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**INSIDE:**

**PUBLICATIONS  
RESULTING FROM  
SOCIETY FUNDED  
PSP RESEARCH**

**MORE SPECIAL  
EVENTS**

# YOU CAN ALSO BE A PSP SPECIAL EVENTS VOLUNTEER

*Help Raise PSP Awareness  
Help Raise Funds to Support Society Services*

## “Bikers, Streetrodders, and Classic Car Fans Show Support for PSP”

## It Takes Just One Person And...

Nancy Brittingham  
Editor, *The PSP Advocate*

### THE JIMMY DOWNS CURE PSP HOT ROD/HAWG BENEFIT



*Jimmy Downs and  
Jackie Allison at the  
Benefit.*

The “Jimmy Downs Cure PSP Hot Rod/Hawg Benefit” was held on September 7, 2003 on a beautiful fall day in Lawton, MI. The event was a HUGE success attended by over 2,500 people and netting over \$17,000. Jimmy and his wife, Pat, have owned and operated Downs Manufacturing for 20 years,

manufacturing numerous streetrod bodies and chassis across the country.

After Jimmy was diagnosed with progressive supranuclear palsy, the family felt a great need to “do something”. The Downs family (Pat, Jimmy, their son, Jamie, their daughter, Angie, along with their spouses) planned a Hot Rod Show to raise awareness of PSP. The event came together very quickly with the help of over 40 volunteers who worked tirelessly to make this event so successful. With a live band, DJ, lunch & drinks, a silent auction, two raffles, tee-shirts, a clown, and over 100 hot rods (whose owners gave a donation to have their cars in the show), spectators had plenty to see and enjoy. As an extra treat, over 100 Harley Davidson Hawg motorcycles pulled into the show to lend their support. It was quite a day! Hats off to the Downs family, all the volunteers and those who donated items and their time!

The Society for PSP made many good friends on this day, friends we will keep forever.

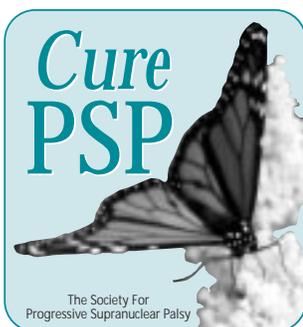


*Dave, Sam, Zach, and Tracie Sansavera*

Relocating to a new state, settling two young children in a new area, handling the duties of being a military spouse, training for a new job, struggling through a mandatory hurricane evacuation and recovering through the destruction caused by Hurricane Isabel could not stop Special Event Planner and Society friend, Tracie Sansavera! Planning a fundraiser to support the efforts of The Society for PSP is tremendously important to Tracie. Tracie’s mom, Mary Peck, was diagnosed in 1998 with PSP and has been struggling through the difficult challenges this devastating disease causes.

Tracie’s mom is in a nursing home in Ohio living near Tracie’s sisters and brother. Tracie said that “Watching my mom suffer took a toll on my belief system. I felt that there must be a reason such a loving, giving, and selfless person is suffering. I contemplated this for a while and decided that a lesson must be learned and some good has to come from her affliction. I took it upon myself to ensure her suffering would not be in vain. That is the reason I started doing a benefit.” Tracie goes to see her mom as often as possible but has to cope with the feelings that sometimes go with being the child away from home. Many family members not involved with the daily caregiving responsibilities wonder—what else can I do?

*Continued Page 18*



# The Society for Progressive Supranuclear Palsy

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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.*

The Society for Progressive Supranuclear Palsy, Inc. is a nonprofit 501 (C) (3) organization, that exists to promote and fund research into finding the cause and cure for PSP. PSP is a fatal degenerative brain disorder that has no known cause, treatment or cure. The Society provides information, education, support and advocacy to persons diagnosed with PSP, their families and caregivers. The Society educates physicians and allied health care professionals on PSP and how to improve patient care.

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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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## Director's Doings

Dear Friends of the Society,

In the past years, funding for the Society has been ample with donors responding in kind to a thriving economy. Our staff consisted of 4-5 people. We have grown knowing that PSP families are being better served through expanding our outreach and education program, initiating new services on the internet, and increasing research.

Like other nonprofits report, goals and budgets are increasingly difficult to meet and we are in danger of being unable to fund the excellent grant applications that have been submitted to the Society as well as maintaining and expanding our support to PSP families. The quality of the research proposals is improving due to the base of knowledge that has been built by the Society's research program. We are traveling throughout the country bringing hope and help to PSP families who are isolated by the disease. We are building on our successes—but the firm foundation of funding is dwindling. I am very concerned. What can you do?

Overall funding for operations in outreach, education and research should make The Society for PSP Number 1 on your charitable giving list. We can only go to our friends who understand the disease to get help. Funding research is expensive because our grants average about \$50,000 for a one year grant.

Here are some strategies:

1. Make a pledge to restricted research or to unrestricted purposes to be spread over several years.
2. Establish a research or outreach and education fund in a loved one's name.
3. Do a letter writing campaign or hold a special event. The Society's Development Director, Kathy Specca, can help you.
4. Enlist the support of your employers through matching gifts.
5. Tell us the names of foundations and or corporations where we can solicit funds.
6. Make a planned gift through a bequest, a will or some other philanthropic entity—trust, insurance or real estate.
7. Give through the United Way. You can designate the Society by writing our name in.

We have always had a team spirit as we move forward together to fight PSP. Raising funds is a great challenge but we can do it together!

Please contact me to explore opportunities to raise funds. We must keep accelerating our programs so the cure can be found and we can help families coping with this disastrous disease. We can't flounder and we can't wait.

*Ellen Sam Katz*

**Thank you, PSP Special Event Planners!**  
**Not only have you raised PSP awareness**  
**but during September and October you**  
**raised over \$37,000 for the Society.**

**Congratulations!**

**Liz Brisson and the**  
**Board of Directors**



## President's Corner Urgent Message from the Society's President

*"We'll have all eternity to celebrate our victories, but only one short hour before sunset to win them."*

Robert Moffat.



In this article I would like to focus your attention specifically on research funding. You may be interested to learn that the volume of grant applications has increased significantly and the quality is impressive. In fact, out of the 17 applications submitted for the most recent semiannual review cycle, 12 were judged as excellent by our Scientific Advisory Board. Unfortunately, we were only able to fund the top four due to limited financial resources. Obviously, ongoing research is vital to the Society's existence and its mission to finding the cause and cure of PSP.

While there needs to be a balance between funding for outreach, education and research, it would be tragic if we could no longer fund research and run the risk that potentially important PSP research would not take place. Even worse, we could run the risk that young neuroscience researchers with good ideas could turn their attention elsewhere. All the effort that the Society has devoted to attracting bright researchers to the issue of PSP could be lost.

Ellen has provided a number of strategies on ways in which you may be able to help to fund overall operations, outreach, education and research. I assure you that this is a priority for the Board of Directors and we have already started to plan solutions. In combination with your help, I'm confident that we'll be able to continue to fund top quality applications for research and continue to fund the services that the Society offers through outreach and education programs. Ongoing funding to our programs and services is so very important to many of you coping with this dreadful disease every day. Please contact the Society to explore how you may be able to help.

Sincerely,  
Elizabeth Brisson, President



### *A Special Thanks*

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

## Neuroscience 2003

More than 25,000 neuroscientists attended The Society for Neuroscience 33rd Annual Meeting in New Orleans, November 8-12, 2003, and Nancy Brittingham represented The Society for PSP with an educational exhibit to inform neuroscientists from all over the world about the successes of the Society's research program and to recruit more scientists to do work to accelerate finding the cause and cure for PSP. This meeting is considered the most important annual forum for the neuroscience research community. It offers attendees the opportunity to learn about the latest research and to meet and network with their colleagues. Because of all the great numbers that came by the booth to learn more about our research program, the Society for PSP is expecting a record number of grant applications to be submitted during the next grant selection process. This will be an exciting opportunity for research in PSP but also a challenge for the Society to raise funds to support the growing number of excellent research grant proposals that have been continuing to increase over the past years.

The Society for Neuroscience is a nonprofit membership organization of basic scientists and physicians who study the brain and nervous system. Neuroscience includes the study of brain development, sensation and perception, learning and memory, movement, sleep, stress, aging and neurological and psychiatric disorders. It also includes the molecules, cells and genes responsible for nervous system functioning. Recognizing the tremendous potential for the study of the brain and nervous system as a separate field, the Society for Neuroscience was formed in 1970. It has grown from 500 members to more than 34,000 and is the world's largest organization of scientists devoted to the study of the brain.

The Society for Neuroscience's primary goal is to promote the exchange of information among researchers. For this purpose, the Society publishes the scholarly journal *The Journal of Neuroscience* and holds its annual meeting each fall, attracting attendees from around the globe. The Society for Neuroscience is also devoted to education about the latest advances in brain research and the need to make neuroscience research a funding priority.

In 1970, neuroscience barely existed as a separate discipline. Today, more than 300 training programs exist in neuroscience alone, and neuroscience is one of the most exciting areas of biomedical research.

The field of neuroscience has made startling discoveries that have transformed our understanding of the healthy brain and helped to deliver treatments for disorders affecting millions.



**Society volunteer, Brenda Gremillion, and Allison Kupferman, Director of Government and Public Affairs, Society for Neuroscience.**

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### GRANT ANNOUNCEMENT:

The Society for PSP announces its Regular Grant Program up to \$50,000 supported by the Erwin and Pearl Poizner Memorial PSP Research Fund, The Dudley Moore PSP Research Fund, The Eloise H. Troxel Memorial PSP Research Fund and other designated funds.

Deadlines: April 1 and October 1

The Society also announces the Annual Eloise H. Troxel Memorial Fellowships, each of \$50,000 for research in PSP.

Deadline: October 1

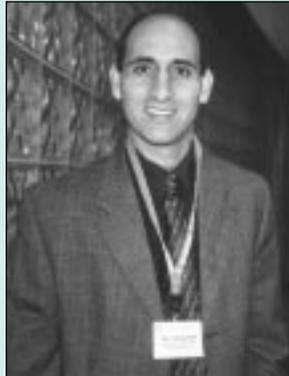
For information contact: Dr. Lawrence I. Golbe, Chairman of the Medical Advisory Board at [golbe@umdj.edu](mailto:golbe@umdj.edu) or Fax 732-235-7041.

## The Meredith C. Teel Regional Symposium

### *Southern Hospitality Meets Clinical Expertise in the Lone Star State*

Jessica Quintilian  
Director of Outreach and Education

Here in Maryland, the leaves are changing and the air is cool. But temperatures remained balmy in Houston, Texas, where the Society for PSP proudly sponsored the Meredith C. Teel Regional PSP Symposium on October 11, 2003. Dedicated to the memory of Meredith Teel by the Teel family, this full-day conference was attended by over 80 family members and caregivers from the southwestern United States. Houston is home to the Baylor College of Medicine, which is ranked among the nation's top academic health science centers and medical schools. The Society felt fortunate to have several speakers who have affiliations with this leading medical facility present at Saturday's symposium. The outstanding and diverse program brought together experts from the fields of neurology, ophthalmology, speech pathology, psychology, nutrition, hospice care and music education. Speakers included Dr. Ron Tintner, Assistant Professor of Neurology, and Dr. Rod Foroozan from Baylor College of Medicine in Houston;



*Dr. Rod Foroozan was one of several speakers from Baylor College of Medicine.*

Dr. Sunita Kavrie, a speech-language pathologist based in Houston; Dr. Naomi Nelson, Co-Associate Director of Education, and Dr. Michele York, Neuropsychologist, from the Department of Veteran's Affairs Medical Center, Parkinson's Disease Research, Education & Clinical Center; Terry Dildy, Clinical Nutrition Manager at St. Luke's Episcopal Hospital; Jan Parks, Patient Care Manager based in Houston; Susan Imke, Gerontological Nurse Practitioner from the Fort Worth area and Ellen Katz, Executive Director at the Society for PSP. The wide range of topics presented included Understanding PSP, Common Misdiagnoses and Current Research, Eye Movement Problems, Swallowing Problems, Family Dynamics and Impaired Thinking in PSP, End Stage Nutrition and Hospice Care and Music and Joy for Persons with PSP. Two special highlights of the program were the 45-minute "Ask the Doctor" panel and a lunch time presentation entitled "Visions and Opportunities" by Ellen Katz, the Society's Executive Director. Gerald Teel did



*Molly Dean poses beside the news article "Someone to Lean On" a feature about her husband Joe's experience with PSP that was published in the Houston Chronicle on June 8, 2003.*

a superb job as master of ceremonies and kept the day's program running smoothly.

This event was the first symposium on progressive supranuclear palsy to be held in the southwest region. Not only were symposium participants able to glean knowledge from a large panel of experts, they were able to meet other PSP families and members from the PSP Network of Houston, a large and active PSP support group in the region chaired by Karen Kennemer. This connection and sharing time with other families continues to be the most valuable aspect of each event the Society sponsors.

As always, the Society's visit to Houston was chocked full of activity during the few days that Ellen Katz, Executive Director, and Jessica Quintilian, Director of Outreach & Education, were able to spend in the Lone Star state. On Friday evening, the Society sponsored a thank you dinner in honor of Houston area families who have generously contributed to the Society for PSP. Ellen Katz gave an outstanding presentation about the Society, particularly the need for more research and research funding, which prompted many questions and stimulated conversation among the Texas families in attendance.

Several corporate sponsors supported the Meredith C. Teel Regional Symposium. Symposium participants were able to receive information and materials about many companies that serve the PSP community, including BIOTENE, Calmoseptine, Honey Luveen Long Term Care Insurance, LiftVest USA, No Rinse Laboratories, U-Step Walking Stabilizer, Advanced Respiratory, Simply Thick, and MedCare Central.

The Society for PSP gratefully acknowledges the Meredith C. Teel family, the Edward H. Andrews Foundation, the Memorial Hermann Healthcare System, Douglas and Barbara Bloom (in memory of Sophia Shapiro), Jack Hetrick (in honor of Doris Hetrick and in memory of Albert Katz), family and friends in honor of Kathryn Daniels, Marion "Buddy" Podraza and Joe Dean, and family and friends in memory of Frank Branisa, Mary McNicoll Cheslak, Harold Lipp, Artie McMahan and Jimmie S. Veale for their support of the Houston symposium. The Society wishes to thank our speakers, Karen Kennemer, Nancy McMahan, Gerald Teel and all of the wonderful volunteers from the PSP network of Houston who generously gave of their time to make this event such a success. Everyone who assisted with this symposium truly went the extra mile to make PSP families, caregivers and professionals feel welcome, proving that old-fashioned Southern hospitality is alive and well in the bustling city of Houston!



*Karen Kennemer, Chair, PSP Network of Houston and contact person for New Mexico*

## Outreach and Education

# Society for PSP Collaborates with Struthers Parkinson's Center to Offer a Wonderful Learning Opportunity

Autumn has been a busy season here at the Society. September brought Executive Director Ellen Katz and Director of Outreach & Education, Jessica Quintilian, to the Twin Cities of Minneapolis, Minnesota for The Minnesota Regional Conference for Persons Diagnosed with PSP, Caregivers, Families and Allied Health Professionals. Held on September 20, 2003 at the

Southwest in Minnetonka, this wonderful PSP learning opportunity was attended by 75 families from all over the Upper Midwest. This conference was particularly special, because the Society was able to collaborate with the Struthers Parkinson's Center, who held their annual Parkinson's Disease conference on the same date at the Marriott. Although the two conferences were separate from one another, this collaboration enabled the Society to gain much more exposure than if we had held our conference alone. Between 300-400 families attended the Parkinson's conference, and many stopped to ask questions about PSP. Several of our PSP families attended a free carepartner session offered by Struthers prior to the PSP conference. Our conference participants were also able to visit a variety of vendors who were on site for the Parkinson's conference and collect materials from sponsors such as Advanced Respiratory, Calmoseptine and LiftVest USA.

By collaborating with a prominent local movement disorders center, the Society was able to bring an excellent panel of speakers to our conference participants. Experts in both progressive supranuclear palsy and Parkinson's disease, the speakers for the day included Dr. Sotirios Parashos, Adjunct Assistant Professor of Neurology at the University of Minnesota and Clinical Research Chair at Struthers Parkinson's Center; Dr. John Anderson, Associate Professor at the Balance & Eye Movement Laboratory and Department of Otolaryngology at the University of Minnesota; Rosemary



*Participants enjoyed the variety of topics presented.*

Wichmann, Physical Therapist and Center Manager at Struthers Parkinson's Center; and Marjorie Johnson, Senior Speech Pathologist at Struthers Parkinson's Center. Topics presented included Update on Recent Developments in PSP, Eye Movement Problems in PSP, Physical Therapy & PSP and Swallowing Issues in PSP, as well as a presentation by Ellen Katz, Executive Director of The Society for PSP, about the Society and its services.

While the activities may have culminated with Saturday's conference, the trip to Minnesota provided Ellen and Jessica with several unique opportunities. First was a one-day conference held on September 19, 2003 at Struthers Parkinson's Center for support group facilitators from five states. Ellen had the great pleasure of presenting to more than 50 facilitators and educating them about progressive supranuclear palsy and the Society for PSP. Many families living with PSP attend Parkinson's disease support groups, particularly early on in the disease, so it is important to educate these group leaders about the differences between the two diseases. While attending this support group conference, Ellen and Jessica were able to tour Struthers Parkinson's Center and experience firsthand this incredible facility and the wide variety of activities offered to Parkinson's patients and their families. The center also receives visits from PSP families. It is inspiring to think that an inclusive center like Struthers could one day be established for PSP families. Until that happens, the Society is excited about continuing to collaborate with movement disorder centers across the country to help our families find the best resources available.

A second opportunity to touch PSP families in Minnesota took place on the evening before the conference. A thank-you dinner was held in honor of eight families who have generously given to the Society for PSP. Ellen Katz gave a presentation entitled "Visions and Opportunities" which gave these families a clear picture of how the Society operates and specific ways that their gifts are used to provide support, education and, most importantly, research into finding the cure for PSP.

The Society wishes to thank Charlotte Tripet, the wonderful volunteers from the Golden Valley support group, Struthers Parkinson's Center and Karen Kennemer for their invaluable assistance in weekend a success.



*Society Executive Director, Ellen Katz, presents Charlotte Tripet with a special thank you gift at the conference.*



*Speakers Marjorie Johnson, MA, SLP-CCC, and Rosemary Wichmann, PT, pose with volunteers Pearl Jackson and Ginny Smith at the Minnesota Conference.*

## Ask the Doctor

**Question:**

Does PSP lead to dementia like in Alzheimer's disease?

**Answer:**

Although mental confusion in patients with PSP is more apparent than real, most patients do eventually develop a mild or moderate degree of mental impairment. Some are mislabeled as having Alzheimer's disease. This is not very different from the situation in Parkinson's disease.

In PSP, the dementia, if it does occur, does not feature the memory problem that is so apparent in Alzheimer's disease. Rather, the dementia of PSP is characterized by slowed thought and difficulty synthesizing several different ideas into a new idea or plan. These mental functions are performed mostly by the front part of the brain (the frontal lobes). In Alzheimer's, on the other hand, the problem is mostly in the part of the brain just above the ears (the temporal lobes), where memory functions are concentrated.

Alzheimer's disease also includes either difficulty with language (such as trouble recalling correct names of common objects) or difficulty finding one's way around a previous familiar environment. Fortunately, these symptoms almost never occur in PSP.

Slowing of thought can cause major problems for people with PSP by making it difficult to partake in conversation. A question may be answered with great accuracy and detail, but with a delay of several minutes.

**Question:**

How is PSP different from Parkinson's disease?

**Answer:**

Early on, PSP may be difficult to distinguish from Parkinson's disease and indeed, PSP is an important cause of "parkinsonism." Both PSP and Parkinson's disease cause stiffness, slowness, and clumsiness. However, shaking (tremor), while prominent in most people with Parkinson's disease, is rare in PSP. When tremor does occur in PSP, it is usually quite irregular, mild, and present only when the hand is in use, not at rest as in Parkinson's disease. Patients with PSP usually stand up straight or occasionally even tilt the head backwards and tend to fall backwards, while those with Parkinson's usually are bent forwards. The problems with vision, speech and swallowing are much more common and severe in PSP than in Parkinson's. Parkinson's causes more difficulty using the hands and more stiffness in the limbs than does PSP. Finally, the main treatment for Parkinson's disease, Sinemet (and a few other drugs) is of much less benefit in PSP.

Parkinson's disease responds better to Sinemet than does



Lawrence I. Golbe, MD



PSP because in PD, deficiency of dopamine is by far the most important abnormality, and Sinemet is an excellent way to replace brain dopamine. In PSP, however, deficiencies of several other brain chemicals are at least as severe as the dopamine deficiency, and no good way exists to replace those. Also, in PSP, the brain cells that receive the dopamine-encoded messages are damaged, while these remain intact in Parkinson's.

**Question:**

Do any of the new brain operations for Parkinson's work for PSP?

**Answer:**

Not so far, unfortunately.

The fetal brain tissue transplant operation for Parkinson's disease has been tried in a few patients with PSP without success. The reason is undoubtedly that in PSP there is other, equally important, damage in the brain cells that would receive the signals from the area where the transplant goes. Pallidotomy is an operation that heats part of the globus pallidus, a structure (a nucleus) deep in the brain that is overactive in Parkinson's disease. It has been tried in PSP without success. The reason is probably that the globus pallidus is not damaged in Parkinson's and is actually overactive because of insufficient inhibition by the damaged area. In PSP, on the other hand, the globus pallidus is itself damaged and already partly paralyzed. Therefore, paralyzing it further with a pallidotomy would, if anything, worsen things.

Another operation that can help Parkinson's disease is thalamotomy, destruction of part of the thalamus, an important nucleus that serves as a relay station in the brain. However, thalamotomy helps little besides the tremor of Parkinson's, and tremor is never an important symptom in PSP.

Two newer procedures for Parkinson's are pallidal stimulation and subthalamic stimulation. In fact, subthalamic stimulation has become the standard surgical procedure for PD. In these, the same effect as pallidotomy is achieved by delivering a constant string of tiny electrical shocks to the globus pallidus or subthalamic area via wires implanted deep in the brain and attached to a battery-powered device under the skin of the chest. The advantage over pallidotomy is that the wires can be removed or repositioned without leaving much permanent injury. Because the electrical shocks merely temporarily paralyze the area of brain, they would be no more likely to help PSP than would permanent destruction of those areas, for reasons described in the preceding paragraph.

GIVE A GIFT ONLINE

[www.psp.org](http://www.psp.org)



## Hey doc, what does that mean?

### General Neurological & Medical Terms Part II

(Part I - *The PSP Advocate* 2003, Vol. 14, No. 3)

**GI TUBE** - a tube inserted through a surgical opening into the stomach is used to introduce liquids, food, or medication into the stomach when the patient is unable to take these substances by mouth.

**GLOBUS PALLIDUS** - a part of the basal ganglia; the internal part of the globus pallidus is what is targeted by pallidotomy to treat PD.

**HALLUCINATIONS** - perception of something that is not really there

**HEALTH MAINTENANCE ORGANIZATION (HMO)** - A risk-bearing organization with management responsibility for providing comprehensive health services, with an emphasis on preventive care, on a prepayment or capitated basis to voluntarily enrolled people in a designated population. Services are provided at an HMO-owned facility.

**HOSPICE** - hospice is a multidisciplinary team approach to the care of terminally ill patients. Nurses, social workers, clergy, volunteers, specially trained home health aides, etc. team together to provide comfort and relief to terminally ill patients and their families during the last months of life.

**HYPOMIMIA** - the mask-like expression typical of PSP.

**INCIDENCE** - the occurrence of new cases of a condition. The incidence rate describes the frequency with which cases are identified. Incidence is commonly measured in new cases per 1,000 (or 100,000) of population at risk, per year.

**INFORMED CONSENT** - the right to have information explained to you so that you fully understand and agree to treatment.

**INTRAMUSCULAR** - into a muscle.

**LEVODOPA** - the chemical precursor of dopamine and the most effective treatment for PD.

**LEWY BODY** - the spherical marker seen in the dopamine-producing nerve cells of the substantia nigra indicating a damaged and dying cell.

**MRI** - magnetic resonance imaging. A medical diagnostic technique that creates images of the body using nuclear magnetic resonance. A sensitive and powerful tool that can generate thin-section images of any part of the body from any angle, without surgical invasion and in a relatively short period of time. MRI gives biomedical and anatomical information that may allow early diagnosis of many diseases. MRI scanners provide imaging supplementary to X-ray images because MRI can distinguish soft tissue in both normal and diseased states.

**MANAGED CARE** - provision of health care in which access, cost, and quality are controlled by direct intervention before or during service. Programs rely on primary care physicians to manage patient care and control costs; they encourage the use of case managers to plan and accelerate high-cost care when it is necessary. The program's objective is to provide a comprehensive care system where patients get medically necessary treatment and care in the most cost-effective manner while maintaining quality and member satisfaction.

**MEDIAN SURVIVAL** - median means the middle value. An equal number of people live longer as die earlier than the median.

**MENTATION** - mental or cognitive function.

**MICROGRAPHIA** - the very small handwriting seen in PSP.

**MOTOR NEURON** - a neuron that conveys impulses from the central nervous system to a muscle, gland, or other effector tissue.

**MUSCLE ATROPHY** - loss of muscle fiber volume characterized by a visible decrease in muscle size occurring because muscles are no longer receiving messages or impulses from nerve cells.

**MUSCLE TONE** - used in clinical practice to describe the resistance of a muscle to being stretched. The muscle tone of some muscles may become increased and they resist being stretched—a condition called hypertonicity or spasticity.

**NERVES** - bundles of axons in the peripheral nervous system enclosed in a sheath of connective tissue.

**NERVOUS SYSTEM** - the system of cells, tissues, and organs that regulates the body's responses to external and internal stimuli.

**NEUROLOGIST** - a physician who specializes in the nervous system and its disorders.

**NEUROLOGY** - the medical science that deals with the nervous system and disorders that affect it.

**NEUROMUSCULAR** - relating to, or affecting both nerves and muscles.

**NEUROMUSCULAR JUNCTION** - a synapse between a nerve cell and a muscle.

**NEURON** - a neuron is a nerve cell that makes up the central nervous system of which the brain is the major part. It consists of a nucleus, a single axon which conveys electrical signals to other neurons and a host of dendrites which deliver incoming signals.

**NEUROPATHOLOGIST** - a pathologist who establishes the diagnosis in diseases of the nervous system by careful microscopic examination of the tissue. (see PSP Brain Bank information)

**NEUROTRANSMITTER** - a chemical messenger; dopamine is a neurotransmitter.

**NON-AMBULATORY** - not able to walk.

**NUCLEUS** - the center of the cell containing the genetic information (genes and DNA, chromosomes, etc).

**NURSE PRACTITIONER** - a registered nurse with advanced training in a particular area of health care, e.g., neurology, pediatrics, etc.

**NURSING VISITS** - a nurse from a home health care agency, that comes into your home for short visits to do assessments or other specialized care for a patient as directed by a physician.

**OCCUPATIONAL THERAPY** - occupational therapy strives to help individuals with physical or mental disabilities perform activities of daily living as independently as possible both at home and in the workplace. It differs from physical therapy, which deals mainly with the restoration of strength, endurance, coordination, and range of motion through

# Education

exercise, heat or cold therapy, and massage. Occupational therapy focuses on helping people find ways to master everyday activities such as eating and drinking, buttoning clothes, using zippers etc.

**ONSET** - the time of appearance of the first symptoms of a condition, prior to seeking diagnosis.

**PALLIATIVE CARE** - caring for a patient by maintaining the best quality of remaining life while offering support and guidance to the patient and family.

**PALLIDOTOMY** - surgical destruction of a small group of cells in the internal globus pallidus, the major area from which information leaves the basal ganglia, most effective in relieving dyskinesias and other symptoms of advanced PD.

**PARKINSONISM** - the motor picture that makes up PD: bradykinesia, rigidity, tremor, balance and gait problems.

**PATHOGENESIS** - the abnormal processes in the body that produce the signs and symptoms of a disease.

**PATHOLOGY** - the study of a disease process, including what is affected and what it looks like under a microscope.

**PHYSICAL THERAPY** - scientific physical procedures used in the treatment of patients with a disability, disease, or injury, to achieve and maintain functional rehabilitation and to prevent malfunction or deformity. Treatments are designed to minimize physical disability, to hasten recovery, and to contribute to the patient's well being.

**PLACEBO** - an inactive substance given as a substitute for an active drug ("dummy" or "sugar pill") - usually used as a treatment for a control group in an experiment.

**PLACEBO EFFECT** - symptom or change of condition seen when a placebo is given but is not attributable to an active drug agent.

**PREFERRED PROVIDER ORGANIZATION (PPO)** - applies to a variety of direct contractual relationships between physicians, insurers, hospitals, employers, or third-party administrators for a network in which providers negotiate with group purchasers to provide health services for a defined population at a negotiated rate.

**PRIMARY CARE** - health services provided by a family practitioner, pediatrician, internist, or obstetrician/gynecologist including preventive care in an ambulatory setting.

**PROGNOSIS** - the outlook or probable course for a patient.

**PROPULSION** - propelling forward as the patient accelerates with rapid, short steps.

**PSYCHOSIS** - a mental syndrome in which the patient loses contact with reality; psychotic manifestations include delusions, hallucinations, and paranoia.

**QUALITY OF LIFE** - refers to the level of comfort, enjoyment, ability to pursue daily activities.

**RANGE OF MOTION (ROM)** - refers to movement of a joint.

**REFLEX** - automatic response to a stimulus.

**REGISTERED NURSE (RN)** - a trained medical professional who assists people in health care under the direction of a physician.

**RESIDENT** - a medical doctor who has completed medical school and internship, and is receiving training in a specialized area and completion of the residency program is required for board certification in a medical or surgical specialty.

**RETROPULSION** - stumbling or falling backwards.

**RIGIDITY** - a tightness or increase in muscle tone at rest or throughout the entire range of motion of a limb; it may be felt as a stiffness by the patient.

**SEROTONIN** - a neurotransmitter.

**SIALORRHEA** - drooling.

**SIDE EFFECT** - drug's effect that is different from the beneficial effect for which the drug is being taken.

**SOCIAL WORKER** - an individual, usually with a university degree in social work, who provides counsel and aid to individuals with emotional and family problems.

**SPEECH THERAPIST** - an individual trained to assist patients in restoring, maintaining or improving speech and communication functions.

**STRIATUM** - part of the basal ganglia circuit; it receives connections from the substantia nigra and contains the dopamine receptors.

**SUBSTANTIA NIGRA** - meaning "dark substance" - the part of the brainstem that produces dopamine.

**SYNAPSE** - The junction/gap between axon of one neuron and a dendrite of another where a signal is passed by neurotransmitter chemicals.

**TOXIN** - a poisonous substance.

## 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!*

*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.*



## Medicare Learning Network (Medlearn) Hospice - Education Guide

### ELIGIBILITY:

- Hospice care is covered under Medicare Part A for terminally ill patients when: patients are eligible, have a physician certification, have chosen hospice care and care is given by a Medicare-approved Hospice program.
- Hospice care is covered under Medicare Part A (Hospital Insurance). Beneficiaries are eligible for Medicare hospice benefits if:
  - You are eligible for Medicare Part A (Hospital Insurance)
  - Your doctor (attending physician) and the hospice medical director certify that you are terminally ill and have less than six months to live;
  - You receive care from a Medicare-approved hospice program.
  - You sign a statement choosing hospice care instead of routine Medicare covered benefits for your terminal illness. The revocation of Medicare coverage applies only to palliative care services for the terminal condition; therefore, any services that are not related to the terminal illness should continue to be billed as usual.

### LENGTH OF CARE:

- Hospice care is available for two (2) periods of ninety (90) days and an unlimited number of sixty (60) day periods. The beneficiary can terminate their enrollment during a hospice period without a delay or lapse in Medicare coverage. If they terminate their enrollment during a hospice period, they do lose hospice coverage for the remaining days in the period. However, they can re-enroll in the hospice program again without losing hospice care days. Any change in enrollment is effective immediately.
- Medicare Covered Services – Medicare covers services such as doctor and nursing care, certain medical equipment and supplies, certain drugs for pain or symptoms, home health aide services, therapy, social work and counseling (including family) and short term inpatient stays.

### WHAT IS COVERED?:

- Physician services
- Nursing care
- Medical equipment ( such as wheelchairs or walkers)
- Medical supplies ( such as bandages and catheters)
- Drugs for symptom control and pain relief
- Short-term care in the hospital, including respite care (see below)
- Home health aide and homemaker services
- Physical and occupational therapy
- Speech therapy
- Social worker services
- Dietary counseling

Counseling to help you and your family with grief and loss  
*Beneficiaries will only have to pay a small co-payment for medications and inpatient respite care.*

### WHEN YOU CHOOSE HOSPICE CARE, MEDICARE WILL NOT PAY:

- Treatment to cure your terminal illness. As a hospice patient, you can get comfort care to help you cope with your illness, not cure it. Comfort care includes drugs for symptom control and pain relief, physical care, counseling, and other hospice services. Hospice uses medicine, equipment, and supplies to make you as comfortable and pain-free as possible. Medicare will not pay for treatment to cure your illness. You should talk with your doctor if you are thinking about potential treatment to cure your illness. As a hospice patient, you always have the right to stop getting hospice care and go back to your regular doctor or health plan.
- Care from another hospice that was not set up by the elected hospice. The beneficiary must get hospice care from the hospice provider chosen. The beneficiary cannot get hospice care from another hospice provider, unless he/she changes the hospice provider.
- Care from another provider that is the same care that you must get from your hospice. All care for the beneficiary's terminal illness must be given by the chosen hospice team. The beneficiary cannot get the same type of care from a different provider unless he/she changes the hospice provider.

### RESPITE CARE:

- Respite care is care given to a hospice patient by another caregiver so that the usual caregiver can rest. As a hospice patient, you may have one person that takes care of you every day. That person might be a family member or a friend. Sometimes they need someone to take care of you for a short time while they do other things that need to be done. During a period of respite care, you will be cared for in a Medicare-approved facility, such as a hospice facility, hospital or nursing home.

### PHYSICIAN CERTIFICATION:

- The hospice benefit is intended primarily for use with patients whose prognosis is terminal, with six months or less of life expectancy. The Medicare program recognizes that terminal illnesses do not have entirely predictable courses, therefore, the benefit is available for periods of time beyond six months provided the proper certification is made at the start of each benefit period.

*Please see additional instructions regarding physician certification in [http://www.cms.hhs.gov/manuals/pm\\_trans/AB0109.pdf](http://www.cms.hhs.gov/manuals/pm_trans/AB0109.pdf) (Program Memorandum AB-01-09)*

*For further information regarding Medicare Hospice Benefits see: <http://www.medicare.gov/Publications/Pubs/pdf/02154.pdf>*

## Education - Helpful Hints

### Home Healthcare Products

#### Series II

#### MOBILITY ASSISTIVE DEVICES

The following products can be ordered from:

#### Products From Functional Solutions

1-800-235-7054 or [www.healthcraftproducts.com](http://www.healthcraftproducts.com)



#### SUPERPOLE™ SYSTEM

Get in and out of bed independently!

The SuperPole™ Basic provides assistance to persons who need extra help getting from a seated position to a standing position. This floor to ceiling pole is held by a jackscrew expansion. The SuperPole™ fits a floor to ceiling range of 93" to 101" (236 to 257 cm). The heavy-gauge steel pole has a 1½" (3.8cm) diameter, and the base has a 5" (13 cm) outer diameter. Rubber pads prevent marring of the ceiling or floor. Installs easily in minutes—no structural reinforcements are needed. Professional installation is recommended.

The SuperBar™ pivoting and locking rail is ideal for persons who need added support when transferring or getting up. Measures 58" (147 cm) from the ceiling to the top of the bar. The 16" (41 cm) long rail moves with you in small increments, providing support similar to a walker. Features eight locking positions at 45°. It can lock in an instant to assist you to a seated position. A gentle lift is all that's needed to unlock the bar for movement. Keep the bar raised to pivot, or release it down at any time to lock in place.

Sit up easily with the Super Trapeze™ Plus. This trapeze system provides support during the transition from lying down to sitting up as well as standing assistance. Measures 42" to 70" (107 to 178 cm) from the ceiling to the top of the 12" (30 cm) long trapeze handle. Eliminates the need for special beds or bulky attachments. Stores out of the



way when not in use. Delivery is shipped by ground.

NC93020 SuperPole™ Basic	\$169.95
NC93021 SuperBar™	\$249.50
NC93022 SuperTrapeze™ Plus	\$249.50

#### Products From Dynamic Living

1-888-940-0605

#### SUPERPOLE™ TRAVELER

Breaks down into 2 pieces for easy traveling and storage.

The SuperPole™ Traveler brings a new level of convenience and flexibility for mobility on the road.

While one's home may have suitable adaptations for independent living, this is not typically the case for travel lodges, such as cottages, hotels, cruise ships (check with the cruise line first) and residences of other family members.

The Traveler is different from the standard SuperPole™ only in that the main pole easily separates into two 51" pieces making it easier to transport in the family car or other transport service.

DL2051 SuperPole™ Traveler \$179.99

#### Products From Independent Living Aids

1-800-537-2118 or [www.independentliving.com](http://www.independentliving.com)

#### ROLLATOR AVANT WALKING AID

by Etac of Sweden

It allows the active person to move about easily while in a comfortable seated position. Other attractive features include:

- supports up to 300 lbs.
  - removable basket included
  - 8" tires especially adept at moving over grass and rough surfaces
  - frame that adjusts from 30" to 40" with the seat height moving from 18½" to 28"
  - a flip up seat with a handhold makes the walker easy to fold
  - lightweight - (17 pounds)
  - hand brakes that require minimal effort to slow/park walker
  - gray, attractive steel frame with orange seat
- #307522  
\$330.00  
Shipping \$25.00  
Return Restocking Fee \$30.00



#### 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.

## Education - Helpful Hints

*I recently attended a PSP fundraising event in Lawton, MI and there was a vendor there that had dogs who assisted those with disabilities. Their name was CCI. My husband is diagnosed with PSP and I was thinking this special dog could be such a great companion. Can you provide any further information on this organization?*

### Canine Companions for Independence

Canine Companions for Independence (CCI) provides highly trained dogs to assist those with disabilities. Founded in 1975, CCI is the largest non-profit of its type in the country. CCI ensures the success and longevity of each human-canine partnership by carefully matching each participant to the dog that best fits his or her unique needs and circumstances. The result is a life of increased independence and loving companionship.

CCI puppies are born in the homes of volunteer Breeder Caretakers, who provide permanent homes to CCI's breeder dogs. Breeder Caretakers nurture the pups until they reach about 8 weeks of age and are placed with volunteer Puppy Raisers. Puppy Raisers give the pups loving homes until they reach 13 to 18 months of age. During this time, the puppies learn basic obedience and receive plenty of socialization, play-time and love. As healthy, happy, confident young dogs, they are ready for Advanced Training at CCI.

Advanced training is provided by CCI's professional instructors. During six to nine months of training, each assistance dog masters about 40 specialized commands before being matched with a participant.

Participants attend a two-week Team Training at one of CCI's training centers to learn how to work in partnership with an assistance dog. Graduation marks their significant

achievement and the beginning of a new stage in CCI's commitment to their success. For the duration of the partnership, CCI provides each graduate team with a variety of support services, including in-person visits, telephone and email communications, and regular training workshops.

Service dogs assist adults with physical disabilities by performing practical daily tasks such as turning light switches on and off, opening and closing doors, pulling manual wheelchairs, and retrieving dropped items.

Canine Companions for Independence is a non-profit organization that enhances the lives of people with disabilities by providing highly trained assistance dogs and ongoing support to ensure quality partnerships. There is no charge to participants for the canine, its training, or for the ongoing follow-up services provided to each team for the working life of the dog. CCI is a 501(c)(3) nonprofit supported entirely through the generosity of donors. Call 1-800-572-2275 for a region serving your area. [www.caninecompanions.org](http://www.caninecompanions.org)

#### 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](mailto:psp.eur@virgin.net)  
Website <http://www.pspeur.org>

### SIXTH NATIONAL BIENNIAL PSP SYMPOSIUM VIDEOTAPE ORDER FORM

The Sixth Biennial PSP Symposium May 17-18, 2002 Baltimore, MD Video Tapes-3 pack \$75 plus \$7 shipping in US and \$10 outside the US

**Please make checks payable to The Society for PSP.**

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

Please send me \_\_\_\_\_ set/s. Total amount including shipping \$ \_\_\_\_\_ .

**YOU CAN ORDER THE VIDEOTAPES ONLINE AT [WWW.PSP.ORG](http://WWW.PSP.ORG)**

Name \_\_\_\_\_

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Charge to:  VISA  Master Card  American Express

Name \_\_\_\_\_ Signature \_\_\_\_\_

Acct# \_\_\_\_\_ Exp. Date \_\_\_\_\_

# Support Groups As Of December 1, 2003

*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.*

## ALABAMA

MIKE & SUE MCINTIRE\*  
DOTHAN  
334-699-2091  
seminole1@graceba.net

## ARIZONA

KRISTINA WATTS  
Phoenix  
602-406-4931 • k2watts@chw.edu

## CALIFORNIA

CAROLYN GRIFFITH\*  
Santa Ana  
714-832-3731 • wgriff1@earthlink.net  
CERI WILLIAMS  
Sherman Oaks  
818-343-3259  
medianet@earthlink.net  
KATHY SCHWAIGER  
Thousand Oaks  
805-496-7018  
MARY MIANO  
Laguna Woods  
949-855-3972 • mjm941@juno.com  
CAROL PLATT  
Antelope  
916-332-6041  
DOTTIE GEORGENS  
Encinitas  
760-230-1130 • dgeorgens@cox.net

## COLORADO

KIM MARTIN  
Englewood  
303-788-4600 • kamsark@aol.com

## CONNECTICUT

MARION WELLS  
Waterford  
860-442-1161 • mlwells1@juno.com  
FRANK CADWELL\*  
Clinton  
860-664-9524

## FLORIDA

HELEN LAVELLE\*  
Naples  
941-352-2909 • hlavelle@yahoo.com  
LINDA IVES\*  
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\*PHONE/EMAIL GROUP

*Let us post your support group news and announcements in the PSP Advocate. Deadline dates are Jan. 15, March 15, July 15, Oct. 10. 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](http://www.psp.org)*

*I care for my mother who has PSP and is 76 years old. My father just passed away from Parkinson's two months ago at the age of 78. We had to move my parents to Wisconsin from their home in Florida almost two years ago to live with us. That was when my mother was having symptoms she couldn't hide anymore and we didn't know what was going on with her. We have remodeled the house and added on to make room and to make it all wheelchair ready!*

*We have had unbelievable experiences having both "disabled" parents here. These stories could go on and on. Things not funny at the time have become a source of humor now.*

*I have the most wonderful husband in the whole world to allow such dramatic changes in our lives. When we moved my parents up here they were to move into a retirement community. That was put to a fast halt when the neurologist saw what shape Mom was in, who was the caregiver for my father. Then we began the dilemma of what to do. We ended up all surviving a major remodeling and addition. If anyone has done that, you have sympathy I'm sure. The home was finally totally complete only for 3 months when we lost my Dad. It still breaks my heart to think of him not here and finally enjoying the outcome. During all of this, we were doing major testings on Mom to find out what was going on with her. Well, since I'm on this site, we all know what she has.*

*She is a sweet thing to everyone BUT me. At least I am the only one that she is taking her frustration out on. It is hard and I know will get worse.*

My mother is 66 and has had PSP for about 6 years, she too is lovely to everyone but me, but she also tells me I am the one she trusts, so maybe it is the same for your Mother, she knows you'll always forgive her and love her, I bet you did the same to her as a child! Never the less, it is not the easiest thing to deal with, PSP comes with all sorts of things that the doctors don't seem to have a grip on. We are the people living with PSP and so we are the people that understand. As for funny stories, I'm sure we could all use some of those.

Although this is a family none of us want to be a part of...welcome. I thank God every day that He led me to this forum. It has been a tremendous source of love, caring and support. Being able to express your multitude of feelings and experiences will hopefully be as therapeutic for you as it has been for me. Feel free to vent ... it helps to get things off your chest.

I completely understand the aspect of having both parents disabled at the same time. My mom had a lift chair delivered 11/12/02 for my dad. He was standing behind the chair and she came up to him to give him a kiss and wish him an early Merry Christmas. He started to fall and she "tried" to catch him. In the process, they both went down. Daddy (as in most of his falls) was not hurt ... however, my mom was not so lucky. The bone in her right arm (between the elbow and shoulder) was crushed in five places. As well as this, she suffered severe nerve damage ... and she's right handed.

From the time of her fall until my father began his new life at a nursing home in June 2003, there was someone with my parents 24/7. My mom had surgery in May to replace tendons and repair nerves and to this day is still trying to recuperate. She still does not have full use of her hand/arm and is still in

pain daily. The pain in her arm is minimal though compared to the pain in her heart. It was a very tough decision to make to place Daddy into the nursing home, but it was the best thing for everyone involved, especially my parents. We are very blessed, and the home that Daddy is in is absolutely wonderful. They have taken the best care of him...better than we were able to provide at home. When Daddy entered the home, he was still able to walk without assistance, although he would still fall sometimes. He was not able to feed himself, but he could still take himself to the bathroom. Today, he is totally dependent on others for his care. He can walk as long as we are by his side holding on, but he must be helped getting into and out of his wheelchair and bed and he must be fed and diapered.

This dreadful disease has taken the wind out of the sails of a truly wonderful, loving, caring man ... one that never met a stranger. It has torn my heart out to see him go from a man that was strong, outgoing and talkative to a man that is frail and non-communicative. It breaks my heart to see him struggle to speak.

I am sad that we have met this way, but I'm glad that you are here. Most definitely, the angels on this site are here with listening ears and open hearts. Please lean on us!!!

My dad is 68 years old and was diagnosed about 2-1/2 years ago with PSP. Believe me when I say that I and all of the others here know what you are going through. Just in the last 6 days, we've had a couple of set backs with Dad. He is choking more and more when he eats. It use to be only when he drank liquids, now solids are also choking him. The nursing home is trying to chop/smash his foods into soft or VERY small pieces. Dad is refusing to have his food pureed. Can't say I blame him, it doesn't sound to appealing to me either. I'm not sure if it is because of the swallowing/choking, the smashed foods, or decrease in appetite, but Dad has hardly eaten anything in the last week.

Dad has also started to get up frequently in the middle of the night. He cannot stand or walk anymore, not even assisted. So, when he gets up, he immediately falls. We cannot convince him to not do this; his mind tells him he can. The nursing home moved him to a room right across from the nurse's station. They think that they can keep a better eye on him at night. I'm frustrated - don't know how to keep dad safe anymore.

My father was also Mom's caregiver until he died of a stroke almost two years ago, which is when I took over. He was 91 at the time, and Mom is now 92. It's not easy to watch a parent fail, and you've indeed had your share with both. Mom has pretty much decided not to try to get up by herself and for that I'm thankful. As for the food, we too are having more and more trouble. The one advantage I have is that by having her at home I can fix things I know she likes. At this point she requests creamed chicken on toast a lot! I cut the toast in tiny pieces and the chicken is also cut fine and she gets it down. I often mix a can of peas with it. The hospice nurse rolls her eyes as it's not too appealing to her, but agrees that it is good, nourishing food. Years ago I wouldn't have dreamed of serving the same thing two days in a row, but things have changed and I think now whatever she wants goes.

### 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.

# 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.

## Life of a PSP Patient and the Caregiver

Regarding John Gawlik's PSP

Dear Nancy,

I want to give you our story. We have had a complete turn-around in our lives. As I wrote, thoughts just kept coming to me. John was in the printing trade for 40 years. He was president of his company and a very active person. We had a very full life doing everything together, even contracting our own homes. I am very glad he is still with me even with the 24/7 care he needs. Many couples do not have that chance.

Forever grateful, Pat

In 1992-93, we noticed his left foot drag; he was slower, couldn't walk as fast and tired easily. We were taking country western dance lessons and the instructor would tell him to move that foot. We noticed slower walking and then he often fell. We had a lake home; he fell off the dock, fell down stairs, fell in the living room and bathroom.

In 1994-95, he still got around but with a much slower pace. We decided to see a neurologist as his family physician said it was old age. We would not buy that opinion.

In 1996, the problems greatly increased. His driving was getting scary—so I did most of it. His foot did not react and then he would hit the brake hard. He had difficulty staying in his lane, drove too fast in heavy traffic and too slow at other times. We finally decided between the two of us that it was best if I drove all the time.

In 1997-98, we had several appointments with our neurologist. Our physician prescribed Sinemet and told us to return in 6 months for a return visit. He then told us he was not sure of the diagnosis and to go to Mayo. Our HMO would not send us there and we were referred to another facility that told us he had peripheral neuropathy in his leg—which also proved not to be correct.

John wanted another opinion and we went down to Mayo on our own and he took all the tests. Their answer—some parkinsonism. An increase in the dosage of Sinemet was prescribed, which did not help. We went back to the hospital for him to undergo more tests—eye movement, cognitive, sleep, etc. Finally, they came up with the diagnosis of progressive supranuclear palsy. They tried John on Miraplex, Requip and Permax and there still was no improvement. Finally, we relaxed and went with their opinion. Meanwhile, he went



John & Pat Gawlik, August 10, 2003  
on their 57th Anniversary

from a cane to a walker and then we decided on a wheelchair to prevent more accidents. We had the wheelchair customized for him with a special back and cushions.

John's bladder started acting up and he had frequent bladder infections. He would lose control. We struggled with that problem until we were advised to get a supra-pubic catheter. We did and that made our lives much easier. It has enabled us to go out and not worry about leakage.

Also in 1997, John's speech started getting softer and he shortened his sentences. Then, slowly, it kept getting more difficult to understand. By, 2000, he would have to repeat and repeat. Now, it is very hard to know what he is saying—muffled, not clear. This is very stressful.

In December, 2002, I was told to have him evaluated for a hospice program. They determined that he was eligible. This has been a great help because a nurse comes in once a week and checks his lungs, heart and blood pressure. She also keeps us in good supply of thickeners, leg and bed bags.

As of Sept., he is not on any medications. He takes Vitamin E and C, Fish oil, and calcium. He does have a lot of heartburn, which I suspect he gets from putting too much in his mouth at one time, and he gets relief from "Tums." His appetite is good but everything seems to taste sweet. He is getting weaker while eating. He breathes heavily while eating and makes a noise. He also makes this noise when he moves and tries to do things. His drooling is worse—almost all the time.

Helping him is a 24/7 job. He needs help getting in bed, in the shower, dressing, any movement or lifting. He also now is having trouble at night—sometimes he takes the catheter tube off the night bag on his leg. He does not know he is doing this and sees it first thing when he wakes up in the morning. But, all in all, we have been trying to keep our lives as normal as possible. I take him with me shopping. I have a transport chair always in the trunk. I get him in it and go to the malls, movies, and friends. We play card games which don't require holding too many cards in the hand—like cribbage. He also works jigsaw puzzles with 100-125 pieces to keep his hands and mind busy. We are using bibs, magnifying glasses, Dr. Scholl's velcro shoes, elastic waist trousers, small spoons, large-mouth cups and bed rails.

John likes watching movies on cable as well as baseball and football games. We are looking into a Dynavox System to help him better communicate with me and others. We enjoy our days together and hope to keep our spirits going great. We have had 57 years of a very wonderful marriage. We get up every morning and give thanks as we count our blessings. We have three wonderful children who take us on day trips and care for us when we need help. So, we thank them some more.

Patricia Gawlik

# Support - Our PSP Stories

## Special Friends in New Orleans

Almost three years ago, the Society sponsored a Caring and Sharing in New Orleans. I was fortunate to attend and meet several wonderful PSP families. While attending the Neuroscience 2003 meeting in New Orleans this November, Albert Palumbo graciously offered his home for local PSP families to gather for cocktails and hors d'oeuvres while I



*"Mr. Tony"*

was visiting the city. When we saw each other, he said that we had met before. Suddenly, it all came back.

I recalled meeting Albert as he brought his dad, Tony Palumbo, Mark Lescale and Joyce Hamilton (additional caregivers) to the conference. I vividly recalled how "Mr. Tony" put his feet in motion to move his wheelchair—as he sat in it—to get right in front of the TV so he could get a better view of the video presentation. He shielded light from his eyes so he could see better. I was impressed that his team of caregivers let him do what was important to him and did not go chasing after him to move him back. At the end of the meeting, "Mr. Tony" held onto my hand and gave it a kiss. He reminded me so much of my dad.

Tony Palumbo died from PSP in August. From the memories we shared that evening, I learned "Mr. Tony" was one special character/person and is sorely missed!

Thank you, Albert, for such a nice evening.  
Nancy Brittingham



*Albert Palumbo, Mark Lescale, and Joyce Hamilton*

**In Remembrance of Henry Ogiba**  
By Phillip Hales



On this day, November 11, 2003, Veterans' Day I would like to write about my grandfather and to thank him this day. He is a veteran because he has fought in many wars, served his country, and has done his duty to God and his country. It takes a lot of courage to join the military. My grandfather has traits that I hope to have one day. Examples of these are bravery, courage, and honor.

My grandfather is a great man because he has risked his life to protect individual's freedoms, lives, and rights. That is what the Military is all about. He has shown bravery in an extremely difficult time when he faced his illness, PSP. Many family members and I were sad because he did not make it through his illness. I really wish he were still here so I could thank him and tell him that I was proud of him and was the best grandfather yet. I also miss him dearly, even though I did not know him very well. I just want to say, "thank you for protecting my country and for being a wonderful grandfather."



**PROCLAMATION**

WHEREAS, the Mayor of Baltimore City has proclaimed October as PSP Awareness Month.

Mayor Martin O'Malley of Baltimore City proclaimed October as PSP Awareness Month.

# Special Events

## It Takes Just One Person And...

*Continued from Page 1*

And Tracie knew just what she was going to do!! Plan an event to increase awareness of the disease and raise funds for the Society's programs. She did it last year in Utah and she was going to do it again this October, no matter what obstacles came her way.

So, on Saturday, October 25, 2003, at Deep Creek Landing, Newport News, VA, a small but mighty group came together to honor Tracie's mom (and my dad, who died several years ago from the ravages of PSP) and enjoy a wonderful evening of family, new friendships, great food, terrific music and lots of fun. The added bonus—this group of 7 families raised more than \$2300 for the Society

### *How?*

I received a wonderful unexpected phone call from Tracie last summer. I knew of her Utah event last year but had not met her. Her husband is now stationed at Langley Air Force Base in Hampton, VA. Coincidentally, my father, who died from PSP, was also in the Air Force as I was growing up and we were stationed at Langley. Living near Tracie, I was only a cheerleader as I watched Tracie plan and organize "At the Hop." This one person arrived in the summer "cold turkey" to a new area and planned a wonderful event. This is how she did it.

## Special Event Planning "TIPS FROM TRACY"

1. **LOCATION:** First, search for places to hold the event. Hotels and conference halls can be very expensive. Go online and through the yellow pages and research possibilities. I found the right place at the right price—after the owner graciously gave a discount.
2. **CORPORATE SPONSORS:** Write a sponsor request letter based on a sample letter that you can obtain through The Society for PSP. Go through the local yellow pages and call companies that you feel will have some knowledge or contact with PSP, i.e. neurologists, medical supply companies, physical therapists, etc. Contact companies you feel have the funds to provide sponsorship, i.e. banks, credit unions, large corporations, etc. I had to go through many, many "no's" before I found someone who said "yes."
3. **FOOD:** Call several catering companies and tell them your story. I called several companies, but it was the catering director at Second Street who listened to my story and empathized with me. Her mother is currently suffering from a debilitating disease. She offered a great discount and the food was excellent!
4. **DECORATIONS:** Get back on the phone and call shops to ask for a discount on decorations and tableware. The owner of "Big Top Party Shop" listened to me and wanted to help in any way he could—from donating a dance floor to giving a huge discount on wonderful decorations and tableware.
5. **INVITES:** Design an invitation, get it approved by the Society and then distribute them at work, church, grocery stores, any place that will allow you to put up the flyer. Contact local newspapers and TV stations announcing the benefit. There are online editions of local newspapers that post local events.
6. **RAFFLES:** Prepare a list of different prizes that anyone

would like to win and go through the local yellow pages asking for a donation of a gift certificate from different types of companies, ranging from massage therapy to a bowling alley. Virginia requires a request in writing at least 2 weeks prior to the event.

7. **DJ:** Fortunately for all guests, one of my oldest and dearest friend is a DJ in Cleveland, Ohio. Mike "Big Daddy" Jones drove 9 hours donating his time and talent to make this event a great one! To give every family an opportunity to acknowledge their loved one who had PSP, we provided a time to dedicate a song in honor of that person. Watching Nancy's family sing the song they dedicated in memory of their dad was very touching. Being able to dance a polka in honor of my mother made me feel like she was there. I just kept thinking, "Mom would love this!"
8. **FRIENDS/FAMILY:** Start with family and friends. If they do not want to attend or cannot, ask if they would like to make a contribution. The cause is too important to be squeamish when asking for donations or help. This holds true from sponsor requests to ticket sales. When you speak from your heart, people listen.
9. **FOLLOW-UP:** The week before the event is the most stressful time. It is important to follow up with everyone who has a hand in the event, from the hall and caterer to those who volunteered to help in any capacity.

After the 2 events I have coordinated, there is such a euphoric feeling. To have people gather together for the same cause is an amazing thing. When I started on this endeavor I did it to honor my mother, but I have gotten so much more. One of my favorite quotes is by Ralph Waldo Emerson, "It is one of the beautiful compensations of this life that no one can sincerely try to help another without helping himself." How true this is.

None of us can wait until next year's October Awareness Month Event—Casino Night. So watch for news about Hampton Roads 2nd Annual October PSP Fundraiser 2004—Tracie's third event!!

Special thanks to our corporate sponsors: The Ritz Carlton, Washington, DC; The Hairphenalia, Debbie Gallagher Massage, Galeria, AMF York Lanes Bowling (Grafton, VA); Tysinger Dodge, Venetian Nail Salon, David Miller, DDS, Gear-Up Printing, Glamour Shots, Langley Federal Credit Union (Hampton, VA); Big Top Party Shop, Deep Creek Landing, Applebee's, Second Street (Newport News); and the Yorktown Flower Shop.



*"At the Hop"*

# Special Events

## Fundraising Update

Kathy Metarazzo Specca  
Director of Development

### PSP TRAVEL:

Jackie Allison, Society Assistant Director, and I were invited to inform the employees of Mikron, a family owned business in Seattle, about progressive supranuclear palsy as well as the Society's services. Mikron is a business that manufactures vinyl window and door systems, decking, blinds and shutters. Mr. Ron Sandwith, the founder and owner of Mikron, recently passed away with PSP. He owned and operated this successful family business, which is now managed by his three sons - Jeff, Mark and David. Mr. Sandwith's daughter, Susan, resides in California and is very supportive.

Since Mr. Sandwith adopted the United Way Campaign as an annual giving opportunity for his staff, the employees expressed an interest in donating to The Society for PSP in his memory through their United Way contributions. The sons requested presentations at their quarterly meetings with the employees. Three presentations were provided on October 16th. Jackie and I were able to reach more than 500 employees. The presentations were so well received that Jeff asked us to fly to Kentucky (all expenses paid by Mikron) on October 21st and give the same presentation to more than 300 employees. Both the family and staff were moved by the information we provided. The employees finally understood the PSP journey that Mr. Sandwith took with his family.

The Sandwith family was most gracious and appreciative. Plans for long-term fundraising efforts in memory of Mr. Ron Sandwith are in the making. Gifts from The Society were presented in person to the three sons, who will take care of getting the Society's gift to their sister Susan as well. This is truly a wonderful, caring, and loving family.

### ADDITIONAL SPECIAL EVENTS:

On October 1st a fall fundraiser was held in New York to raise awareness and funds for PSP. Approximately 100 people attended. In just one short evening, this successful event raised \$5,000. Hats off to James Bernard, Lisa Boren and Bob Juneja for a job well done. The event included an open bar with food.

September 19th became a dress down day in a San Diego California law firm. Employees paid a fee to wear jeans. Special thanks to Nadine Hylander for spearheading this event to bring in \$545 to The Society for PSP.

Keeping with the jean trend, Dave Bosworth had a special dress down day, too, with his automotive buddies on October 17th and raised \$750. Dave got a lot of mileage for his efforts!

## Collinwood Middle School 2nd Annual PSP Walk-A-Thon

The Beta Students at Collinwood Middle School held their second annual PSP Walk-A-Thon on October 14, 2003. Sixty-four students raised \$2800. for the PSP Society. The Beta Students and Beta Sponsors were very pleased with the amount that was raised by the students this year.

The Walk-A-Thon has a special meaning for one of the club sponsors. Ms. Sherri Collie's dad was diagnosed in 1998 with PSP. Mr. Odell Harper was unable to attend this year's walk



PSP. Mr. Odell Harper was unable to attend this year's walk due to his health. But his two daughters, two grandsons, sister-in-law, grandnieces, and grand nephew represented him.

The walk this year was held in honor of Mr. and Mrs. Odell Harper. Sallie is her husband's caretaker. She has never wavered in her strength and has faithfully taken care of him everyday. Mr. Odell has accepted his disease with dignity. He is a strong man who has a deep, everlasting faith in God. This faith is what helps him get through each day.

The event began by recognizing the top ten students who raised the most money for the Society. Jake Calton raised the most out of the Beta students. Jake is Mr. and Mrs. Harper's grandson. After the presentations of awards, the students posed for pictures. Many of them were wearing their PSP T-shirts. The students are very proud of their shirts. The students began their walk soon after the pictures were made. After their walk around the school, the students came into the gym for refreshments.

The Walk-A-Thon was a success and everyone had a good time walking. The students hope that a cure will be found soon for this disease. It would be wonderful if the cure was found in time to help Mr. Harper. Special thanks to Sherri Collie, who spearheaded this event.

## Vermont PSP Support Group

Vermont Support Group member, Gale Cass, organized a unique fund-raising event to support October PSP Awareness Month. In Vermont, interstate rest areas do not have vendors that serve food, but the state does allow non-profit groups to provide food and coffee for "safety breaks". The Vermont group set up on both the north and southbound sides of I-89 in Williston, Vermont on Sunday October 12, serving up Green Mountain Coffee Roasters coffee, freshly-pressed cider, straight-from-the orchard apples, baked goods and a warm welcome to travelers. Many people passed through and made cash donations to the Society. Group member Guylaine Beaudoin, daughter of Claude Beaudoin, set up lap-top computers at each location with continuous-running Power Point displays of "Facts about PSP." Visitors were curious to know about PSP and support group members and family were on hand to greet people as they entered the attractive, gallery-style rest areas. Columbus Day weekend is a big tourist time in Vermont when multitudes come to see the fall foliage. The Vermont group has already reserved the same rest areas for Columbus Day weekend 2004. In all, 27 support group members, assisted by family and friends participated by contributing baked goods and being present to greet travelers. Gale's father, Clyde Spooner, gets the award for traveling the greatest distance to volunteer: he came from Florida where his wife, Leslie, is in a nursing home. Clyde was an enthusiastic volunteer along with Gale's son Darnel...true ambassadors for the Society! Did we say it was a magnificent, warm and sunny day with spectacular vistas of foliage on the mountains all around?

# Report Of Gifts - September 1 to December 1, 2003

*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.*

## **GOLDEN MONARCH (\$10,000+)**

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Duanne & Laurie Phillips In Memory of Kevin Keogh

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Jimmy & Pat Downs In Honor Of Jimmy Downs  
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John & Jami Miller In Memory of  
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Clarice Rosen  
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Beverly G. Weiser In Memory of  
Bernard William Weiser

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Mrs. John G. Zimmerman In Memory of  
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Edith Siskin  
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Henry Lyman (Tad) Bretting  
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Janice Niehaus In Memory of  
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Rick & Laura Willett In Memory of James Thomson  
Bill & Vicki Williams In Memory of Jimmie Veale  
Wojnar Family In Memory of David C. Donohue  
Roger & Heather Wright In Memory of Ruby Wright  
Gary & Suzanne Wuillschlager In Memory of Mary Lou Cobb  
Richard & Kay Yuspeh In Memory of Judith Vick  
Cris Zamplieri  
Mrs. John G. Zimmerman  
Diana LaFave Zuzek

## 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: • Ellen Katz, Executive Director  
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 The Society for PSP/National Institutes of Health PSP Brainstorming Conference/Dr. John Steele meeting with the Maryland Support Group \$25, plus \$3 shipping in US and \$5 outside the US.
- #18 Beautiful Acknowledgment Card to someone special for any occasion and will personalize your message. By donation only.
- #19 Planned Giving Information
- #20 Information About PSP translated in Spanish
- #21 I Have Been Diagnosed with PSP
- #22 Challenges in the Management of PSP
- #23 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.

You Can Help By Becoming A Volunteer

## 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

Woodholme  
Medical Building  
Suite 515  
1838 Greene Tree Rd.  
Baltimore, MD 21208

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