. This educational tool was greatly appreciated by all who received it.

Upcoming Events

BALTIMORE SUPPORT GROUP DESSERT RECEPTION

Sunday, September 12, 2004 • 2:30 - 5:00 p.m.
BWI Airport Marriott Hotel
1743 West Nursery Road • Baltimore, MD 21240

Join us for a "meet and greet" session of the new Baltimore support group. Come enjoy some tempting treats, meet other local PSP families and learn practical tips for living with PSP and the benefits of being part of a PSP support group. Speakers include Paul S. Fishman, MD, PhD and JoAnn Hart.

This event is free. For information, contact Jessica Quintilian, The Society for PSP, 1-800-457-4777 or email: outreach@psp.org. Kindly RSVP by September 3, 2004

THE WASHINGTON STATE REGIONAL FAMILY CONFERENCE ON PSP

Sunday, September 26, 2004 • 12:30pm-4:00pm
(11:30am-12:30pm - Pre-conference meet & greet)
Tukwila Community Center
12424 42nd Avenue South • Tukwila, WA 98168

Speakers will include Dr. Parvoneh Poorkaj-Navas, Research Assistant Professor from the University of Washington, physical therapists Laurel Beck and Ann Zylstra and speech-language pathologist Roberta Kelley from Virginia Mason Medical Center. \$25 registration fee.

PSP Advocate, Second Issue 2004

CONFERENCE ON PROGRESSIVE SUPRANUCLEAR PALSY, PARKINSON'S DISEASE AND ESSENTIAL TREMOR

Friday, October 8, 2004

Kellogg Center, East Lansing, Michigan

The Society for Progressive Supranuclear Palsy is teaming up with the Michigan Parkinson Foundation and International Essential Tremor Association to host a program for professionals and patients and families. The University of Michigan Medical School will offer continuing education credits for physicians and other health professionals. Two conference tracks will be offered: a full day for health professionals and a half-day for patients and families. The family track will include a breakout session of PSP as well as general sessions on family adjustment to chronic illness, music therapy and support strategies for patients and care partners.

For information, contact Jessica Quintilian, Director of Outreach and Education, 1-800-457-4777, email: outreach@psp.org

THE SAN DIEGO FAMILY CONFERENCE ON PROGRESSIVE SUPRANUCLEAR PALSY

Saturday, October 30, 2004 • 11:30am-5:00pm
The Embassy Suites Hotel
601 Pacific Highway, San Diego, CA

Speakers will include Neal Hermanowicz, MD, Director Movement Disorders Program, University of California Irvine, Zeba Vanek, MD, MBBS, DCN, Assistant Professor of Neurology, UCLA, and Nancy Sedat, MS/CCC-SLP. \$25 registration fee.

THE NEW JERSEY/NEW YORK PSP FAMILY CONFERENCE

Saturday, November 6, 2004

Robert Wood Johnson University Hospital
New Brunswick, New Jersey

Speakers will include Lawrence Golbe, MD, Chair of the Society Medical Advisory Board, Katharine Towlen, SLP, Laura Glick, PT and Marcus Garand, RD. Presentations will include research, nutrition and swallowing, physical therapy tips and much more.

For information, contact Jessica Quintilian, Director of Outreach and Education, 1-800-457-4777, email: outreach@psp.org \$25 registration fee.

3-WHEEL SCOOTER FREE TO A GOOD HOME!

Model: Shuttle SC100
manufactured by Pride Mobility Products Corp. Foldable molded plastic seat with removable seat cover and foam insert. Includes armrests, user adjustable seat height and positioning. Length: 46.5 inches. Width: 24 inches. Weight 109 lbs. (without batteries). Very durable, with a weight capacity of 300 lbs.

FREE to a PSP family in need, but must make arrangements to pick up the scooter from Tampa, Florida. For more information, contact Jessica Quintilian, Director of Outreach & Education, 1-800-457-4777, outreach@psp.org



Living Day-To-Day With PSP: A Spouse's Perspective

FIRST OF A SERIES

Joyce Munsell is a registered nurse and primary caregiver to her husband of 36 years. Gary was diagnosed in 1998 after experiencing vague symptoms for over 2 years. He is no longer verbal or ambulatory and Gary communicates through the use of a touch screen computer. If you have everyday care questions you wish her to address in upcoming articles, you may contact Joyce at jmunsell1@cs.com



Do you remember that day sitting in the physician's office, observing a serious demeanor on the doctor's face? Actually, this may have been only one of many such encounters. Together you may have seen numerous doctors while continuing to see the progression of troubling symptoms. You may have been very diligent in following the medical directives (medication and testing), only to find yourself listening to descriptive words such as rare, a movement disorder, Parkinsonian-like symptoms, progressive, etc. etc. etc.

And so you learned your lives would be forever changed. A once strong and robust individual was enduring a diagnosis sometimes termed as an "orphan condition." That's a euphemism for a condition which occurs infrequently in the general population. For this reason, it receives little or no funding for research, is often difficult to diagnose and is even more difficult to find out how to treat the symptoms which arrive so subtly that you may not notice a new and significant change. Indeed, many practitioners may not come across such a diagnosis for years in their practice of medicine, if at all.

But here you are. How do you begin? What do you do day-to-day to make living with PSP as easy as you can? How do you keep your loved one safe from the falls that seem to be coming more frequently now? How do you address the numerous health issues which may reveal themselves over the course of time?

In each article I'd like to explore some of the most common areas of concern I have experienced and share how we have managed each of the new challenges the condition presents to us.

AS THE CAREGIVER, THE IMPORTANCE OF SAFETY IS OF HIGH PRIORITY.

Falls and maintaining stability are two of the first serious areas affected by PSP. Some daily activities that are affected include driving a vehicle, walking, and working on activities which require fine dexterity.

Simple common sense tell us that someone with PSP who is experiencing balance, ocular (eye) or movement symptoms should not drive. But, often times, family members are very reluctant to suggest that perhaps the time has come to have someone else drive. Sensitivity and understanding must factor in to the formulation of such a request. Don't wait for even the slightest "accident" to address the serious consequences that driving while impaired can have on a family. A consultation with the physician to explain how PSP affects the speed

of reactions might be in order. You may want to suggest to your loved one that he/she be tested at a driving school (many schools will do this for free), or best of all, sit down and have a frank talk about how you care and you will do all you can to keep them from feeling a loss of "independence."

AS THE INDIVIDUAL EXPERIENCING THESE CHANGES, YOU HAVE PLENTY TO KEEP IN MIND.

The strange thing with PSP is that just when you think you have reached a way to accommodate a new (and distressing) symptom, something else pops up. Take walking for example... you can be in your own home or in an area where you feel most comfortable, and then it happens. Something as unexpected as a slight nudge can knock you off your feet. At first, simply taking someone's arm is stabilizing enough. Keep in mind that you don't want to wait for a fall before you begin using a cane.

Throughout the progression of the condition, it is very wise to identify a good physical therapist that can help ease each transition. It is important to have a professional to teach the proper gait, correct use of the cane or walker and to establish a good exercise pattern to maintain strength and conditioning. A professional will be able to identify the correct, safe equipment for you. Your insurance may well assist in payment as well.

Getting in and out of bed will become an issue. While there are rails and aids which can assist for awhile, we found that a semi-electric bed was by far the best investment for the longest time. (Again, ask your insurance for coverage). The height of the bed is adjustable so that as you find it more difficult to pull up from a low position, you can more simply turn and place your feet flat on the floor in a stable sitting position – it gives you more leverage to push upward to a standing position without falling backward. Also, as time goes on, it's more difficult to sleep lying down. The head and knees rise to accommodate a more comfortable sleep position. It's easy to add a trapeze and side rails for additional comfort and safety.

To accommodate continued comfort at the dinner table, you can use a number of cost effective methods before using a wheelchair. A side chair with wheels worked best in the beginning and then we found an inexpensive "executive" chair on wheels best offered support to the back and neck. One can be easily assisted in and out of the chair and it actually could be raised and lowered to accommodate different heights of tables. A high-backed wheel chair which reclines to a comfortable position keeps you part of the "family action."

Looking for early warning signs can help to virtually eliminate random falls, thus preventing potential injuries. Don't put off embracing an aid or a suggestion from your health-care professionals. The goal is always safety first! I hope that some of these suggestions will help you and your family as you continue on your journey day-to-day.

Joyce Munsell, RN, CCM, MPA

When giving a gift to United Way, you can designate The Society for PSP at 1838 Greene Tree Road, Suite 515, Baltimore, MD 21208 as a recipient.



Ask the Doctor

Question:

Is there any success with stem cell treatment and PSP?

Answer:

PSP involves many parts of the nervous system from the cerebral cortex (i.e., the surface of the brain, where most thinking occurs) down to the end of the spinal cord. Stem cells can only work in or close to the area in which they are surgically implanted. Any treatment to restore lost brain cells or connections in a widespread number of brain areas would have to be delivered via the bloodstream. So, while we may in the near future be able to ameliorate one aspect of PSP by implanting stem cells in one area (for example, helping the the slowness of limb movement by implanting stem cells into the striatum), this would not help the difficulties with thinking, eye movement, speech, swallowing, balance or bladder control, to name a few. It would not be practical to implant stem cells in many of the involved areas of the brain, some of which are very tiny and present a difficult surgical target.



Lawrence I. Golbe, MD

Stem cells in the brain would be useful for helping strokes or localized brain injuries, but I have little hope for them in PSP, or even Parkinson's disease, another disorder with involvement of many disparate brain areas. For those disorders, we should work on finding drugs that stimulate brain cell regrowth that can be delivered via the bloodstream after being swallowed or injected in conventional fashion.

Research in such drugs is proceeding quickly and I am optimistic that PSP will benefit from such advances before too long.

Think Safety

More than one-third of adults ages 65 years and older fall each year. Among older adults, falls are the leading cause of injury deaths and the most common cause of non-fatal injuries and hospital admissions for trauma. In 2001, more than 1.6 million seniors were treated in emergency departments for fall-related injuries and nearly 388,000 were hospitalized (CDC 2003).

GENERAL HOME MODIFICATION OPTIONS

TO IMPROVE LIGHTING AND VISIBILITY:

- place light switches close to room entrances
- install light switches at the top and bottom of stairs.
- install lighted switch plates
- use high-watt light bulbs in stairways and other hazardous areas
- provide sufficient, even lighting throughout the home
- install additional lighting, if necessary
- install a voice or sound activated adapter to turn on

- lights and appliances
- install under-the-cabinet lights in the kitchen
- place a night light in the path between the bedroom and bathroom
- install cordless battery-operated lights inside closets and cabinets
- install motion-sensitive exterior lighting
- use bright colors
- use contrasting colors

TO ENHANCE SAFETY AND SUPPORT:

- remove loose rugs
- secure mats with non-skid backing or double-sided carpet tape, secure telephone and electrical cords
- install non-slip flooring, especially in kitchens and bathrooms
- use non-skid mats or adhesive strips in bathtubs
- remove thresholds
- rearrange furniture, move it out of paths and walkways
- place barriers at dangerous locations
- edge stairs with bright non-skid tape to highlight changes in floor levels
- install rubber treads on uncarpeted indoor and outdoor stairs
- install handrails and grab bars, particularly in stairways and bathrooms
- clamp adjustable safety rail onto edge of bathtub
- install anti-scald devices on faucets and shower heads
- install smoke detectors near kitchens and bedrooms
- install plug-in carbon monoxide detectors
- install a portable security intercom
- install an emergency response system

TO IMPROVE ACCESSIBILITY, EASE OF USE AND CONVENIENCE:

- install a wheelchair ramp
- arrange furniture to leave wide corridors for wheelchairs or walkers
- ensure chairs have arms and seats that are high enough to allow for easy sitting
- widen doorways by removing moldings and replacing hinges
- install revolving shelves
- convert a ground-floor room into a bedroom
- install a bed rail and/or handrails
- install a commode (portable toilet) in the bedroom
- lower closet shelving and cabinets,
- install slide-out shelving, adjustable rods, baskets and other closet organizers
- replace round doorknobs with lever handles
- attach lever adapters to round doorknobs
- install lever-handle faucets in kitchens and bathrooms
- replace shower heads with hand-held shower heads
- install a raised toilet seat, shower or tub chair
- Install crank-operated windows
- buy clocks with large numerals, telephones with large buttons

Fitness Counts

Some of the symptoms of PSP include rigidity, slowness and impaired movement. Evidence suggests that regular exercise can improve some of these symptoms and enhance quality of life. This article includes a sample workout, but you should consult closely with your doctor, physical therapist or health care professional when devising your own exercise program.

Some of the benefits of regular exercise for the person with PSP can include:

- Improved coordination and balance
- Increased muscle strength and flexibility
- Reduced muscle cramping.
- Improved posture.
- Improved control over gross motor movements, such as walking.
- Reduced stress levels.
- Greater confidence in performing daily activities.

Seated Exercises

ENHANCING FACIAL EXPRESSIONS

(If possible, monitor facial movements in the mirror)

- Practice varied facial expressions: happy, angry, surprised, etc. Exaggerate each expression.
- Press lips together. Alternate with opening the mouth widely.
- Stick out the tongue. Move tongue slowly from side to side.
- Raise eyebrows up and down.
- Alternate broad smiling and puckering of lips. Hold each pose for a few seconds.

DEEP BREATHING

- Inhale deeply through the nose, allowing the diaphragm to expand. (The stomach will expand as you inhale if the diaphragm is engaged.) Keep shoulders down and relaxed.
- Slowly exhale through the mouth to a count of "5".
- Remember to practice this technique at any time throughout the day to promote relaxation.

PSP EUROPE

We are pleased to have a cooperative relationship with our sister organization, PSP Europe Association. For information on what is happening in the United Kingdom and throughout Europe, contact:

Michael Koe
The Old Rectory
Wappenham, Nr Towcester, Northamptonshire
NN12 8SQ
Telephone 0044 (0) 1327 860299
E-Mail psp.eur@virgin.net
Website <http://www.pspeur.org>

NECK SWEEPS

- Bring chin down to chest.
- Rotate head to look over shoulder as far as possible.
- Hold position for count of "5".
- Repeat toward the opposite side.



SHOULDER SQUEEZES

- Place hands in front of chest.
- Pull elbows back, squeezing shoulder blades together.
- Avoid shrugging shoulders.

SHOULDER CIRCLES

- Rotate shoulder up, back, down, and forward in a circular motion.
- Do one shoulder at a time.
- Keep hand and arm relaxed.
- Repeat in opposite direction.



THE MAGIC WAND (seated)

This set of movements requires the use of a "wand"—30" to 36" in length is about right. You can use a dowel, yardstick or lightweight cane if desired. Hold the wand in both hands, shoulder width apart using an overhand grip.



WAND OVERHEAD

- Raise the wand overhead as far as possible.
- Slowly lower wand to lap level. (Keep elbows straight.)

WAND CIRCLES

- Move the wand in a large circular motion in front of you.
- Practice circles in both directions.



WAND "FIGURE 8"

- Move the wand in a "figure 8" motion in front of the body. (A smooth motion like paddling a kayak.)

GIVE A GIFT ONLINE

www.psp.org



Education

WAND DIAGONALS

- Follow arm movements with head and torso throughout these exercises.
- Start with wand near the hip.
- Raise wand up and across the body toward opposite shoulder. (see photo)
- Repeat, starting with wand near opposite hip.



FOREARM MOTION

- Place hands palms down, resting on knees.
- Flip hands over, so palms are toward the ceiling.
- Vary speed of rotating hand movements during practice.



PRAYER STRETCH

- Press palms together, maintaining total contact from wrists to fingertips.
- Hold fingertips toward ceiling, raising elbows out to sides.
- Hold praying hands position for a count of "20".



WRIST CIRCLES

- Move hand in slow complete circles. (Do one hand at a time.)
- Practice circles in both directions.
- Stabilize the forearm to isolate wrist motion.

FINGER/THUMB CIRCLES

- Touch each finger to thumb alternately.
- Form round circles between thumb and each finger.
- Vary speed of motion to promote good coordination.



PELVIC ROCKS

- Place hands on knees.
- Push one knee straight ahead, rocking hip and pelvis forward.
- Repeat motion on opposite side.
- Progress to "walking" hips forward and backward in the chair.

BACK ARCH

- Scoot forward to edge of the chair.
- Place hands in small of back.
- Thrust chest forward, creating inward curve in small of the back.
- Hold for a count of "20".



ANKLE CIRCLES

- Extend foot in front of you.
- Move foot in slow, complete circles.
- Repeat in both directions.

TOE MANEUVERS

- Place foot on opposite knee.
- Bend and straighten toes.
- Use hand to assist with motions, if needed.



SOLE STRETCH

- Roll small juice can or other object along the sole of the foot.
- Move slowly from heel to toes and return.

Reprinted from "Parkinson's Disease Fitness Counts"
NPF, Inc.

Education - Helpful Hints

Home Healthcare Products

Series IV

DAILY ASSISTIVE DEVICES

The following products can be ordered from:

Crestwood Communication Aids

1-414-352-5678 or www.communicationaids.com

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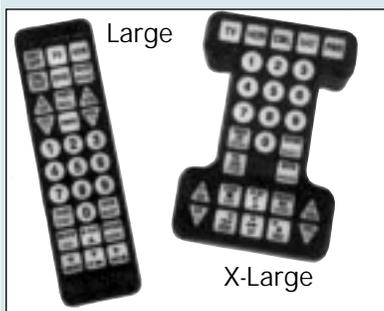
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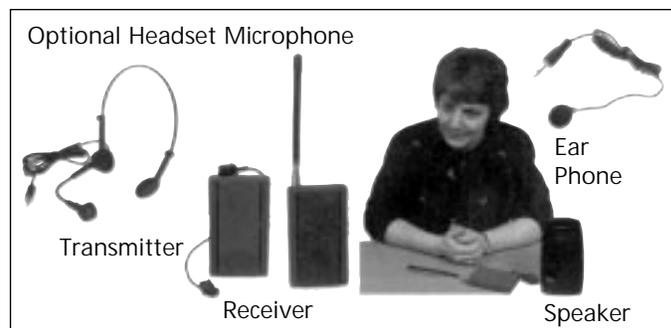


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DISCLAIMER

Information, reference material concerning research being done in the field of PSP and answers to reader's questions are solely for the reader. It should not be used for treatment purposes but only for discussion with the patient's physician.

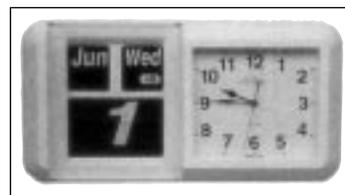


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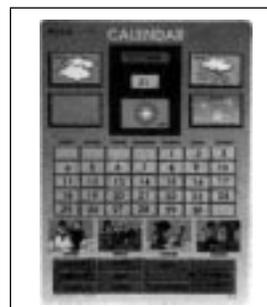
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Start each day by discussing the day, date, month, season, and weather. Award winner! 51 magnetic pieces.

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Special Events

Fundraising Update

From our Director of Development
Kathy Matarazzo Specca

Special thanks to Mary Connolly, with the help of her sister-in-law Joan Connolly Cholette, for raising more than \$1,000 from a garage sale held in June in New York.

UPCOMING EVENTS:

1. Saturday, October 2, 2004 "PSP Casino Night," in Hampton, Virginia.
Time: 7:30 p.m.
Cost: \$35 per person
For ticket and sponsorship information contact Tracie Sansavera at 757-766-8383 or email at igothands@cox.net (See website for full details)
2. Saturday, October 9, 2004 "The Richard Swiderski Memorial Wine Tasting Party," at the Narcisi Winery, 4578 Gibsonia Road, Allison Park, Pennsylvania.
Time: 6:30 - 9:30 p.m.
Sampling an assortment of wines along with food, entertainment, prizes and an auction.
Cost: \$50 per person.
For ticket information contact Mrs. Rose Swiderski at 412/486-8152 or email Susan McLaughlin at smclaughin@zoominternet.net (See website for full details)
3. Friday, October 8, 2004 "Longaberger Basket Bingo - In Memory of William A. DaRoja, Jr." at Northwest Middle School in Taneytown, Maryland.
Time: Doors open at 5:30 p.m.; bingo starts at 7:00 p.m.
Enjoy more than 20 games of bingo to win Longaberger baskets, along with special games, prizes, raffles and great food and refreshments.
Cost: \$10 per person in advance, or \$12 per person at the door.
4. Saturday, October 9, 2004 "Rest Stop" fundraiser, Vermont. Organized by Gale Cass. Last year, Gale and friends, sold baked goods and snacks to passers by while providing information about PSP.
5. Sunday, October 31, 2004, Halloween Masquerade Ball in Maryland More details will be posted on the website.

With the help of the Special Events Committee, PR packets will be distributed to TV and radio stations nationwide to spread the word about PSP for the month of October. If anyone would like to help with this effort, please contact me at 800-457-5777, Canada 866-457-4777 or email - development @ psp.org and I will provide you with complete instructions and PR packets.
- Kathy M. Specca

HIGHLIGHTS FOR 2005:

Sunday, January 16, 2005 - "Regional PSP Awareness Walk" in Naples, Florida. 2:00 p.m. - 4:00 p.m. at the Naples Bath and Tennis Club. (See website for more details)
Father's Day Race, golf tournaments and much more to come!

Golf Tournament Raises More Than \$23,000 For PSP

By Stefanie Carano

On June 5, 152 golfers took to the green for the McAlpine-Peitz Golf Tournament, held at Hartland Glen Golf Course in Hartland, Michigan, to raise funds for the Society for PSP.

Don McAlpine and Don Peitz coordinated this successful event with the help of a wonderful committee of volunteers that included the McAlpine Family and friends of both coordinators.

A "best-ball scramble" tournament was held in honor of two families who's loved ones have been affected by PSP. Honorees included Edward Peitz, father of Don Peitz and the late Donna Jean McAlpine, mother of Don McAlpine.

Donna was a casual golfer and an active volunteer in her neighborhood community until the PSP slowed her life to a halt in June of 2003. Shortly after her death, her sons Don and Andy, decided to hold a golf tournament to raise money for the disease that took her life - PSP.

This was the first golfing event held for the Society for PSP and raised \$23,513 for the cause.

"This is by far the best turn out I have ever seen for a first time golf tournament," said Kathy Matarazzo Specca, Director of Development for the Society. Kathy has worked on several first time golf tournaments

A shotgun start at noon began the tournament. Ed Peitz's grandson Travis and Ken McAlpine, husband to the late Donna, performed the ceremonial shots.

From a wheelchair outside the clubhouse, Ed Peitz proudly watched the progression of the tournament until he was not strong enough to stay any longer. A successful man highly regarded by friends, family and co-workers, Peitz is battling the disease with all his supporters by his side.

The tournament concluded with a steak dinner and a presentation by Kathy who asked the attendees to be ambassadors for the Society for PSP by helping to educate others about this disease. Betty Gulish provided a presentation along with a recitation of the poem she wrote in memory of her late husband, Fred, who succumbed to PSP in 2003.

A silent auction, 50-50 drawing, prizes for the golfers and a setting sun ended the successful event.

The McAlpine and Peitz families have already drawn plans for next year's tournament.



Left to right Don Peitz (son of Ed Peitz),
Kathy Matarazzo Specca (Society's Director of Development)
and Don McAlpine (son of the late Donna Jean McAlpine)

Special Events

Glantz Family Open House

May 22, 2004

In Memory Of Arthur Goldberg



Lynne Glantz with Ralph and Audrey Goldberg

On Saturday, May 22, 2004, more than 100 people gathered at the home of Lynne and Elliot Glantz for an open house fundraiser in memory of Lynne's father, Arthur Goldberg, who succumbed to PSP on August 2, 2003. Lynne organized this event to make a difference for those affected

by PSP. Lynne's enthusiasm and dedication to help the Society find a cure for PSP, brought in more than \$20,000. She, her family and circle of friends produced a fun filled, exciting event that featured a silent auction, raffles, prizes and scrumptious food. Dr. Lawrence Golbe, MD, chairman of the Society Medical Advisory Board and his wife, Devra, joined the festivities. Lynne introduced Dr. Golbe, who gave a brief presentation on the Society and the effects of PSP. This elegant evening also provided education and awareness of this disease.



Helen Goldberg (Lynne's mom), Dr. Golbe, Lynne Glantz and Steve Goldberg (Lynne's brother)

Words of encouragement from Lynne Glantz regarding the above event:

Dear Friends,

My dad, Arthur Goldberg lost his battle with PSP on April 2, 2003. My family and I had been through several difficult years watching my dad suffer. He did seem at peace during the last week,

refusing food, water, a feeding tube, and chose to die at home with his family at his side.

Since my dad's diagnosis, and more so as the disease progressed, I became convinced that we desperately need to join together to find a cure. After mourning my dad's death and grieving for a year, I decided it was time to take action.

My husband Elliot and I, as well as our two children Danielle and Ethan, helped to plan the event at our home for 100 guests. We sent out 150 invitations asking for a minimum donation of \$75.00 per person. The Society for PSP accepts checks, MasterCard and Visa. I had all the donation envelopes returned to me so my kids could be involved in counting the donations and see everyone's generosity. More than 100 people attended our event on May 22, 2004 and almost everyone that didn't attend sent a donation anyway. Some sent the minimum donation (\$75.00) and others sent in much more. I think that having the responses come directly to me may have had a positive effect on the amount of the donations we received.

We raised over \$20,000!!!! It took about one month to plan. We kept our expenses to a minimum by having a cocktail reception at our home. Friends donated wine, liquor, homemade hors d'oeuvres, desserts and time to help me set up. Local restaurants and caterers also donated hors d'oeuvres and desserts. Local merchants generously donated items for a silent auction that raised over \$3,000. Kathy Matarazzo Specca, the Society's Director of Development helped me with the invitations and sent sponsorship packets and PSP materials to me to help solicit both in-kind and monetary sponsors.

I'd love to encourage everyone out there to plan an event; however big or small, whether at home or what ever is most comfortable for you and your family. It is a very gratifying feeling to know you are helping to find a cause and cure for PSP.

Sincerely,

Lynne Glantz

P.S. Please feel free to contact me at my home - 973/379-4679 or email lynneglantz@aol.com and I will share my experiences with you. Be sure to call Kathy at the Society and she will be happy to help you with all the materials you need to coordinate a successful event. (800/457-4777)

Support Groups As Of July 27, 2004

PSP Support Groups will encourage and organize activities that foster communication, exchange and interactions of comfort and mutual benefit to Support Group members who are family, friends, caregivers and persons with PSP. The Society would like to thank the following Support Group Leaders and Communicators who take their time and show their concern by sponsoring support groups, phoning and visiting PSP families. For information about support groups please contact: Jessica Quintilian, Director, Outreach and Education at 1-800-457-4777.

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seminole1@graceba.net

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501-663-4493 • maryjo2060@aol.com

ARIZONA

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602-406-4931 • k2watts@chw.edu

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714-832-3731 • wgriff1@earthlink.net

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818-343-3259
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KATHY SCHWAIGER

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805-496-7018
MARY MIANO
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949-855-3972 • mjm941@juno.com
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303-788-4600 • segro@megapathdsl.net

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941-748-4028

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KATHY THOMAS*
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770-939-2612
JOAN CARPENTER
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706-721-9445

ILLINOIS

DARREN LOVELESS
Glenview
847-729-0000

INDIANA

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765-825-2148

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MARIAN GOLIC
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BRENDA GREMILLION*
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504-467-6658 • bgrem737@aol.com

MAINE

FAYE RYAN*
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207-259-2152

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410-486-2822 • music@comcast.net

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781-595-4431
parmanagement@aol.com

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JOANNIE McARTHUR
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852-461-2089 • gpm461@aol.com

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*PHONE/EMAIL GROUP

Let us post your support group news and announcements in the PSP Advocate. Please send your support group news/photos to The PSP Editor at NancyB501@cs.com or to the Society office.

PSP Forum

These messages were posted on the Society's web site.

Visit the PSP Forum today at www.psp.org

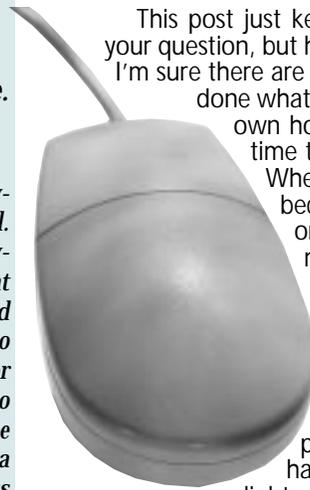
I'm a little beside myself as my stepfather, my mom's caregiver, wants to put her in a nursing home as she is starting to fall. It doesn't seem right to me just yet. She has a very hard time saying anything that makes sense, but she can sure let me know that she doesn't want to go. I think that these people are so lonely and to put them in, if it's not really time, just doesn't make sense to me. The last time and first time she went for a respite care for her husband, it broke my heart to visit her in there. She still likes to dress well and understands my jokes, or maybe only laughs to be polite, but I know she gets it. I have offered to send him on a vacation, but he won't hear of it... I don't want to second guess him as he has been so good to her through all of this... but I'm not ready for this! I don't know how much time she has left, and I want her to be as comfortable as possible... Any advice would be so greatly appreciated.

Responses from the PSP Forum:

The nursing home decision is definitely one that is agonizing. Everyone's reason for wanting or needing to make this decision can vary, although we are all dealing with the same devil named PSP. Personally for my mom, she felt this was the only choice she had. I know if she could have done things differently, she would have, as I was there the day that Daddy went into the nursing home and I saw how it hurt her. It wasn't a walk in the park for myself either as I had Power of Attorney and signed all of the paperwork.

There are 5 siblings, but 99% of the care was provided by myself and my 2 sisters. Mama was usually able to find someone to stay with them during the day...although there were times that it was just my parents at the house. This always scared my mom to death because she knew she wouldn't be able to handle my dad if he needed help. My sisters and I took turns going to their house after work to take care of both parents and generally we were not able to sleep. Daddy would get up sometimes 6 times during the night to go to the bathroom. At this point, he was still able to walk without assistance (shakily). We had a baby monitor set up in his room and where we laid down. When we knew (or more often thought) that he was getting up, we would go to his room to walk with him to the bathroom to keep him steady. We could see in his eyes that it was not easy for him to have his daughters standing by as he went to the bathroom. Life has a way of going full circle.

My mom wanted my dad to be in a home back in the country... she didn't want him in the big city. The home she originally had chosen did not have a room available for someone that would require skilled care. I contacted another home and from the minute they answered, I knew that Daddy was going to be in good hands. They have been absolutely awesome and have taken excellent care of Daddy. The day he was admitted was the hardest day of my life and the second hardest was seeing him for the first time 4 days after that (which was Father's Day). He looked so tired and when we read his Father's Day cards, he cried. My mom had never seen my dad cry before and it really tore her up. I asked him a couple of weeks later if he understood why we had to make the decision and he said that he did. In his heart, he knew that we were not able to provide the level of care that he needed. Everyone at the nursing home treats us like family and they truly do love Daddy.



This post just kept growing. I'm not sure if I've answered your question, but honestly, each person's situation is different. I'm sure there are people out there that think we should have done whatever possible to see that Daddy stayed in his own home. From the heart though, the quality of time that we spend with Daddy now is priceless. When he was still at home, my sisters and I became walking zombies and a toll was taken on our physical and mental health. Believe me, if the decision is finally made to place your mom in a home, there WILL be guilt... no doubt. As I said before, it was the hardest thing we've ever had to do, but looking back at the decision now, I thank God that we had the strength to make it. My sisters and I have always been close to our parents, but the past two years our bond has grown even more. To see Daddy's eyes light up when he sees us helps to make up a little bit for all of the pain that PSP has caused. My love and my strength go out to you now as there is a difficult decision ahead for your family. Your mom will know that if that decision finds her in a nursing home, it was made out of love, not out of you all wanting to "put her away and forget about her."

Well, I don't believe there is a set time when one reaches a point in the disease where the rule books say... next step is to admit the patient to a long term care facility. Each and every situation is different and influenced by many external factors. Interestingly, my Dad has actually improved a bit thanks to all the specialized care he is receiving. Those of us on the outside will see the situation differently than those living it everyday. You have your thoughts as to why you believe the time is not right, your stepfather has his and yes, your mother has hers as well. For what it is worth, here is my advise to you... COMMUNICATE. Talk to your stepfather, mother, siblings, family, and friends if they are closely involved. Ensure that you are closely involved with their doctors and ask questions. Do it individually and as a group. Ensure that everyone understands the other. Listen to and respect each others thoughts. This will not resolve itself after just one talk. It needs on-going work. The answer will evolve - trust me. Your particular family situation will dictate the "right" time. A second piece of advise, make sure that your mother's personal paperwork is completely in order. Now... not at the time extended care becomes a necessity. The Will, Power of Attorney (Personal Care), Power of Attorney (Property) etc. I strongly advise that in the Power of Attorney, a substitute attorney should be named in the event that the primary attorney is unwilling or unable to make decisions. This is quite common in highly stressful situations and can save making some irreversible mistakes. Ensure that anyone involved in your mom's care, even today, is aware of her wishes regarding "heroic measures" to sustain life. Research and discuss the feeding tube issue. Make sure that you have and know the answer to the question that will probably be asked one day about feeding intervention. I could go on... I am speaking from experience on all of these issues now. Thankfully, my parents were prepared. It has made my difficult job a lot easier.

Daddy's been in the nursing home for 11 months now. It is still not easy to see him there, but in my heart, I know that is where he will live out his days. I have a picture that we recently took of my dad that I'll always treasure... others have seen it

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Happy Mother's Day, Mom

By Jim Kimball

Sunday, May 11, 2003, was the first Mother's Day since my mom passed away last October. I've been thinking of her a lot lately, as I always do, but maybe especially now as the day gets closer. See, my mom was the one that really got my younger brother and me into motorcycles. After bugging my dad for months – heck, it seemed like years! – she was the one that convinced Dad to buy us a used Honda Trail CT70. She would come out in the back yard and watch us run around in circles all day. She even took some turns on it!



A couple years later, we outgrew the CT70 and moved up to an old, used Honda SL100 for my brother and a Honda SL125 for me. It was around this time that we started hearing about motocross, and soon the lights came off, the mufflers were cut off, and number plates added – we were now MX racers! During this time my dad was off on business a lot, and I can remember the many times my mom hauled us around to our favorite riding spots or to the local motorcycle dealership. I know my mom loved this time together; it was a way for her to spend time with us as we were moving into our teens.

Soon my brother and I were moving on to high school and riding more often than not. Growing up in western Michigan, we became aware of the outdoor nationals and Trans-AMA events at Red Bud Track 'N Trail. Like most kids, we were so into it – peering through the fences, trying to catch a glimpse of one of the riders or their bikes. We would wait for hours to see if one of the riders could sign our programs. My mom, never shy, would do her best to try to sneak us into the pits. My fondest memory from those days is when we came upon Jimmy Weinert and Mom asked him if we could take some photos with him. The picture of mom with the Jammer was always a classic in our family photo album!

As we began racing more, while my dad worked on the bikes, mom was on the side of the track cheering for us, cleaning our gear, and helping with our scrapes and bruises. She was always there for us, never put herself first, and gave up a lot so we could go racing on the weekends. Like a lot of kids, we gradually went to college, got too interested in partying, and sold our bikes, but I still kept up with racing by subscribing to Motocross Action. As I finished my education, entered my career, and became a “productive member of society,” my interest in motocross intensified. I began to attend as many pro races as I could, driving straight for up to eight hours at a time. Even though I wasn't living at home, Mom would always ask about who was doing the winning.

After attending an open house at a local dealership and winning a helmet, I took it as a sign to get another dirt bike

– and after 15 years, I was back riding. Of course, my mom wanted to hear all about it. As we lived six hours away from my parents, and my wife, Laura, would send them photos of me riding with my good riding buddy, Forrest. And whenever I had a big accomplishment (like doing a new jump), I'd call my mom and tell her about it.

While living in Ohio, I received some bad news from my dad. Mom had been having many problems with her vision and coordination. After months of visiting different doctors and clinics my mom was diagnosed with PSP (progressive supranuclear palsy), which is a very rare disease that gradually destroys the brain. A cruel disease, it eventually leaves the victim unable to walk, talk, or eat – and there's no cure for it. My wife and I (now with two young daughters) had already been homesick for our families, and this new information tipped the scales, so to speak. I found a job near where my parents lived, and we moved back home.

We were now able to spend a lot more time with my parents, and my wife – God bless her – helped out with my mom as if she were her own mother, doing things for her that no one else could. My mom still liked hearing about the big pro races, and when I had my first interview uploaded online, she printed off copies and gave them to her visitors. And then when Racer X magazine published one of my “5 Minutes with” interviews, she ordered my dad to go to the store and buy 10 copies! My mom was super proud of me and let everyone know about it!

She was hospitalized near the end, and her condition had significantly deteriorated and she was unable to see, eat, walk, or talk; the only enjoyment she had was when one of us read to her. With hospice helping us out, and with little time left, we brought her back home to where she was comfortable. Spending every minute that I could with her, I was able to tell my mom how much she meant to me, and how thankful I was to have her as my mom. She was by far one of the most generous people I have known, a person who always put others before herself. She didn't have to spend her weekends at race tracks and use her money for motorcycles, but she did. Watching my mom go through what she did, I often thought it was best for someone to just die suddenly – but now I'm so thankful that we had that precious time together so I could be there for her as she was leaving us.

As each Mother's Day approaches, I think about my mom all the time. Just the other night, I finally did the “big 40-foot double” at my local track, and although I told my wife and kids, what I really wanted to do was call my mom and tell her. But, of course, I couldn't. Yet I had literally dialed the phone number. This was the special bond I had with my mom; she loved hearing everything about my life, and I really miss telling her about it. But actually, I'm sure she's already watched me do it.

Next Mother's Day I'll be enjoying racing – and missing my mom, of course.

Mom, I love you.
Jim

Support - Our PSP Stories

Vandana Juneja

I have read many of the heart wrenching stories of PSP afflicted patients and their families in *The PSP Advocate*. On many occasions, I have tried to write about my wife who was diagnosed with PSP in December, 1998. But unfortunately, every time I sat down in front of my computer, my eyes swelled up and I could not think straight. Finally, I have been able to pull all my courage to express our experience with this disease.

My wife, Vandana Juneja, and I were married in 1968 and came to this country in 1969. She gave birth to three very smart children and as a stay-at home mom helped them grow into wonderful and successful adults. She was rarely sick prior to this illness. At the age of 53 in 1995, the onset of menopause made her somewhat unhappy and uncomfortable but she was very reluctant to undergo hormone therapy. After several discussions, persuasions and visits to the physician, she started to take Prempro grudgingly. Very soon, she developed some heart palpitations which eventually turned into slight-tachycardia. In late 1997 and early 1998, we observed that her facial expressions had begun to show signs of fear and loss of confidence. In April 1998, we took a trip to India to visit our families. Some of the family members remarked that she looked weak and somewhat "lost." At this point, her gait and speech did not appear abnormal. We hence ascribed her symptoms to the life cycle changes she was going through.

In the summer of 1998, things began to suddenly change. Her speech started to become monotone and sometimes difficult to understand. Her gait was wobbly and unbalanced. In the hallways, she was rubbing against the walls as if she was trying to balance her step. A couple of times, she fell down inside the house without any obvious reasons. She started to have some difficulty in getting up from the sofa.

Finally, in September 1998, we went to see a neurologist. After an examination that lasted 30 to 40 minutes, the neurologist concluded that my wife was most probably developing Alzheimer's disease. This scared her very much. Her sleep became very disturbed and marred by scary dreams and thoughts. We were not at all convinced that she had the makings of AD and took her to the Mayo Clinic in Rochester, MN in early December 1998. It was there that we were told that my wife had many of the symptoms of PSP, an ailment with no known treatment.

We saw several local neurologists but none of them had anything to offer. Some of the standard medications usually prescribed for Parkinson's patients were tried but provided no relief. During 1999, although she was able to handle herself inside the house, she had a couple of falls with injury. Finally in 2000, we hired some help to stay with her during the day while I worked. We also started a program of physical, speech and massage therapies. Unfortunately, her motor functions or balancing abilities continued their slow paced downward trend. In late 2001, she underwent a surgical procedure for total knee replacement as she had lost most of the cartilage to arthritis in her left knee. During my discussions with the surgeon and the

anesthesiologist prior to the operation, they felt sure that the surgery would not impact my wife's disease. They turned out to be wrong. This surgery took a major toll on her health by exacerbating the rate of decline in her functionalities. Furthermore, the anesthesia and / or morphine used during the operation caused my wife to develop an undesirable side-effect of diaphoresis (excessive sweating) that continues unabated even now.

We continue to do at home some physical therapy in order to give her some relief from the rigidity. Whenever possible, she exercises on the stationary bike for 15 minutes. Also, a few times a week, I put a safety belt around her waist and let her walk with me while I walk backwards. We also practice standing where she has her hands on the sofa arm and I stand directly behind her with my hands on the safety belt around her. The toughest moments are those when she asks, "When will I be able to walk by myself?" It is at these moments when I wish I could have a direct talk with the Almighty.

Beginning with 2002, I accepted my employer's offer of early retirement in order to provide more attention to my wife's needs as well as meet my employer's unending appetite for restructuring / layoffs. Having seen my vibrant wife go through five years with PSP has changed my perspective on life. Perfection that was always my hallmark has lost its significance. In spite of many frustrations during these five years, I feel that my wife's illness has made me into a better person. She laughs once in a while, never cries nor does she ever complain. Although I was always very fussy about my food, she quietly eats whatever I cook. We were always a close knit family. This disease has brought us even closer. I am hopeful that the love of my family will get us through all the pain that comes with any long-term illness.

Thank you.

Sincerely

Prem S. Juneja

513-891-5475 • Email: psjuneja@cinci.rr.com



BALTIMORE SUPPORT GROUP

Are you a PSP caregiver or family member living in Maryland? Whether you are new to the world of PSP or have been a caregiver for years, the Society is here to support you! If you are interested in joining our support group, please contact Jessica Quintilian, Director of Outreach & Education, at 410-486-3330 or 1-800-457-4777.

Meetings will be held monthly at the Society headquarters in Baltimore, 1838 Greene Tree Road, Suite 515, Baltimore, MD 21208. Don't travel this road alone!

Support - Our PSP Stories

Please continue to share your "PSP Stories." Each journey will be unique—but each journey is filled with love, strength, determination and courage of persons diagnosed with PSP and their families. You may email your story to *The PSP Advocate* Editor at NancyB501@cs.com or mail to Nancy Brittingham, 6 Bramston Drive, Hampton, VA 23666. Please include photographs if possible.

Dear Nancy,

Over the past several years, the *PSP Advocate* has been so very helpful to us in so many ways. There were practical solutions and suggestions to common experiences and challenges, insights into research and most of all, the loving tributes and stories. I read the *Advocate* from cover to cover both as a registered nurse and as the daughter of a PSP patient.

Several years ago, it became apparent to us that our mother needed neurological evaluation and more living assistance. She moved to Raleigh to be near my sister, Jane, and her family. We lost her to this illness almost a year ago.

Please find the enclosed photo and note "The Beautiful Birdsong" that I have written for you to consider for publication in an *Advocate* issue.

In personal and professional ways, I continue to provide information to others about PSP and promote awareness of this disease.

Thank you for all you do.

Sincerely,

Joan Conway

"The Beautiful Birdsong"

A year ago last spring, our mother left us. Everything was in bloom with the vibrant colors of the season. For several minutes we heard an extraordinarily melodic and captivating bird song just outside her window. In that moment, we all knew that the song was a call to her. What happiness and joy the birds and flowers had brought to her—they had always been a special part of her life.

We have read our mother's story in every loving tribute written by other families. In so many ways our experiences are much the same. We talk about struggles and perseverance, but mostly we share our devotion and love.

She was an army nurse, a loving wife and mother, and an activist in organizations that benefited children and those most in need of help. She became the family's caretaker because of her nursing training, her dependability, and her caring nature. And, as her disease progressed, our caretaker needed to depend upon others – a fate she accepted with incredible grace.

Her story is the same heart-breaking story we have read over and over... the falls, the slowed mobility, the slurred speech, the visual disturbances, and the initial diagnosis of Parkinson's disease. Then came the remarkable media attention to Dudley Moore and his courageous decision to speak publicly about PSP. It gave us a diagnosis... a name for our mother's illness, a new awareness and understanding. And it brought us to the Society for PSP... where we have gained so much valuable knowledge, taken advice and received validation, support and even consolation.

Eventually her joyful facial expression disappeared, her single word responses became whispered and we faced the difficulties with swallowing. But what the disease never took from her was her clear intellect, her strong spirit, her sense of

humor and her faith.

We will always appreciate this organization's efforts to fund research, to educate medical providers and the general public about PSP and to continue to be advocates for those with this disease and their families.



Joan Conway (left) with sister Jane Rooker and mother Madeline Rossi.

Forum

Continued from Page 16

and looked at me funny, but they haven't lived with PSP and don't understand that the littlest things are precious. We were sitting out on the patio at the nursing home. It was a little breezy outside and my mom didn't want my dad to get drafted by the wind. We took a throw (like you would put on a couch) and put it on top of his head and then we took the parts hanging down and crossed them in his lap. If you saw the movie E.T. and remember the scene where Elliott has E.T. in the basket of his bicycle, well, that is what my dad looked like. We called him E.T. and he just smiled at us. That vision and that smile is forever in my mind.

PSP affects everyone differently, the speed of progression, the order of progression and the person themselves. This is also true of the people around them. As has already been said, their will be guilt, but consider this, if your stepfather isn't coping with your mother's care, then is she getting the best care possible with him? There will never be the perfect care package, because that would be a cure. I am not the main caregiver for my mother but the times I have spent with her (a couple of weeks at a time) are exhausting, physically, mentally and emotionally. I have chosen to employ carers at home for mother and she accepts this but never the less feels that I should be taking care of her. I know that if I were to do this then her care would suffer, just because we love someone doesn't mean that we are capable of providing them with all they want and need. It is such a difficult situation for you to be in but you do need to talk to your stepfather and understand where he is coming from.

PRIVACY POLICY/DISCLAIMER

The information provided on the Society website is intended to foster the communication of progressive supranuclear palsy, both for health care professionals and the public. It is not intended to take the place of professional medical advice.

Report Of Gifts - February 29 - July 17, 2004

The Society for PSP extends its thanks to our donors who have given so generously to help find the cure for PSP while helping families meet their difficult challenges.

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Kiki Cahn In Memory of Anne F. Cahn

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Maureen Carkeek In Memory of Arthur Carkeek

A. Bruce Carlson

Judith Carretta In Memory of Richard H. Young

Carl C. Carter In Honor of Christine Carter

Phyllis R. Cartwright In Memory of Kenneth Fowler

Stephen & Beth Carveth In Memory of Tom Harrington

Roy Chappell In Memory of Tommie Ruth McAnally Eskew

Mr. & Mrs. Richard Chatham In Memory of

Charles E. Flanigan

Carol Cheek In Memory of Lawrence Schwartz

Laurie L. & Robert M. Chefitz In Memory of Arthur Goldberg

Diane Child In Honor of Dalcie M. Child

Katherine N. Choquette In Memory of Denis Choquette

R. Craig & Janet Christie

Joan Clarke In Memory of Jean Varin

Claudette Cloutier In Memory of Patrick Cloutier

Kathleen Cobb In Memory of John R. Cobb

Dorothy Ann Coffin In Memory of Alfred J. Coffin

Richard A. & Linda Cohen In Memory of Leontine P. Klem

Ron & Liz Cohen

Scot & Carolyn Cohen In Memory of Arthur Goldberg

Cheryle Cooper In Memory of Buck Sykes

Robert E. Corbin

Denise & Alan Core

Robert L. & Bobby J. Cornford In Memory of

Robert L. Cornford

Mary Jane Corpuz In Memory of Josephine Vukovich

Frances M. Covello In Memory of Eleanor McCarthy

Dee Cox In Memory of Robert Cox

Mr. & Mrs. Trammell Crow In Memory of Locke Purnell, Jr.

Joan Da Roja In Memory of William Da Roja

Robert P. & Margreth Dadigian In Honor of

Robert P. Dadigian

Daniel Gale Agency, Inc. Corporate Office In Memory of

Eleanor McCarthy

Daniel Gale MacCraty Glen Cove/Sea Cliff In Memory of

Eleanor McCarthy

Daniel Gale Associates, Inc. East Norwich/Brookville

In Memory of Eleanor McCarthy

Deborah O. & Danilo Danti In Honor of Alda Mocogni

Robert Davey In Memory of Diane Davey

Elizabeth de Manio In Memory of Charles E. Flanigan

Debbie Crook, Marsha Webster, Marta Nemy, Henry Kitts,

Peggy Smith & Nancy Hill In Memory of Dalcie M. Child

Nicholas A. & Rachel L. Defilippis In Memory of

Arthur Goldberg

Patrick J. Deiling In Memory of Lois K. Deiling

Alan & Lynne Dembner In Memory of Arthur Goldberg

Orrin & Deborah Devinsky In Memory of Arthur Goldberg

Gloria R. DeWitt In Memory of Irving Brown

Marcella Dolgin In Memory of Morris Dolgin

Joyce & Richard Donovan In Memory of Leontine P. Klem

Dorothy Gordon In Memory of Bill Gordon

Report Of Gifts

PATRONS (\$100 AND OVER)

continued

Neil T. Douthat In Memory of Lawrence Schwartz
Duquesne Light Company In Memory of
Richard J. Swiderski
Maureen & Drew Durkin In Memory of
Msgr. Lawrence Costello
Bruce & Fern Eatroff In Memory of Arthur Goldberg
William R. & Gisele F. Egge In Memory of John L. From Jr.
Steven & Jane Eitman In Memory of Arthur Goldberg
Ken Elconin, MD In Memory of Myra Goldberg
Ralph K. Enander In Memory of Joan Enander
Eric Erickson In Memory of Joan Erickson
Shirley Ernest In Memory of Norman Reiffer
Ethicon, Inc. In Memory of Charles E. Flanigan
Martin W. Faust In Memory of Charles E. Flanigan
Willie Faust In Memory of Pat Brainard
Harriet Feiner In Memory of Sidney L. Feiner
Goldie G. Feldman In Memory of David J. Feldman
Ronald & Dale Ferris In Memory of Raymond Thibault
Kathryn Fike
Ben & Michelle Fillichio In Memory of Charles E. Flanigan
Robert & Marian Fish In Memory of Esther S. Cohen
Marc & Robin Fisher In Memory of Arthur Goldberg
Joe & Judy Flanigan In Memory of Charles E. Flanigan
Flexible Steel Lacing Co. In Memory of Dalores Loskot
Alexandra Kissinger Florimonte In Memory of
Johana A. Kissinger
E. Elizabeth Floyd
Alan S. Fogg In Memory of William F. Briggie
George & Laurie Fox In Memory of Sylvia Goldenbach
Nicole Fraiman In Memory of Agnes Zaldouondo
Mary Frank In Memory of Cyril Frank
Friends at Suffolk County Clerk's Office In Memory of
Barbara Lardi
Friends of the Family In Memory of Geraldine Bellis
Sarah E. Fuchsman In Memory of Arthur Goldberg
Don & Carol Gaines In Memory of Leonard Lipstein
Tom E. & Pamela J. Gann In Memory of Fred Gulish
Mildred Gauss In Memory of Floris Gauss
Anna Geiger In Memory of Ray Geiger
Lawrence & Mindy Gelman In Memory of Arthur Goldberg
Kurt Gertner In Memory of Florence Gertner
Dorothy Gilbert In Memory of Alek W. Gilbert
Margaret E. Gillenwater In Memory of
William E. Gillenwater Jr.
Judith Gilmore In Memory of Charlotte B. Wernick
Barry & Winifred Glantz In Memory of Arthur Goldberg
GlaxoSmithKline Foundation In Memory of
Walter J. Greenleaf, Jr.
H. & R. Goldberg In Memory of Arthur Goldberg
Helen Goldberg In Memory of Arthur Goldberg
Mel Goldberg In Memory of Myra Goldberg
Steve & Janice Goldberg In Memory of Arthur Goldberg
Cheryl Goldring In Memory of Arthur Goldberg
Jay & Marjorie Goldsmith In Memory of Myra Goldberg
Mark P. & Tina N. Goldstone In Memory of
Arthur Goldberg
Theresa Gordon-Knapp In Memory of Bill Gordon
Gothard Business Center, LTD. AAA Self-Storage
In Memory of Robert Cox
Alan & Rena & Doris Gould
Col. Philip S. Grant
Robert E. & Margaret H. Grassle In Memory of
William (Bill) Gordon
Greg & Diane Marra In Memory of Joseph Latragna
Robert D. Griffin In Memory of Lisa Carabello
Mary Gualandi In Memory of Gino Gualandi
Joseph Guarino In Honor of Mary Guarino
Betty Jo Gulish In Memory of Fred Gulish
Norman & Diana Hageboeck In Memory of
Raymond C. Robinson, Jr.
Cheryl Hall In Memory of Stella J. Hall
Margaret E. Hall In Memory of Dorothy Saunders
James W. & Diane K. Hamburg In Memory of Lola Hamburg
Warren K. Hamburg In Memory of Lola Hamburg
John Hammock In Memory of William Ron Sandwith
Sallie Harper In Memory of Waylon O. Harper
Jill Hartmann In Memory of Gladys Stephens
Dieter Hausmann In Memory of Gunnar Hausmann
Lawrence N. & Georgia A. Hawthorne In Memory of
Jessie Kiersey
James F. Heegan In Memory of Florence Heegan
Henry Rossi & Co. In Memory of Richard J. Swiderski
Virginia High In Memory of LeRoy B. High
George B. Hills, Jr. In Memory of Covington Shackleford
Carl R. & Betty M. Hogan In Memory of
Elaine Loflin Pignataro
Bradley Hogreve, P.A. In Memory of Charles E. Flanigan
Donald & Kathleen Hollenbeck In Memory of
Kenneth Fowler
Charlies Holmes In Memory of Henry D. Holmes, Jr.
Richard & Sarah Holter In Honor of Sarah R. Holter
Debra Horowitz In Memory of Arthur Goldberg
Edward J. Horvat
Bob Hughes In Honor of Karen Hughes
Timothy H. & Jean C. Hughes In Memory of
Richard J. Swiderski
Fred & Nancy Hull
Wallace Humalo In Memory of Marilyn Goetsch
Jane H. Hunt In Memory of Ardis W. Holt
John & Laverne Hyneman In Memory of Dalcie M. Child
Susan Ishkanian In Memory of Sally Ishkanian
Jacco & Associates, Inc. In Memory of Gunnar Hausmann
Marcia Jackson In Memory of Philip Jackson
Jane Adams, Linda Limon, Dora Cook, Beth Ryan, Amy
Harris-Gwilt, Ileana Santiago, James Moses, & Rodney
Kellar In Memory of Dalcie M. Child
Jane Adams, Linda Limon, Dora Cook, Beth Ryan, Amy
Harris-Gwilt, Ileana Santiago, James Moses, & Rodney
Kellar In Memory of Nancy Spraker
Michelle Binder Jarboe In Memory of Ralph Poe
Barbara Jenkins In Memory of Dorothy Saunders
Wallace & Marianne M. Jenkins In Memory of
Kenneth Fowler
Tom & Karla Jennison In Memory of Clayton K. Gute
Jenny Pruitt & Associates, Inc. In Memory of
Eleanor McCarthy
Paula John In Memory of Bill John
Daniel Johnson, D.D.S. In Memory of Richard R. Beems
Sue Johnson
G. L. & Bernice Jordan In Honor of Bernice Jordan
Marjorie M. Kade In Memory of Bert Van Denn
Ed & Audrey Kancler In Memory of Margaret Percy
Kansas City Equity Partners, L. C. In Memory of
Lawrence Schwartz
Brian M. & Leslie P. Kaplowitz In Memory of
Arthur Goldberg
Akiko Kaput In Memory of Roland Kaput
Debbie A. Karel In Honor of Mildred Karel
Patricia A. Kelly In Memory of Josephine Kelly
Joan King In Memory of Thomas E. King
Paul King & Debbie McNamara In Memory of
John Lipani, Sr.
Mary Ellen McCabe Kirschner In Memory of
Leontine P. Klem
Richard B. Kissinger In Memory of
Johana A. Kissinger
Robert H. Klein In Memory of Myra Goldberg
James F. & Jean W. Klem In Memory of Leontine P. Klem
Dr. David & Karen Klugman In Memory of Arthur Goldberg
Judy Ann Knapp In Memory of William (Bill) Gordon
Knight Ridder Digital In Memory of Leontine P. Klem
Rob Koenig In Memory of William Ron Sandwith
Herbert H. & Lorraine Koshgarian In Memory of Robert Cox
William & Joyce Kravec In Honor of Joyce Kravec
Elena & Benito Krawczyk In Memory of Addison Jenrette
Jeanette Krokus In Memory of John Triunfo
Dr. Robert & Barbara Krotenberg In Memory of
Arthur Goldberg
Toby Kruh In Memory of Raye Heksel
Henry & Irmgard Kull In Memory of Gunnar Hausmann
Ricardo Kuri Jr. In Memory of Pilo Kuri
Paul L. Lacy, Jr. In Memory of John L. From Jr.
W. K. Lake In Memory of Esta Miracle
Amedeo & Maria Lamberti In Honor of Alda Mocogni
Wallie Lambrecht In Memory of Donald Lambrecht
Michelle Lambrecht In Memory of Donald Lambrecht
Gray Laney In Memory of Pamela Laney
Hazel Langhans In Memory of Herman Langhans
Birdie & Bob Lape In Memory of Charles E. Flanigan
Lena M. Latragna In Memory of Joseph Latragna
Peter & Patricia Laughlin In Memory of Charles E. Flanigan
Norma Lawler In Memory of Floyd Lawler
Jeffrey & Diane Lebenger In Memory of Arthur Goldberg
James & Catherine LeBlanc In Memory of Myra Goldberg
Benjamin Jr. & Carmen LeCompte
Susan & David Lederman In Memory of Myra Goldberg
Diana C. Lee In Memory of Lawrence Schwartz
Margaret LeGris In Memory of Richard R. Beems
Sachiko Lenk In Memory of John Lenk
Gina Lenzini In Honor of Alda Mocogni
Javier I. & Susan M. Lescano In Memory of
Charles E. Flanigan
Muriel Leslie In Memory of Thomas F. Leslie
Levittown United Teachers Local 1383 In Memory of
John Lipani, Sr.
Lewis Tree Service, Inc. In Memory of Richard J. Swiderski
Richard J. & Connie J. Leyba In Memory of
Donald Lambrecht
Bonnie L. Lindahl In Memory of Dan Davis
Neal & Patricia Linhardt In Memory of Jack A. Scott
Bill & Karen Lloyd In Memory of Donald Lambrecht
Lomurro, Davison, Eastman, & Munoz, P.A. In Memory of
Ernest H. Schriefer, Sr.
Edwin H. & Dawn M. Loos In Memory of
Gunnar Hausmann
Maureen Lowe In Memory of Amelia Levinsky
Merle & Victoria Lundstrom In Memory of
Violet Livingstone
Richard & Denise Lunoe In Memory of Catherine E. Souder
R. K. & Cecile Lynch In Memory of Lawrence Schwartz
Daniel Gale MacCrate In Memory of Eleanor McCarthy
John Madson In Memory of Dora Madson
Daniel G. & Diane Mahoney In Memory of
Charles E. Flanigan
Robert & Tracy Maitin In Memory of Arthur Goldberg
Hal & Elissa Mandel In Memory of Arthur Goldberg
Rolf & Nancy Margenaum In Memory of Leontine P. Klem
Marylynn M. Marino In Memory of Jacqueline Marino
Jane G. & Alan M. Mark In Memory of Arthur Goldberg
Lester J. Marks In Memory of Valeria Ann Marks
Robert & Ellen Marks In Honor of Stephen Reich
Dr. Rey & Doris Martinez In Honor of Alda Mocogni
Gene Mason In Memory of Mabel Mason
Masonry by Fernando, Inc. In Honor of Alda Mocogni
Kathy Masters In Memory of Vivian Davisson
Richard & Irene Matices In Memory of Richard J. Swiderski
John & Maria Mato In Memory of Jose Da Cunha
John & Maria Mato
Marge Mattered In Honor of Alda Mocogni
Chris & Cathy May In Memory of Shirley Arch
Gene & Maureen McCabe In Memory of Leontine P. Klem
Steven McCarthy In Memory of Jose Da Cunha
Rose McCarty In Memory of Charles R. McCarty
Robert E. McCluskey In Memory of Roselee McCluskey
Michael & Wendy McGowan In Memory of
Elaine Loflin Pignataro
Margaret L. & Daniel P. McKenna In Honor of
Alda Mocogni
Mary McKown In Memory of Oval McKown
John R. & Pauline Mecedda In Memory of Dalf Hammerich
Ronald & Melissa Mocogni In Honor of Alda Mocogni
Michael Umen & Co., Inc. In Memory of Charles Nomides
Michigan Proving Ground—Ford Motor Company
In Memory of Marguerite R. Boerger
Harold E. Miller, Jr. In Memory of Lawrence Schwartz
James & Saranna Miller In Memory of
John Harold Brown, Jr.
Edward Moll, Jr.
Karen Morris
Matthew P. & Maureen E. Morris In Memory of
Charles E. Flanigan
John Morrow In Memory of Locke Purnell, Jr.
Isaiah & Ethel Mosby In Honor of Ethel Mosby
Mr. & Mrs. Lee R. Yott In Honor of Lee Yott
Mrs. John G. Zimmerman In Memory of
John G. Zimmerman
Patricia A. Mueller In Memory of Margaret Kane
Joyce Munsell In Honor of Gary Munsell
Patricia D. Murray In Memory of Paul D. Daffer
Robert & Fran Muscatello In Memory of Frances Muti
Marion Muskiewicz In Memory of Jack Muskiewicz
William & Anna Myers In Memory of Mary Cembalski
Jonathan & Marjorie Myers In Memory of Arthur Goldberg
Mylan Pharmaceuticals, Inc. In Memory of Mary S. Thomas
N & T Mason Contractors Inc. In Honor of Alda Mocogni
Kenneth & Ellen Nadel In Memory of Arthur Goldberg
Lew Nadien In Memory of Bonnie Nadien
Souhel & Marwa M. Najjar In Memory of Arthur Goldberg
Neel Title Corporation In Memory of Locke Purnell, Jr.
Nestle Foundation Matching Gift Center
Frank & Margaret Neua In Honor of Alda Mocogni
Marjorie G. Neuwirth In Memory of Beatrice K. Goreff
Helen E. Newell In Memory of Warren H. Newell
Niantic Lions Club In Memory of John Caywood
Frank & Janelle Nigro In Memory of Alice C. Shultz
Gary L. & Diane M. Nilo In Memory of Doris A. Nilo
Francis & Marcia Nizzari In Honor of Francis Nizzari
NMAPC, Inc. In Memory of Richard J. Swiderski
Carol Nomides In Memory of Charles Nomides
Richard B. & Pamela P. Noonan In Memory of
Leontine P. Klem
Thomas E. O'Brien
Susan Olson In Memory of Virginia Koallick
John & Janet Osenkowsky In Memory of Charles Nomides
Eugene C. & Joan A. Ostrander In Memory of
Ernest C. Johnson
Julie Page & Aram Orudbegian In Memory of
Benjamin Pena
Makarios Palios In Memory of Vernon Reed
Ted & Mary Pappas In Memory of Virginia Nakis
Jean Patterson In Memory of Robert L. Patterson
Rajni Paun In Honor of Aruna Paun
Carolyn Peirce In Memory of Rev. Thomas E. Peirce
Diann Perry In Memory of Roland Guilkey
Lloyd Peskoe In Honor of Florence Peskoe
Peter L. Stern & Co., Inc. In Memory of Harvey Tucker
Elizabeth Petricone, RN In Memory of Dr. Boris Schwartz
Stephen & Rosina Pilhartz In Memory of Gunnar Hausmann
Stephen & Lisa Plavin In Memory of Arthur Goldberg
Georgia Pontious-Butler In Memory of
Stanley Pontious
Dorothy Popovich In Memory of Nicholas Popovich
Lolo & Klaus D. Post In Memory of Gunnar Hausmann
Mr. & Mrs. Larry W. Powers In Honor of Alda Mocogni
Providian Financial In Memory of
Christopher Ludwig Mengis

Report Of Gifts

Purvin & Gurtz, Inc. In Memory of Tommie Ruth McAnally Eskew
Jennifer L. Rabinowitz In Memory of Ruth McKean
Marion J. Randall In Memory of Richard E. Randall
Harvey Raschke
Randolph J. Ray In Memory of Donald H. Ray
Randal E. Reardon & Mary C. Copperwaite In Memory of Leontine P. Klem
Reconstructionist Synagogue of the North Shore In Memory of Sidney L. Feiner
RecordTrak In Memory of Jack A. Scott
Lois Rehman In Memory of Paul E. Linell
Ken & Lisa Reisen In Memory of Gerald Zimmerman
Joyce M. Reisman In Memory of Norman B. Reisman
RELO In Memory of Eleanor McCarthy
RELS Management Company In Memory of William (Bill) Gordon
Kelley Elston Remy In Memory of William K. Harrison
Don & Marie Rennie In Memory of Dorothy Ann Kimball
Jerry & Diane Richman In Memory of Myra Goldberg
John Ridge In Memory of Betty Ridge
Mr. & Mrs. Howard Riggs In Memory of Phyllis N. Heck
Sandy Riley In Memory of Jett Riley
Allan & Sharon Rimland In Memory of Arthur Goldberg
Dr. Kenneth & Dr. Sheryl Ring In Memory of Arthur Goldberg
Meg H. Robbins In Memory of Henry Bertram Holmes
Robin Rodgers In Memory of Beverly Montpetit-Eimer
Jan Como Rodriguez In Memory of Ilio G. Como
Elie Rosen
Nathaniel Rosen
Karen M. Rosenberg In Memory of Arthur Goldberg
Marc A. & Amy Rosenberg In Memory of Arthur Goldberg
Richard & Berta Rosenman In Memory of Roberto Roz Mussa
Gerry & Ingrid Rosenthal In Honor of Alda Mocogni
Charles W. Roska In Honor of Constance Roska
William & Debra Roth In Memory of Arthur Goldberg
Frank G. Rourke In Memory of Harold A. Adamiak
Betty L. Rousselto In Memory of Charles E. Flanigan
Virginia Rudge In Memory of Robert Rudge
Gary Rudnitsky, D.D.S. In Memory of Arthur Goldberg
Jack Rudolph In Memory of Arthur Goldberg
Rugby IPD Corp. In Memory of David Dykes
Anna Saladino In Memory of Nan Scelzi
Imelda Salnoske In Memory of Carlton Salnoske
Gino Santi In Honor of Alda Mocogni
Louis & Ida Santi In Honor of Alda Mocogni
Santora Family In Memory of Julia La Magna
Dr. Richard & Jill Scharf In Memory of Arthur Goldberg
Mark E. & Randi A. Schlanger In Memory of Charles E. Flanigan
Cheryl Fisher Schneider In Memory of Arthur Goldberg
Wayne & Pat Schneider In Memory of Donald Lambrecht
Steven Schoen In Memory of Arthur Goldberg
John E. Schoenecke In Memory of June Clarice Schoenecke
Clifford & Susan Scholz In Memory of Charles E. Flanigan
Victoria R Schreck In Memory of Albert Schreck
William & Barbara Schulman In Memory of Arthur Goldberg
Jeanne Scott
Scripps Financial Service Center In Memory of Leontine P. Klem
Ernest C. Segundo, Sr. In Honor of Constance F. Segundo
Guy Seymour In Honor of Stella Seymour
Shanley Family Fund In Memory of Leontine P. Klem

Carl Thomas Sharp In Memory of Mary S. Thomas
Donna H. Shaw In Memory of Arthur Goldberg
Stuart S. & Marjorie S. Shepard In Memory of Vivian G. Elliot
Lola R. & John D. Shine In Memory of Jack K. Molz
Georgia Jane Shipp In Memory of Stanley L. Cole
G. & S. Shkapenko In Memory of Gunnar Hausmann
Dean & Leslie Shulman In Memory of Arthur Goldberg
Edith Silcox In Memory of Jack Silcox
Mike R. Silverberg In Memory of Donald Lambrecht
Lloyd Silverman In Honor of Majorie Silverman
Michael & Marilyn Sincevich In Honor of Marilyn Sincevich
Donna & Chuck Sisney In Memory of Robert F. Evans, Jr.
Sko-Die, Inc. In Honor of Alda Mocogni
Andrew & Stephanie Slavin In Memory of Jack A. Scott
Warren & Esther Sloan In Memory of William H. Foster, Jr.
Robert Slominski In Honor of Mary Slominski
Robert F. Smith
Gerald Souder In Memory of Catherine E. Souder
James B. Sparks In Memory of Marie C. Sparks
Kathleen Matarazzo Specia In Memory of Eileen Matarazzo
Clyde A. Spooner In Honor of Leslie H. Spooner
St. Joseph's Wayne Emergency Department In Memory of Mahesh C. Trivedi
Margaret C. Standard In Memory of Jack A. Scott
Stephen M. & Sandra A. Stay In Memory of Charles E. Flanigan
Angela L. & Paolo T. Stefani In Honor of Alda Mocogni
Sandro & Rosa Stefani In Honor of Alda Mocogni
Bill & Ursula Stephens In Memory of Donald Lambrecht
Larry C. & Mary Ann O. Stewart In Memory of Kenneth Fowler
John & Kate Stinebring In Memory of Marguerite R. Boerger
Lane & Nancy P. Stokes In Memory of Martha C. Christian
John Strada In Memory of Marcia N. Strada
Sue's HDR Co-Workers and Friends In Memory of Jessie Kiersey
John & Sheryl Sullivan In Memory of Donald Lambrecht
Wendy O. Sutton In Memory of Eleanor McCarthy
James E. & Terry Swarthout In Honor of Alda Mocogni
Rose Marie Swiderski In Memory of Richard J. Swiderski
Jerry R. & Joan M. Swormstedt In Memory of Kenneth Fowler
James & Dawn Sykora In Memory of Fernando Vela, Jr.
Sylvia Simon Tansey, PhD In Memory of Martin Simon
Barry Tarallo In Memory of Guerrino J. Tarallo
Taylor Building Products, Inc.
Donna Taylor In Memory of Julian T. Morris
Karen Lewis Taylor In Memory of Hughie Lewis
Peter & Caryl Taylor In Memory of Stanley Berkowitz
The Doucette Family In Memory of Calvin Stambaugh
The Phiffer Family of Warren Michigan In Memory of Geraldine Bellis
The Prudential Foundation Matching Gifts In Memory of Angelo Battista
The Savick Children In Memory of Dorothy Savick
The St. Thomas Bridge Group In Memory of Gunnar Hausmann
Thomas M. & Elizabeth C. Thees In Memory of Leontine P. Klem
Thomas McGuire, MD In Memory of Charles E. Flanigan
Kathy Thomas In Memory of Nellie Ross Peacher
Margo Todd In Memory of Lee Anna Myers
Patsy Tolleson In Memory of Betty Upton
Constance Tomsick In Memory of Ernest C. Johnson

Philip J. & Virginia H. Torsney In Memory of Leontine P. Klem
Denise Townsend
Russ Townsend In Memory of Mary F. Townsend
Transitional Assistance Department, County of San Bernardino In Memory of Dalcie M. Child
Lynn Trinchera
Mary Trotta In Memory of Jerome Trotta
Cor Trowbridge & Hugh Silbaugh In Memory of Lorna S. Trowbridge
Steven A. & Amy G. Tulip In Memory of Arthur Goldberg
Betty M. Twiggs In Memory of Nancy Spraker
John H. & Caroline Tyers In Memory of Charles E. Flanigan
Corrado & Jeanne Ugolini In Honor of Alda Mocogni
Underwriters Safety & Claims, Inc. In Memory of Myrtle Flake
Susan & Patrick Vail In Memory of Helen Saroyan
Van Nest Coleman & Associates In Memory of Doris A. Nilo
William & Tanya Vena In Honor of Alda Mocogni
Pteven & Patti B. Veneziano In Memory of Arthur Goldberg
Verizon In Memory of Joyce Deacon
Suzanne Vinson In Honor of Buddy Podraza
Paul & Mary Virtue
Charles R. & Jeanette A. Wagner In Memory of Gunnar Hausmann
Mary Walters In Honor of Robert Walters
Jack F. & Caroline S. Waltz In Honor of Jack Waltz
Paul Warner In Memory of William Ron Sandwith
James & Mary Warshauer In Memory of Leontine P. Klem
Alfred H. & Barbara Wassinger
Jeffrey Waters & Nancy Greene In Memory of Arthur Goldberg
Angela Wavra In Memory of William Wavra
Leo & Betty Weber In Memory of Oliver H. Grotelueschen
Linda B. Webster In Memory of Robert E. Webster, Jr.
Weinstein, Eisen & Weiss LLP In Memory of Benjamin Pena
Richard & Julia Weiss In Honor of Julia Weiss
Doryce Hills-Wells In Memory of Ruth Bromfield
Frank Jr. & Judy Wells
Doug & Amy Welp In Memory of Richard Riester
Westside Medical Associates, LTD. In Memory of Oliver H. Grotelueschen
Tommy Q. White In Memory of Tara T. White
Tyrell & Patricia White In Memory of Benjamin Randle
W. Wilson & Mary Julia White In Memory of Clarence Nuthals
Karen Whitton In Memory of Geraldine Whitton
Keith and Kristina Wilson In Honor of Keith Wilson
Lisa Klem & Kenneth R. Wilson In Memory of Leontine P. Klem
William V. Wolbach In Memory of Lawrence Schwartz
Betty Wood In Memory of Robert Wood
Dorothy T. Worobe In Memory of Betty F. Taylor
Mary & George Wurster In Memory of Lawrence Schwartz
Ronald R. Wyatt In Honor of Alda Mocogni
Arlene J. Wynia In Memory of Melvin Wynia
Lily Sun Yang
Frank P. & Mary E. Youtsey In Memory of Frank P. Youtsey
Adam Zakrzewski In Memory of Marjorie Zakrzewski
Georgia Zampathas In Memory of Stratis C. Zampathas
Leo & Marianne Zanotti In Honor of Alda Mocogni
John Zbikowski In Memory of Richard J. Swiderski
Admiral Lando W. & Josephine K. Zech In Memory of John L. From Jr.

How To Make A Bequest To The Society for Progressive Supranuclear Palsy

To make a bequest of cash or property to The Society for Progressive Supranuclear Palsy, your will or supplemental codicil should state:

"I give and bequeath to The Society for Supranuclear Palsy, a non-profit corporation, organized under the laws of the State of Maryland and having its main office at Woodholme Medical Building, Suite 515, 1838 Greene Tree Road, Baltimore MD 21208, the sum of \$ _____ or _____ % of the residue, rest and remainder of my estate to be used for the general purposes and mission of the organization."

A bequest to the Society is fully deductible for estate tax purposes. To learn more about opportunities for giving, consult your attorney, accountant, estate planner or call the Society for PSP office, 1-800-457-4777.

How To Make A Donation Of Securities To The Society for Progressive Supranuclear Palsy

Contact: • The Society for PSP
Woodholme Medical Building, Suite 515
1838 Greene Tree Rd., Baltimore, MD 21208
1 (800) 457-4777 or 1 (410) 486-3330
FAX: 1 (410) 486-4283 • email: SPSP@psp.org
Or • Ann Wilson, Regional Investment Manager,
Provident Bank of Maryland, Pikesville Office,
3635 Old Court Road, Baltimore, MD 21208
410-277-7815 or 410-274-1244
FAX: 410-602-0932.

A transfer can be easily made electronically.
DTC Number 0443 • Account Number 5LV052345
Account for the Society for Supranuclear Palsy, Inc.
It is the policy of the Society that stocks are sold as soon as they are received in our account.

The Society for PSP, Woodholme Medical Building, Suite 515, 1838 Greene Tree Road, Baltimore, MD 21208
1 (800) 457-4777 • 1 (410) 486-3330 • In Canada (866) 457-4777
PLEASE MAKE ALL CHECKS/GIFTS TO "THE SOCIETY FOR PSP."

Send me copies of:

- #1 PSP Some Answers (Overall guide To PSP)
- #2 Aids for Daily Living Catalogs/Thickening Agents/Personality Changes/Helping the Helpers - four page pamphlet.
- #3 2002 National Symposium Video Tapes - 3 Pack \$75, plus \$7 shipping in US and \$10 outside the US.
- #4 *The PSP Advocate* Newsletter
- #5 Thickening Agents
- #6 Swallowing Problems
- #7 Personality Changes
- #8 Helping the Helpers Who Care for People with PSP
- #9 Eye Movement Problems with PSP
- #10 1999 National Symposium Video Tapes - 3 Pack \$75, plus \$7 shipping in US and \$10 outside the US.
- #11 PSP Fact Sheet (1 page summary can be duplicated and distributed)
- #12 Aids for Daily Living Catalogs Listing
- #13 Publications Resulting from Society Funded PSP Research
- #14 Brain Bank Information Packet
- #15 Physician Referral Cards
- #16 Giving Envelopes
- #17 Planned Giving Information
- #18 Information About PSP translated in Spanish
- #19 I Have Been Diagnosed with PSP
- #20 Challenges in the Management of PSP
- #21 Support Group List

Mail to: _____

Fax to : _____ Email to: _____

FOR PHYSICIANS ONLY:

- CD "The Diagnosis of PSP" by Lawrence Golbe, MD (Recommended for clinicians and faculty)
- Medical Professional Packet (Grant Award Information/PSP Rating Scale/copies of all other info.)
-
- I no longer wish to receive the *The PSP Advocate* and by sending this will save expenses for the Society.

My new address is: _____

Yes, I wish to be included on The Society for PSP's mailing list:

Name _____

Address _____

City _____ State _____ Zip _____ Country _____

Fax _____ Email _____

Person w/PSP Family Physician Other _____

Enclosed, please find my gift to help support The Society for PSP and those impacted by PSP.

\$25 \$50 \$100 \$250 \$500 \$500-\$1000

Name _____

Address _____

Phone/Fax/email _____

Check/Charge to: Visa Mastercard American Express

Card number _____ Expiration Date _____ Signature _____

Thank you for your TAX-DEDUCTIBLE gift. A copy of financial statement available upon request.

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VOLUNTEER PROFILE

Name: _____ Connection to PSP _____
(Please include professional designations; i.e., MD, PhD, etc.)

Spouse or Significant Other's Name: _____

Home Address: _____

Home Telephone Number: _____ Fax: _____

E-Mail Address: _____

Business: _____ Title: _____

Business Address: _____

Business Telephone Number: _____ Fax: _____

Your occupation and job responsibilities: _____

Board Memberships & Professional Organizations: _____

Social Affiliations/Clubs & Organizations: _____

Personal Interests/Hobbies: _____

Areas of Experience or Expertise:

- | | | |
|---|---|---|
| <input type="checkbox"/> Budget/Fiscal | <input type="checkbox"/> Fundraising: | <input type="checkbox"/> Board of Directors |
| <input type="checkbox"/> Legal | <input type="checkbox"/> Special Events | <input type="checkbox"/> Computer Technology |
| <input type="checkbox"/> Accounting | <input type="checkbox"/> Foundations | <input type="checkbox"/> Web site/Internet |
| <input type="checkbox"/> Investing | <input type="checkbox"/> Corporations | <input type="checkbox"/> Newsletter |
| <input type="checkbox"/> Government Affairs | <input type="checkbox"/> Writing | <input type="checkbox"/> Lead a Support Group |
| <input type="checkbox"/> Personnel | <input type="checkbox"/> Media | <input type="checkbox"/> Social Services |
| <input type="checkbox"/> Research/Marketing | <input type="checkbox"/> Graphic Arts | <input type="checkbox"/> Allied Health Professional |
| <input type="checkbox"/> Non-Profit Mgmt. | <input type="checkbox"/> Meeting Planning | <input type="checkbox"/> Counseling/Social Work |
| <input type="checkbox"/> Public Speaking | | <input type="checkbox"/> Other (specify) _____ |

THE SOCIETY FOR
PSP
Progressive Supranuclear Palsy

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Baltimore, MD 21208

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