

Woodholme
Medical Building
Suite 515
1838 Greene Tree Rd.
Baltimore, MD 21208
1 (800) 457-4777
1 (410) 486-3330
FAX:
1 (410) 486-4283
In Canada 866-457-4777
email:
SPSP@psp.org
website:
www.psp.org

INSIDE

**Summaries of 10
PSP-Related
Original Research
Presentations**

**October PSP
Awareness Month
Activities**

WE ARE
LAUNCHING OUR
NEW WEBSITE
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expanded, energetic,
and educational
website!*

Dudley Moore Honored At Buckingham Palace Brings PSP Before Royalty



Dudley Moore received the CBE (Commander of the British Empire) in a ceremony at Buckingham Palace on Friday, November 16. The CBE is one of the top honors awarded in the United Kingdom.

Moore was wheeled into the Palace Ballroom by a page, and the ceremony was conducted by the Prince Charles, who stepped off the podium to present a special medal and to speak with Moore, now confined to a wheelchair. The Prince congratulated the actor and musician, and spent several minutes speaking with him.

Moore traveled to the Palace in a 1954 Rolls Royce, the same vintage car as was seen in the movie "Arthur." Moore was joined at the Palace by his sister, Barbara Stevens, and by close friends Rena Fruchter and Brian Dallow. A small group celebrated after the ceremony with lunch at the Savoy Grill in London.

Moore was "thrilled and touched" by the ceremony, he said, and pleased to make the trip to England, where he caught up with relatives and friends he had not seen in nearly two years.

Denny Neagle's Fine Pitching Yields Awareness And Funds



Denny Neagle visited the Society for PSP in Baltimore on Monday, October 15, 2001. The staff held a luncheon in his honor to thank him for his generous gift. Denny presented the Society with a check for \$13,900 representing the 139 strikeouts (\$100 per strikeout) he made this year as a pitcher for the Colorado Rockies. Denny spoke to the staff and Board Members about how PSP has affected his father-in-law and his family. His goal for next baseball season is to have the Colorado Rockies host a PSP night. The Society is very grateful to Denny and sends best wishes to him and his family and a wish to get even more strikeouts next year.

*For more information on
Dudley Moore's honor
and Denny Neagle's visit
see page 4*

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 501-3(C) organization that exists to promote and fund research into finding the cause and cure for PSP. PSP is a rare, neurological disorder related to Parkinson's disease. The Society for PSP provides information, education, support and advocacy to persons with PSP, their families, and caregivers. The Society for PSP educates physicians and allied health professionals on PSP and how to improve patient care.

Phone 1 (410) 486-3330
Toll Free 1 (800) 457-4777, FAX 1 (410) 486-4283
Ellen Pam Katz, Executive Director

The Society for PSP
Woodholme Medical Building
Suite 515
1838 Greene Tree Road
Baltimore, MD 21208
email-epkatz@psp.org
SPSP@psp.org
website-www.psp.org
List Serve: requests@hydra.welch.jhu.edu
Subscribe psp your name

The PSP ADVOCATE is a quarterly newsletter published by the Society that informs readers of findings in the area of PSP. There is no copyright. Newsletters and other publications can disseminate any information in this newsletter. Please cite attribution to the Society and the author.

EDITOR

Nancy Ogiba Brittingham
NancyB501@cs.com
(757) 838-0777 • FAX (757) 838-6086
(In memory of Henry and Jane Ogiba)
Assistant to the Editor: Debra Thompson
(In memory of Lois Croft Davis)

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Director's Doings



Five years at the helm

I have just celebrated the completion of my fifth year as Executive Director. This milestone has had a profound impact on my professional and personal life. When I began with the Society in November 1996, I came, like you, as a stranger to PSP. My introduction to the disease was the same as a newly diagnosed patient and family. I, too, sought answers,

reasons and ways to cope. At that time, there were only two employees—myself and a part-time secretary—each at 28 hours per week. There was no room for me in the small office at the Johns Hopkins Outpatient Center, so I worked from my home. My home and the growing world of PSP became one place.

Five years at the helm have been a life-changing experience. The personal and professional growth that comes with this position is extraordinary. I have become a more sensitive and responsive person. My skills and expertise in many areas have developed, including management, human resources, organizational development and fundraising. I have met beautiful people along the way—Board members, physicians, donors, staff and volunteers. They have inspired me and challenged me.

In 1996, the database consisted of 3,000 individuals, families, physicians and organizations. There were seven persons on the Board of Directors and the income was \$96,000. The Society needed to be “out there” in the world of neurologists, rare disease and health care organizations, and be easily accessed by patients and families. The networking began. The Board of Directors needed more people who could offer diverse skills and expertise. Fortunately, with the vision of the founding Board of Directors, we were able to use the resources we had to cultivate and nurture the organization.

Luckily, many volunteers emerged who were willing to start support groups, form new committees (Development, Outreach and Education) and begin a strategic planning process. We had wisdom-filled resources to help us: Johns Hopkins University School of Medicine, Maryland Association of Non-Profit Organizations, Association of Fund Raising Professionals, the National Organization for Rare Disorders and the services of Sue Dagurt, our organizational development consultant.

Thank you, PSP families and friends, for assisting me along the way. With you, I aspire to keep shaping the Society to ensure a future for persons diagnosed with PSP and families. With you, I would love to see in my lifetime a cure, better treatment, early diagnosis, more information – the list is endless.

I ask for God's continuous blessings on our organization and its supporters that will enable me, our staff, our Board members, donors and precious volunteers to enrich the Society and go into the future with the spirit, talent and the energy needed to get the job done.

With deep appreciation,

Ellen Pam Katz
Executive Director

MARK THE DATE!

**The 6th Biennial
National PSP Symposium for
Persons with PSP, Families,
Caregivers and
other Allied Health
Professional
May 17 and 18, 2002
Baltimore, MD
*More details to follow***

**PLEASE HELP DEFRAY EXPENSES AND KEEP
REGISTRATION FEES LOW**

The cost for our Sixth Biennial PSP Symposium cannot be covered by registration fees which will be kept at a minimal fee. We are asking your help in underwriting the Symposium. You will become a member of the “2002 National PSP Symposium Honor Roll “ which will be listed in the program and in the *PSP Advocate*. Your gift may be made in memory or honor of a loved one. Please send your gift in the enclosed envelope and note on the envelope and/or on your check that you would like to be a “Symposium Patron.”

WE NEED YOUR HELP!!

The Society is seeking potential corporate/business sponsors to help support the National PSP Symposium. Large corporations, both national and regional, including department, drug, and supermarket chains, restaurants, banks, and consumer products manufacturers most often have “departments of corporate giving” or their own foundations through which they funnel charitable gifts to the community, including cash grants to non-profit advocacy organizations for educational conferences and other worthy projects.

Look around your community and help us to identify these hometown corporations. If you know of any potential sponsors please contact the Society for PSP at 1 (800) 457-4777, (410) 486-3330, FAX (410) 486-4283 or email spsp@psp.org.

Please provide contact information, the names of the president/CEO, sales/marketing directors and the person in charge of corporate giving.

Thank you for your assistance.

**THANK YOU FOR HELPING FAMILIES ATTEND
THIS HIGHLY EDUCATIONAL EVENT.**



ouching: the Prince of Wales congratulates Dudley Moore as he invests him with a CBE

Frail Dudley Moore collects his CBE

By CAROLINE DAVIES

DUDLEY MOORE, the musician and comic actor, raised his top hat to onlookers at Buckingham Palace yesterday after being made a CBE by the Prince of Wales.

Confined to a wheelchair by a degenerative health condition, the 65-year-old Hollywood star from Dagenham, east London, was honoured for his services to entertainment.

He flew from his home in New Jersey, sweeping through the gates of Buckingham Palace in a 1934 Silver Wraith Rolls-Royce identical to the one used in his hit film *Annie*, for which he received an Oscar nomination for best actor.

But, as he revealed last year, he is suffering from progressive supranuclear palsy, which is similar to Parkinson's disease, and has deprived him of his speech and his mobility.

He was wheeled to the bedroom in Buckingham



Comic duo: with Peter Cook

Palace by a page, where the honour was conferred by the Prince sitting on behalf of the Queen. The Prince went down to congratulate the actor.

Moore's condition has deteriorated since he was interviewed on a BBC Omnibus documentary last

year in what was billed as his last television appearance. He sat motionless as the Prince spoke to him, his head tilting slightly to one side.

Asked afterwards if he ever believed he would receive such an honour, with effort he replied: "No".

Moore, who rose to fame with Peter Cook, Alan Bennett and Jonathan Miller in *Beyond the Fringe*, was accompanied to the ceremony by his sister Barbara Stevens, 76.

Moore now lives with his musician friends Brian Dallas, 58, and his wife Berna Frutkin, 54, a pianist with whom Moore performed before his illness prevented him from playing the piano.

Mr Dallas, a British-born US citizen who accompanied Moore to the palace, said: "It's extremely frustrating for Dudley. He understands everything but it's so difficult for him to respond".

Moore was "thrilled" with the ceremony, Mr Dallas added. "It's a great honour for him."

DENNY NEAGLE'S VISIT TO BALTIMORE IS A HIT!!



The publication of the PSP Advocate for the Years 2000 and 2001 have been generously funded by Jay Troxel in memory of his beloved wife, Eloise H. Troxel

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

14th International Congress on Parkinson's Disease PSP Research Presentations

Lawrence I. Golbe
Chair, Society Medical Advisory Board
Professor of Neurology
Robert Wood Johnson Medical School, NJ

The 14th International Congress on Parkinson's Disease was held in Helsinki, Finland from July 27 to August 1, 2001. Although the focus was PD, presentations on PSP were welcome. Here are summaries of the 10 PSP-related original presentations and a brief commentary on each in italics.

1. About half of all patients with Parkinson's disease experience involuntary movements as a side effect of levodopa/carbidopa (Sinemet) within 5 years of the start of their illness. Although patients with PSP typically receive even higher dosages of levodopa, they develop such movements only very rarely. Dr. J. M. Kim and colleagues from Seoul, Korea reported on only the second such patient whose PSP was later confirmed at autopsy. *Interestingly, the abnormal movements waned and disappeared as the patient's modest benefit from the drug gradually disappeared. This is different from the situation in Parkinson's, where the movements most often worsen with time.*

2. Traditionally, the severity of signs and symptoms in PSP has been measured using scales designed for Parkinson's disease. In 1996, with the help of many other neurologists, I devised a scale specifically for PSP that has achieved widespread use in research studies. Now, a mostly French group headed by Dr. C. Payan of the Pitié-Salpêtrière Hospital in Paris have formulated a rating scale for use in both PSP and multiple system atrophy, a brain disorder similar in many ways to PSP. The new scale consists of 86 items, some of which were adapted from the PSP Rating Scale and from 5 other relevant scales. *This scale may be preferable to my PSP Rating Scale for use in those patients who may have either PSP or multiple system atrophy and who must be carefully observed further to permit an accurate diagnosis.*

3. There have been many research papers describing the signs and symptoms of groups of patients with PSP starting with that of Steele, Richardson and Olszewski in 1964. The largest such report was presented at the Helsinki meeting by Dr. U. Nath and colleagues (including Society Medical Advisory member Dr. A. J. Lees) from the United Kingdom. Their 187 cases were mostly from one geographical area and were examined in standardized fashion. Among many observations was the fact that double vision occurred in 39%, light sensitivity in 20% and difficulty moving the eyelids in 17%. *This cohort of patients will be useful in charting the progression of PSP in an organized way over a period of many years. It will also permit studies of environmental and genetic factors that may cause PSP.*

4. The ability of neurologists specializing in movement disorders at a research-oriented referral center to diagnose PSP was assessed by Dr. A. J. Hughes and

colleagues. They found that for the 19 cases of autopsy-confirmed PSP in the United Kingdom Parkinson's Disease Society Brain Bank who had been seen by neurologists at the National Hospital at Queen Square, 16 had been diagnosed accurately during life. *The researchers feel that these rates of accuracy exceed those that are achieved by application of formal sets of diagnostic criteria, although they did not perform a direct comparison. They hypothesize that neurologists who see such patients frequently develop the ability to recognize complex patterns that cannot be adequately captured by necessarily simple published criteria.*

5. The *PSP Advocate* has reported in the past on the cluster of people on the Caribbean island of Guadeloupe who have an illness that both during life and at autopsy closely resembles PSP. Dr. D. Caparros-Lefebvre of the University Hospital of Guadeloupe along with Society Medical Advisory Board members Drs. A. Lees and E. Tolosa update their data. They now know of 54 patients on Guadeloupe with PSP. Farming as an occupation was more common among these people than among Guadeloupeans without PSP. However, there was no apparent relationship to the pesticide levels in drinking water. In two towns and one small island off the main island, the prevalence of PSP was 10 times that in Europe or North America. *These findings extend the previous observation that Guadeloupean patients with PSP consumed certain native fruits more frequently than people without PSP.*

6. A different group of researchers led by Dr. Caparros-Lefebvre reported the autopsy findings in three of the Guadeloupean PSP patients. In two, the findings were typical for PSP and in one they were only slightly atypical. *These data strengthen the relevance of the Guadeloupean story to the issue of ordinary PSP.*

7. More evidence of a relationship of farming to PSP was presented by Dr. N. Vanacore of Rome and colleagues from other parts of Italy, Germany and the UK. They administered a questionnaire to 58 patients with PSP, 58 people without PSP from the same communities and 116 people without PSP from the same neurologic referral clinics. They found that farming was 2.84 times more common among patients than among controls. There was no difference for questions on education, smoking, hobbies, family neurological history, and occupations other than farming. *This is only the third such study for PSP. The other two, both performed at my own center in New Jersey, found no relationship of farming to PSP. This issue requires further study.*

8. The above study was unable to demonstrate a familial predilection of PSP using a group of 58 patients. That may be because only about 1 in 100 patients with PSP has a clear family history of PSP. One more such case was reported by Dr. J. Gascón and colleagues from Spain. Two siblings were diagnosed with PSP. One died and the autopsy showed changes typical of PSP. Both siblings' blood samples showed the same variant in the tau gene on chromosome 17 that has been found in nearly all cases of PSP but in only a minority of the population without PSP. *Of course, an environmental cause of the PSP in these two siblings is at least as likely as a genetic cause. Further study of these and other sibling pairs can shed light on the cause or causes of PSP.*

8. Two studies confirmed the utility of magnetic resonance imaging (MRI) in PSP. One, from Dr. Y. Rolland and colleagues from Rennes, France, tested the agreement between two independent observers on the presence or absence of PSP in MRI scans that were all obtained using the same technique. There was very good inter-observer agreement with a kappa value of 0.8. (Kappa is a measure of agreement between two observers. 1.0 would be perfect agreement). *All of the MRI changes the observers relied on are well-described in textbooks.*

9. The other MRI study, from Dr. M.F.H. Schecke and colleagues of Innsbruck, Austria, used a special MRI technique called "diffusion-weighted imaging" (DWI), which is available at most ordinary MRI facilities, to compare PSP with Parkinson's disease. DWI is ordinarily used to detect strokes. The study found a more severe abnormality in the substantia nigra and globus pallidus in PSP than in PD with almost no overlap between the two disorders. These two brain areas are those hardest hit in PSP. *It remains to be seen whether either of these MRI techniques is better than a good neurologist at distinguishing PSP from PD.*

10. Avid readers of the *PSP Advocate* know that in the brain of those with PSP, tau protein is mostly of the "4-repeat" rather than the "3-repeat" variety. This contrasts with the normal state and Alzheimer's disease (another disorder in which tau protein forms neurofibrillary tangles in brain cells), where there are equal amounts of the two forms. In some other tau-tangle disorders, 3-repeat tau is more abundant than 4-repeat. (The "repeat" number refers to the repetitions of the portion of the tau protein that binds to microtubules, a critical part of the structural skeleton of brain cells.) Now, Dr. M. Takanashi and colleagues from Tokyo have compared levels of 4-repeat and 3-repeat messenger ribonucleic acid (mRNA) in the brain in PSP. mRNA is an intermediate in the pathway from genes (made of DNA) to protein. Knowing the level of mRNA that corresponds to a particular form of protein can pinpoint the source of an abnormality in that protein. They found that the types of tau mRNA in various brain areas correspond only moderately to the types of tau protein in the same area. *This shows that the cause of the abnormal balance of tau protein subtypes in PSP does not rest primarily with faulty transcription of tau DNA into mRNA, but at some other point in the process of protein synthesis. This issue has important implications for the search for a prevention of PSP. Several other research groups around the world are working on the same question. It will be interesting to see if they confirm Dr. Takanashi's results. Watch this space.*

What Are Stem Cells And What Relevance Do They Have To The Treatment Of PSP?

Joseph Jankovic, MD
Member, Society Medical Advisory Board
Professor of Neurology
Baylor College of Medicine, Houston, Texas

One of the most exciting, and most controversial, areas of

On August 9, 2001, President Bush announced his support for limited research on existing (about 60) stem cell lines.

current research involves a novel strategy for brain repair using stem cells. Stem cells are very primitive cells that can be grown in a test tube or a culture dish. Manipulating their environment and allowing them to reproduce (that is, "culturing" them) can coax them to develop ("differentiate") into any type of tissue, including dopamine-producing brain cells. Recent research findings indicate that brain cells that have been lost or damaged as part of the degenerative process associated with Parkinson's disease can be replaced. To a certain extent, this could be relevant to PSP as well because some of the cells that degenerate in PD also degenerate in PSP. There are four types of stem cells: 1) embryonic stem cells (when fertilized egg divides and forms 200 to 250 cells, called blastocyst, a stem cell colony or a cell line that can be established and maintained in a culture dish), 2) embryonic germ cells (derived from cells destined to become part of the reproductive system, taken from a 5-9

week old embryo), 3) umbilical cord stem cells (taken from the umbilical cord near the placenta at the time of birth), and 4) adult stem cells (found in brain, bone marrow and other tissues). It is hoped that when these stem cells are injected into the basal ganglia, one part of the brain affected by Parkinson's disease and PSP, they will acquire the characteristics of the surrounding nerve cells, including synthesizing and secreting dopamine. Some preliminary studies in experimental animals made parkinsonian have already provided encouraging results suggesting that embryonic stem cells may in fact differentiate into nerve cells and survive for several months.

On August 9, 2001, President Bush announced his support for limited research on existing (about 60) stem cell lines. Scientists are currently working to develop a detailed registry of these cell lines, only some of which are in the United States. The genetic origin and quality of these cell lines are not yet well known. Because of the controversy surrounding embryonic stem cell research and the limited number of available, high-quality stem cell lines, efforts are currently under way to identify alternate sources of donor tissues that can potentially be used in restoring damaged or diseased brain or spinal cord.

A large number of scientists at my own institution, Baylor College of Medicine, including Drs. Wei-dong Le and Malcolm Brenner, are conducting intensive research with the primary aim to develop stem cells from adult bone marrow. The chief advantage of such a strategy is that it avoids the controversy and ethical issues surrounding the use of embryonic tissue and, more importantly, if successful, the patient's own bone marrow can be used as a replenishable donor tissue without the fear of immunologic rejection. Exciting progress already has been made by the recent finding by Dr. Ira Black and colleagues at Robert Wood Johnson Medical School in New Jersey that "mesenchymal" stem cells derived from bone marrow can differentiate under certain condition into neurons.

In the proposed study, we at Baylor plan to genetically engineer the bone marrow cells with a Nurr1 gene, discovered at Baylor to be critical for the development and maintenance of dopamine-producing neurons, to transform the stem cells into dopaminergic neurons. We will then test the ability of these neurons to restore dopaminergic function in parkinsonian animals. Furthermore, we plan to use a gene "switch" to regulate the function of these cells. The ultimate aim of this study, of course, is to apply this novel therapeutic approach to treat PD and possibly PSP.

We hope that with the financial support from the National Institutes of Health and other granting agencies as well as grateful patients, this basic science research will eventually translate into clinically meaningful therapy for patients with PD and PSP.

Our Work Is Just Beginning

An update for the PSP Advocate
by: Diane Dorman
Senior Director for Public Policy for
the National Organization for Rare
Disorders (NORD)

On October 16, the Senate Health, Education, Labor, and Pensions Committee (HELP), chaired by Senator Edward Kennedy (sponsor), passed by unanimous consent the Rare Diseases Act, S. 1379, leaving the door open for future consideration of the legislation on the Senate floor. But there is much to be done if we are to ensure passage of this landmark legislation in the Senate.

WHAT DOES THE RARE DISEASES ACT OF 2001 DO?

- Provides a statutory authorization for the existing Office of Rare Diseases (ORD) at the NIH.
- Increases the national investment in the development of diagnostics and treatments for patients with rare disorders.
- Authorizes regional centers of excellence for rare disease research and training.
- Authorizes funding for the NIH Office for Rare Diseases to \$24 million for fiscal year 2002 and "such sums as may be necessary for each subsequent fiscal year."
- Authorizes the funding for the FDA's Orphan Product Research Grants program, which has provided vital support for clinical research on new treatments for rare disorders to \$25 million for fiscal year 2002, and "such sums as may be necessary for each subsequent fiscal year."

To date, the following Senators have cosponsored this bipartisan legislation: Orrin Hatch (R-UT), Ernest Hollings (D-SC), Jeff Bingaman (D-NM), Richard Durbin (D-IL), James Jeffords (I-VT), Hillary Rodham Clinton (D-NY), Gordon Smith (R-OR), and Susan Collins (R-ME).

You are encouraged to write or call your Senators today, asking them to cosponsor the Rare Diseases Act, S. 1379. Of particular importance are those members sitting on the Senate Appropriations Committee. For a membership roster of that committee, or to find the complete text of the legislation, go to <http://thomas.loc.gov>, the official web site of the U. S. Congress. For a sample letter, contact Diane Dorman, Senior Director for Public Policy for the National Organization for Rare Disorders (NORD), at ddorman@rarediseases.org or (202) 496-1296 x 3014.

Note: Because Senate offices have yet to receive any mail due to the continuing threat of anthrax, and because offices are scattered throughout Capitol Hill, you will probably receive a far better response if you work through the state offices.

SAMPLE LETTER ASKING YOUR U.S. SENATOR TO COSPONSOR THE RARE DISEASES ACT OF 2001 (S. 1379)

The Honorable _____
United States Senate
Washington, DC 20510 (or use state office address or fax)

Dear Senator _____:

On August 3, 2001, Senators Orrin Hatch and Edward Kennedy introduced the Rare Diseases Act of 2001 (S. 1379). The legislation provides a statutory authorization for the existing Office of Rare Diseases (ORD) at the National Institutes of Health (NIH) and increases the funding for the Food and Drug Administration's Orphan Product Research Grants Program, which has provided vital support for clinical research on new treatments for rare disorders. S. 1379 also increases the national investment in the development of diagnostics and treatments for patients with rare disorders, authorizes regional centers of excellence for rare disease research and training, and boosts funding for the ORD to \$24 million for fiscal year 2002.

(The second paragraph should go into detail about how S. 1379 will personally benefit you, your family, other rare disease patients and their families.)

We ask that you cosponsor the Rare Diseases Act of 2001 to ensure that the constituents in your state suffering with rare diseases receive the care and treatment they so desperately need and deserve.

We look forward to hearing from you very soon, as we wish to work closely with you to ensure passage of the Rare Diseases Act of 2001 that will provide increased clinical research and treatments for the 25 million Americans in the United States suffering with rare orphan diseases.

Sincerely,

HERE IS A COPY OF A LETTER I SENT WITH THE ABOVE SAMPLE LETTER

From Your Editor

Dear _____,

I am writing to urge you to increase funding for the Office of Rare Diseases (ORD) at the National Institutes of Health. (NIH) The Office of Rare Diseases was established in the early 1990's to meet the needs of 25 million citizens that were suffering from over 6,000 rare "orphan" diseases. The purpose of the establishment of this office was to stimulate and coordinate research into rare diseases. The Office also provided information on the prevention, diagnosis and treatment of rare diseases to physicians, patients, families and researchers.

My father was one of those 25 million Americans as he was diagnosed with a rare, terminal brain disease called progressive supranuclear palsy (PSP). There is no treatment or cure for this degenerative disease that robs a person of speaking, reading, walking, talking and eating. One becomes a prisoner in his or her own body. My dad died from the complications of PSP in 1994. To this day, there is still no known treatment or cure.

Therefore, it is very important for me and other Americans that funding for rare diseases is increased for the ORD. In the year 2000, the ORD was funded approximately \$2,070,000 for the study of these disease. Approximately, \$2,153,000 has been funded for 2001. More money must be appropriated! This year, about 10 cents is spent for each person suffering from one of these rare diseases. If the funding budget is increased to \$25,000,000 - that will mean that about \$1.00 will be spent for each person. That is not a great amount of money to ask for each of these persons. Yet, their lives depend on it, and someday - it may be one of your own.

Sincerely, Nancy Brittingham

To Drive or to Stop Driving

Our society values independence, and the ability to drive is a sign of this independence. But when you or your loved one becomes a danger to yourself or others; it is time to consider giving up this privilege. Certain physical and mental conditions may impair driving. It is advisable for drivers and families to ask their physicians about conditions or medications that may have an effect on driving ability.

It is important for families to observe driving behavior over time. Try to determine a person's attention span, ability to process information and distance perception. Some of the warning signs of driving problems include:

- Hitting curbs
- Dents or scrapes on the car or garage
- Not anticipating danger
- Driving too slowly for the conditions
- Incorrect signaling
- Making turns too widely or sharply (unable to judge a turn's radius)
- Changing lanes without looking
- Too many errors being made, causing other drivers to constantly honk
- Stopping at green lights instead of red lights
- Running stop signs
- Getting confused at freeway entrances and merges
- Driving the wrong way on a one-way street
- Too much noise or cognitive input causes decreased concentration (especially with other passengers in the car)

There is no "right" way to resolve the driving difficulty issue. The responses of individual family members may vary. But everyone involved with the care of the driver needs to remain focused on the self-respect of their loved one and the safety of others on the roadways. What to do?

1. Begin discussions and planning early when there is a physical or mental impairment. Be sure to involve the driver in these conversations. Open and early communication can help to avoid a crisis later.
2. Many caregivers permit their loved ones to drive longer than they know they should, causing caregiver anxiety and fear of putting others at risk.
3. When it is time to "give up the keys," explain everything to your loved one and do not become critical of them. You are there to support them and tell them you understand their feelings.
4. Never leave the keys out where they can be found.
5. Assure your loved one that he or she can depend on you to transport them wherever they need to go when they need to go.

RE-EXAMINATION:

You may talk to your neurologist about your loved one's driving difficulties. Each state differs in its procedures, but you or your neurologist can contact your Division of Motor Vehicles and supply the DMV with a Driver Medical Evaluation

form. The driver will be notified of the need for re-examination. An "in-person" contact meeting is then needed to access cognitive processes, perception and awareness. The driver will be asked questions concerning health, medical treatment, daily routine and need for assistance with daily activities. Further examination will include a knowledge test used to determine the driver's mental competency as well as language and cognitive skills. A special driving test is next (if the driver has thus far passed the knowledge and vision screening test) to access the driver's ability and competency in concentration, attention, perception, and judgment. If the tests are all satisfactory, the driver will be issued an appropriate license and scheduled to retest in one year. For information on physical and mental impairments and driving, contact your local DMV and ask for the Regional Driver Safety Office.

Explain the need for re-examination with your loved one. Discuss with him/her each part of the re-examination as described above. In many instances, once the person with driving difficulties learns about the reexamination tests, he/she opts not to take the tests for fear of not passing and then more willingly gives up their car keys. The person now has ownership in the decision to stop driving.

QUOTES FROM LOVED ONES OF PERSONS DIAGNOSED WITH PSP:

"Several years ago, my husband's driving became quite scary. My comments as a spouse were not appreciated. At a local hospital, I discovered that driving tests were being administered to those who were recovering from a physical trauma and were reapplying for their licenses. The test consisted of eye exam, reaction times and evaluation of decision-making processes. After contacting the DMV, my husband was notified that he had to be re-examined. Because of fear he would not pass the test again he left the driving to me."

"My husband was driving very dangerously and no matter what I told him it did not matter. He thought he was most capable of driving. One day, he wanted to drive himself to the nearby store. I told him I would take him. He insisted on going by himself. After what seemed like hours, he came into the house. When I looked out the window, our mailbox in our driveway had been completely demolished by his car. He never said anything about it, nor did I. He never drove again and we never talked about the mailbox incident."

DISCLAIMER

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



Pressure Sores

Pressure sores, sometimes called bedsores, decubitus ulcers or pressure ulcers are red areas or sores on the skin. A pressure sore is a skin and underlying tissue injury that is usually caused by unrelieved pressure. A small patch of skin suffers prolonged contact and pressure. Pressure occurs if a person lies or sits in one position too long. Unrelieved pressure squeezes the blood vessels that supply nutrients and oxygen to the skin. When skin is deprived of nutrients and oxygen for too long of a period of time, tissue can die and a pressure sore can form. This can occur in less than two hours. Pressure sores appear most frequently on thighs, buttocks, the coccyx (tailbone), heels, or any part of the body that is in constant contact with another object, such as a bed or wheelchair.

Because pressure sores often begin as a blistered or reddened area on the skin, the sore will develop unnoticed. These sores infect easily and if left untreated can rapidly become a large hole reaching to the bone and carrying infection with them.

EARLY TREATMENT OF A PRESSURE SORE

When a pressure sore is discovered in an early stage, the first step is to eliminate all pressure from the area. The sore must be dried and kept dry. Periodically clean the area with hydrogen peroxide or a saline (salt and water) solution. Expose the clean sore to a 100-watt electric light bulb held two feet about the sore for about 10 minutes. After the sore dries, dust it with cornstarch. Applying Benzoin can toughen the healthy skin around the wound. Using a polyurethane film dressing (such as Tagaderm) that creates an artificial skin can be useful for a minor skin pressure sore.

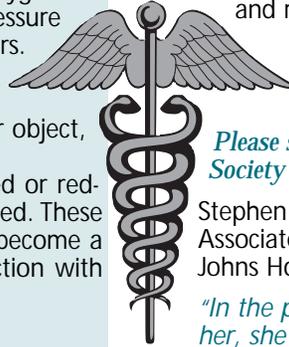
TREATMENT FOR MORE ADVANCED SORES

Trimming away tissue that is dead (debridement) is required when treating advanced sores. Antibiotics are prescribed when an infection is present. An infection can develop rapidly without debridement. After debridement procedures, dressings are changed frequently. Sometimes more involved surgery is required and even possible skin grafting to protect the tissue and allow it to heal. Lack of proper care for an advanced sore can result in an ulcer which can become life-threatening if permitted to advance to a larger size.

TIPS ON PREVENTION:

- Skin should be inspected every day to find and correct problems before a pressure ulcer forms. Pay particular attention to the bony prominences.
- Cleansing of skin should occur with a mild soap, warm water and minimal friction.
- Move or change positions every 2 hours in bed and every hour if in a chair.
- Alternating pressure mattresses, foam wedges and pads helps reduce friction. Consult your health care provider about the use of a special mattress or cushion that contains air, gel, foam or water. The use of "doughnut" cushions and egg crates is discouraged.
- Placing sheepskin under vulnerable areas will cushion the entire body. Sheepskin reduces pressure and friction, absorbs moisture, keeping the patient dry.
- Reduce friction or rubbing when moving by lifting rather than dragging.
- Do use a trapeze to lift if possible.

- Use moisture absorbent underpads or briefs if necessary to reduce moisture exposure from urine and perspiration. An ointment or cream to protect skin from urine or stool drainage may be helpful.
- Raise the head of the bed as little as possible.
- Check with your health care provider about the use of lotions and medicines. Routinely use a good quality skin cream. Ask your physician about products such as Barri Care, Aquaphor, Lac-Hydrin, Care Crème and Lypha Zome.
- Good nutrition plays an important role in the prevention of and recovery from a pressure sore.



“Ask a Doctor”

Please send your questions to the PSP Advocate editor at the Society office or email address: NancyB501@cs.com

Stephen G. Reich, MD
Associate Professor of Neurology
Johns Hopkins University School of Medicine

“In the past six months, my wife tells me that her legs hurt her, she is not getting enough sleep and is tired. I want to know if the leg pain, lack of sleep and loss of energy are part of PSP?”

Although there are many causes of fatigue and insomnia, the combination of these two symptoms, coupled with her uncomfortable legs, suggests a condition known as restless legs syndrome. This is a common problem characterized by an uncomfortable, sometimes “painful” feeling in the legs which typically occurs when people get into bed at night. This is accompanied by an urge to move the legs, forcing some people to get out of bed and walk around. Many people with restless leg syndrome also have jerky movements of their legs while sleeping, and not uncommonly, awaken the spouse who is inadvertently kicked. Restless legs syndrome often causes difficulty initiating sleep and trouble maintaining sleep, leading to daytime sleepiness and fatigue. For more information about restless legs syndrome, I suggest contacting Restless Legs Syndrome Foundation, 819 Second St. SW, Rochester, Minnesota 55902 507-287-6465 RLSFoundation@rls.org. There are a variety of medications which are helpful for restless legs syndrome.

It is important though, that your wife be evaluated by her physician to make sure there is not an alternative explanation for her symptoms. For instance, depression and sleep apnea may cause insomnia as well as daytime tiredness. Other medical conditions may cause fatigue, such as low thyroid, heart failure, or anemia.

“What makes my husband make a humming-like noise all the time?”

Some patients with PSP and other Parkinson’s-like illnesses, including Parkinson’s disease, make abnormal noises. Most patients are unaware of making such noises as they are done involuntarily. Some of these noises are related to weakness of the soft palate and vocal cords and this should be evaluated by an otolaryngologist. Often times though, these noises, which can include humming as well as moaning, are unexplained and generally prove difficult to treat. Sometimes they can be minimized with anti-parkinsonian medications such as L-dopa or a dopamine agonist such as bromocriptine or pergolide.

Continued Page 11

Helpful Speech Exercises Part I

What Is A Speech Language Pathologist?

A speech-language pathologist (SLP) is a health care professional who specializes in the diagnosis and treatment of disorders of communication and swallowing. This includes areas of speech, voice, language, cognition, fluency, hearing, chewing, and swallowing. SLPs work in hospitals, nursing facilities, physicians' offices, schools, home health, universities, and private practice settings. SLPs are required to have a master's degree, state licensure and national certification in order to practice. The Society for PSP is fortunate that Amy Mandlman, SLP Communications Disorders, MS, Licensed Massage Therapist, is a member of the Board of Directors. These exercises are provided by Amy.

FACIAL MOBILITY AND FACIAL EXPRESSION:

You may find that your face is less mobile and expressive than it was previously and that smiling, frowning, grinning and other facial expressions require your conscious effort. While these features do not directly affect speech, changes of facial expression are important for getting across your ideas and enhancing your ability to communicate effectively.

To help you vary your facial expression, make yourself conscious of how facial changes look and feel.

Using a mirror:

- Make faces – smile, frown, laugh, grin, pout, whistle, and puff out the cheeks.
- Exaggerate facial motions as you recite the alphabet and count numbers.

SPEECH/ARTICULATION EXERCISES

These exercises will help others to understand your speech more easily. Use a mirror when you do them. Practice 2-3 times per day for about 15 minutes each time.

1. Practice words with final consonant made with the back of the tongue.

K		
BACK	LUCK	CAKE
DUCK	TOOK	KNOCK
LAKE	SICK	COKE
PICK	RAKE	KICK
OAK	SHAKE	CLOCK

G		
EGG	BAG	SPRIG
RAG	KEG	SHAG
DOG	TAG	PIG
WIG	FLAG	FROG
LEG	LEAGUE	DRUG

Practice words that end with consonant sounds made with the tip or blade of the tongue. Use a mirror to check your tongue placement.

T	D	N	L
CAT	PAID	SEEN	MAIL
SEAT	ROAD	WIN	FEEL
NUT	SAID	MOON	PILL
MAT	NEED	MAN	DIAL
DATE	RED	TEN	NAIL
FRUIT	TIDE	FINE	HOLE
RIGHT	BAD	RAIN	BALL
EIGHT	MUD	MEAN	CHILL

S	Z	DZ
FACE	BUZZ	CAGE
GUESS	HIS	EDGE
KISS	DAZE	LARGE
MASS	LOSE	AGE
LACE	WISE	RANGE
ICE	DOES	BADGE
LOOSE	AS	MERGE
HOUSE	PHASE	WEDGE

PALATE EXERCISES

These exercises will help your speech and swallowing. Please repeat 10-20 times each, 2-3 times per day.

1. Inhale and exhale through the mouth. Use a mirror to see movement of the soft palate.
2. Inhale through the mouth. Exhale through the nose.
3. Practice yawning.
4. Practice panting.
5. Sip air in through the teeth, close your mouth, and expel air through your nose. Reverse these steps.
6. Blow up balloons and allow the air to leak back into your mouth.
7. Puff up your cheeks. Quickly release the air.
8. Hold the "p" sound for a second before exploding it into the vowel sounds. Repeat with "k" and "t".
9. Practice saying "ung", holding on to the "ng" as long as you can. Repeat with "ing".

TONGUE EXERCISES

These exercises will help your speech and swallowing. They should be performed 10- 20 times each, 2-3 times per day.

1. Repeat the syllables "ka - la". . .
2. Make a clucking sound with your tongue.
3. Curl the tip of the tongue back as far as possible until a stretch is felt.
4. Point your tongue up towards your nose and then down towards your chin.
5. Lick your lips 5 times in one direction; then reverse for 5 times.
6. Thrust the tip of the tongue in each cheek.
7. Stick out your tongue and reach towards your nose; then reach towards your chin.
8. Hold a spoon or a tongue depressor against your lips while pushing it away with your tongue. Resist for 5 seconds.
9. Stick out your tongue as far as you can; then pull it back as far as you can.
10. Stick out your tongue and move it quickly from corner to corner.

WE ARE LAUNCHING OUR NEW
WEBSITE
WWW.PSP.ORG
*Visit the new, expanded, energetic, and
educational website!*

Helpful Hints

EDITOR'S NOTE: This information is provided as a service. Please contact your physician to discuss these "Helpful Hints" and the needs of your family and loved one diagnosed with PSP. If you have any hints, medical devices, equipment or services you can recommend to other PSP families, please contact The Editor. The Society DOES NOT ENDORSE any products discussed and neither the Society nor its staff has financial interest in any of these products.

WHEN EXCESSIVE SALIVA IS A PROBLEM, HERE ARE SOME SUGGESTIONS:

- Swallow frequently and wipe your mouth often with a soft cloth or tissue.
- If you have saliva choking problems when lying down, raise your head and flex your neck or lie on your side and let the saliva drain out of your mouth.
- Papaya or pineapple juice has decreased mucus for some individuals. One can slowly dissolve a papase tablet (an enzyme made from papaya) in the mouth.
- Swabbing meat tenderizer in your mouth can sometimes thin mucus.
- Try to drink plenty of liquids to help thin saliva. Thin saliva (rather than thick saliva) is easier to manage.

Dear Editor,

I have found the "COMFORT-CAPE" to be most helpful in shampooing my wife's hair. I had been using a garbage bag to keep her dry. Finally, someone thought about the disabled. The Comfort Care is made of water-resistant fabric with a second waterproof layer for added protection and foam rubber sides. It cost me \$54 plus shipping and is worth every penny. The company's number is (843) 347-0167. Their website is www.comfort-cape.com. Robert Hall, NY



Dear Editor,

Natural genuine sheepskin has been very helpful in soothing relief and adding comfort for my husband as he lies in bed or sits in the wheelchair. They say that sheepskin relieves pressure points and increases circulation, helping to prevent bed sores. I am sure there are many companies



that carry this product but I got my full wheelchair cover (seat and back) and other items from Comfort Care Products, Inc. 1 877-430-3455. I found these products on the Internet (www.aussiemedicalsheepskin.com/products/products.html). I hope this will help someone else.

Thank you,
Janie W.
Kentucky

Dear Dr. Golbe,

My mother died on Nov. 1, 2001 after suffering from progressive supranuclear palsy for several years. My father, 4 brothers and I agreed to and donated her brain to research in hopes that it would help someone someday. We are one of the families who have watched a loved one suffer from this disease and pray that a cure is found in the future. Our Mother/Wife was a strong, vibrant and beautiful woman before being stricken and that is how we shall remember her.

I am hoping to find a PSP support group to join so that I can listen and talk with people who need someone to express their fears and feelings with. Since I have seen just what this disease does to its victims I know what others are facing.

Our prayers are with you and all the researchers in finding a cure for PSP.

Jeannie (Misenhimer) Steele
Rochester Hills, MI

Dear Ms. Steele:

The simple poetry of your note is as touching as your thoughts themselves. Thank you for the support and encouragement. With your permission, I will forward your e-mail to the Society for PSP office so that your words can be published in the *PSP Advocate* to serve as inspiration to families and scientists all over the world who are fighting PSP.

Dr. Golbe

Ask A Doctor

Continued from Page 9

"Why does my husband burst out laughing or crying at inappropriate times?"

Some persons diagnosed with PSP abruptly cry or, less commonly, laugh out of context. This inability to inhibit emotional expression is called emotional incontinence. This behavior may happen spontaneously or be triggered by a minimal stimulus, often one that is neither sad, or happy. Emotional incontinence results from dysfunction of the frontal lobes of the brain in PSP, which serve to keep appropriate behaviors under wraps. If spontaneous crying or laughter is infrequent, short-lived, and not bothersome, no treatment other than reassurance that this is part of the disease and not necessarily a sign of sadness or happiness, is necessary. Yet, when sudden displays of emotion occur frequently and are bothersome, medication is available to help. Ask your physician about antidepressants such as amitriptyline (Elavil) or nortriptyline (Pamelor).

Support Groups

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, and phoning/visiting PSP families. If you would like to help start a support group in your area, please call the SPSP office at 1-800-457-4777. For information on support groups in your area please contact:

ARIZONA

CHRISTINA WATTS
Phoenix
602-406-4931 • maprc@chw.edu
GALE KITTLE
Phoenix
602-406-4931 • gkittle@mha.chw.edu
RENAE VALDES-BIRCH
Gilbert
480-632-1797

ARKANSAS

PATSY CUNNINGHAM
Fort Smith
501-648-1814 • patphillip@prodigy.net

CALIFORNIA

CERI WILLIAMS
Sherman Oaks
818-343-3259 • medianet@earthlink.net
KATHY SCHWAIGER
Thousand Oaks
805-496-7018
LILA KIRKPATRICK
Santa Clara
408-244-5958 • lmomkirk@aol.com
BETTY SCOGGINS
Redding
530-241-6663
MARY MIANO
Laguna Woods
949-855-3972
CAROLYN CHEEK
Torrance/Los Angeles
310-534-8623
cheekspeak@mindspring.com
CAROL PLATT
Antelope
916-332-6041
cplatt@seeyouonline.com
PAMELA FERRIS
Santa Maria
805-938-0385 • web22gzt@gte.net

COLORADO

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

CONNECTICUT

FRANK CADWELL
Clinton
860-664-9524

FLORIDA

JOHN ARNOLD
Cape Canaveral
321-784-5660 • jharoldjr@cs.com
PAULA JOHN
Sarasota
941-927-3955
johnpaulag@worldnetatt.net
BEATRIZ CHIRINO
Miami
305-270-8401 • bchrino@hotmail.com
YOLANDA MEDINA
Miami
305-553-4911
HELEN LAVELLE
Naples
941-352-2909
BUD BRANSON
Quincy
850-627-6216
VIRGIE SALTZMAN
Nokomis
941-484-7259 • vbirdies@aol.com

LINDA IVES-Listserve
DeBary
407-668-7130 • l_r_ives@bitstorm.net

GEORGIA

KATHY THOMAS
Decatur
770-939-2612 • elkt@mindspring.com
JOAN CARPENTER
Augusta
706-721-9445 • jcarpent@neuro.mcg.ed

ILLINOIS

JANET KAISER
Glenview
847-729-1585 • jgk1955@hotmail.com

INDIANA

ELIZABETH RISK
Indianapolis
317-786-8613
risky_46107@yahoo.com

IOWA

ESTHER COOLING
Cedar Rapids
319-362-4752

KANSAS

LINDA SMITH
Salina
785-825-6482 • splumbing@hotmail.com
MARIAN GOLIC
Overland Park
913-381-6972

LOUISIANA

MARY SCHUMANN
New Orleans
504-484-7840
BRENDA GREMILLION
Kenner
504-467-6658 • BGrem737@aol.com

MAINE

FAYE RYAN
Whiting
207-259-2152

MARYLAND

RUTH GOLDSTEIN
Baltimore
410-484-5200 • Music@Home.com

MASSACHUSETTS

PATTI RYAN
Swampscott
781-595-4431
pattiryan966783@aol.com

MICHIGAN

CAROL ANN KLANK
Commerce Twnshp
248-363-9064
JANET MAGUIRE
Kingston
517-683-2187
thereishope2@yahoo.com
SALLY SMITH
Zeeland
616-722-4446 • smiths5@egl.net

MINNESOTA

CHARLOTTE TRIPET
GoldenValley
763-546-1694 • chartrip@yahoo.com

MISSISSIPPI

DENVER FLANAGAN
Jackson
601-372-1784 • denflan@aol.com

MISSOURI

PAT LYNN
Jackson
573-243-3964
AMY MANDLMAN
St. Louis
314-432-5461
amymandlman@hotmail.com
ALICE KITCHEN
Kansas City
816-753-4424 • akitchen44@aol.com

NEBRASKA

NORMA HINCHCLIFF
Elkhorn
402-289-4540 • gammieH@aol.com

NEVADA

CAROL UPTON
Las Vegas
702-731-8329 • parkinsonslv@cs.com

NEW JERSEY

CAROL SOLOMON
Marlton
856-985-1180 • info@chsgeriatric.com

NEW MEXICO

KAREN KENNEMER
Kingwood, Texas
281-358-2282 • kmk1224@aol.com

NEW YORK

MARCY TODD
Port Washington
516-883-7455
MARY CONNOLLY
Canandaigua
716-394-5306 • tomaryconn@aol.com

NORTH CAROLINA

MARGARET AKERS-HARDAGE
Charlotte
704-846-6066 • marg212@aol.com

OHIO

PAT BEEKMAN
Berea
440-234-0007
mombeekman@webtv.net
JENNIFER SMITH
Barnesville
740-425-3253
PUMPKINVILLE@yahoo.com
DAVE & REBECCA DANGLADE
West Jefferson
614-879-6624

OREGON

SANDI HANSEN
Clackamas
503-698-8129
sandhansen@aol.com

PENNSYLVANIA

GEORGE WEAVER
Mill Hall
570-726-6164
RUTH NULPH, R.N.
Butler
724-287-8600 • coachmen1@aol.com
JANE WRIGHT
Philadelphia
215-829-7273
jcwright@pahosp.com

RHODE ISLAND

LAURA EVANS
Kingstown
401-885-7049 • lve@home.com

KELLEY HARRISON, PH.D.
Warwick
401-732-9627 • Kel925@msn.com

SOUTH CAROLINA

DORIS MCCRAY
Myrtle Beach
843-445-1647

TEXAS

JUDY BRANNEN
Benbrook
817-249-0824
SHARYL JOHNSON
Arlington
817-467-9186 • SharylP@aol.com
KAREN KENNEMER
Kingwood
281-358-2282
kmk1224@aol.com

VERMONT

JANICE CLEMENTS
Milton
802-893-1263 • janclem@together.net

VIRGINIA

ALLEN ROHLFING
Virginia Beach
757-426-5281
KATHY SANDS
Vienna
703-242-9322
Kathy.m.sands@saic.com
HOWARD COOLEY
Clifton
703-830-4819 • hgc1235@aol.com

WASHINGTON

ROBERTTA HUNT
Walla Walla
509-529-1364 • robertta@hscis.net
FRAN MCMAHON
Rochester
360-273-9496 • franmcdoll@aol.com
JIM BARRON
Pullman
509-332-6053 • jabarron@pullman.com

WEST VIRGINIA

J.P. SMITH
Glen Dale
304-843-3211

WISCONSIN

BARBARA SHARKEY
Rhinelander
715-362-1777

AUSTRALIA

ANNE MARIE SMITH
Beecroft
smith9754@aol.com

CANADA

JANICE STOBER
Markham
905-472-7082
CAROLYN CONNORS
London
619-630-0430
parkins@hotmail.com
SANDIE JONES
Toronto
416-227-9700

News From Support Groups

Oct. PSP Awareness Month Raises Over \$18,000 & Many New Friends

MINNESOTA

The Minnesota PSP Support Group held our second annual PSP fundraiser dinner on Oct. 25, 2001. A lasagna dinner was served to us by Boy Scout Troop #187 as part of their community service. The dinner was attended by over 70 folks who came to support us in our fundraising for PSP raising over \$3,000.

We were pleased to have Dr. Paul Tuite, neurologist from University of Minnesota, speak to us on what progress is being made in the treatment and diagnosis of PSP. Janice Clements from the Society for Progressive Supranuclear Palsy brought news of what is happening in research on the national level and also informed us about the work of the Society for PSP. Sandi Holton, a music therapist from the Struthers Parkinson Center Club Create, helped us to learn about relaxation with music—a great help for persons diagnosed with the disease and caregivers alike, as well as for all present.

Janice Clements presented Charlotte Tripet with a plaque from the Society for Supranuclear Palsy for her loyalty, dedication and generosity that enables families with PSP to come together, share their experiences and find mutual support.



Janice Clements recognizing Charlotte Tripet

ALABAMA

The First Swimathon for PSP

By Linda Webster

The first PSP Swimathon was held on October 23 at the David L. Bodenhamer Center in Gulf Shores, AL. My husband Bob, who is confined to a wheelchair and can walk only a few steps with grab rails, CAN and does still swim three times a week. If we were going to have an event in his honor, we wanted him to be able to participate.

Goals of the Swimathon were to increase awareness of PSP and to raise funds for PSP research. The Swimathon raised just over \$3,200 in pledges.



The Swimathon was organized by lifeguard Carrie Wilson (standing left in the picture of the four of us) and by therapist Terri Wooley (standing right). A former physical therapist and paramedic, and now a massage therapist and owner of Massage Works in Gulf Shores, Terri has been volunteering her time to work with Bob 2-3 times a week.



Carrie wowed one and all by swimming 72 laps, or 2 miles. Terri completed 36 laps, while assisting Bob to swim and waterwalk. I walked and waterdanced with Bob some, and swam 18 laps. Bob himself completed 15 laps in just about an hour.

Gulf Shores businesses helped out, with Winn-Dixie Marketplace donating refreshments, and MailBoxes Etc. printing fliers at no charge. Local musicians JR Owen and Brent Burns kept us dancing with their songs.

Lovey and Maurice Johnson visited with Bob at the Swimathon. They came to represent NARFE (National Association of Retired Federal Employees) Chapter 1340 of Baldwin County, of which Bob is a member. I had spoken to the Chapter at their October Meeting to tell them a little about PSP and to invite them to the Swimathon. Several individual members sponsored Bob in the Swimathon, and the Chapter made a donation as well.

Bob was never much of a swimmer, but I've been a regular lap swimmer for three decades. Three years ago, when things were going so terribly haywire that we had both stopped working and I pretty much tried to keep Bob with me all the time (there were just too many falls otherwise), I got Bob to try coming in the water with me. Luckily, he took right to it. With walking becoming so difficult and dangerous, the water would still allow Bob to walk and move without falling over. I could never dream of leaving Bob alone in the water—no matter how many floats or lifejackets we tried, it was clear that he still needed someone right with him to make it work. I did the honors myself for the first two years. Then I started having enough joint pain myself that I looked for—and was fortunate enough to find—people to assist Bob in the water. Now while Terri walks Bob, I get to go swim my laps, which seems to be the main thing I need to keep body and soul together.

We thank everyone who planned and contributed to our Swimathon. It was a bright moment for Bob—he doesn't get many opportunities to show off something he does well now, but he did himself proud that night. Our ongoing appreciation to Bodenhamer lifeguards and staff who help us get in and out of the water safely using their hydraulic lift chair.

CALIFORNIA

The Second Annual PSP Walk-a-Thon

By Wayne Stark



Story on Page 14

News From Support Groups



Committee Members Carolyn Cheek, Carolyn Griffith, May Toll and Norma Simon

October 20 Walk on the Beach

The second Los Angeles County Walk was again a wonderful success. We used the same route as last year, along the beach in Redondo Beach and were blessed with comfortable temperatures for walking because of a hazy overcast most of the morning.

The walkers, 33 in number, enjoyed the renewing of old friendships and making new ones as they did their part in raising \$5,000 for the benefit of the Society for PSP and for PSP research. Juice, coffee,

doughnut holes and fruits helped participants stoke up on energy for the walk while taking care of the mundane details – signing in, turning in funds collected, etc.

The Rev. Dr. Harvey Kemp, pastor of the Hawthorne United Methodist Church, gave a short, inspirational talk for the walkers before the “official” start of the walk. He told of the building of a very fancy resort hotel which then decided to build a very high and solid wall to block the view of the nearby down and outers from the guests. He indicated to the walkers that they, instead of building a wall, hiding and ignoring the problem (of PSP) were doing what they could to help, while maintaining their own welfare to be able to continue to help indefinitely.

It was gratifying to see the spirit of the group of walkers and all those who helped even if they couldn't walk. One of the couples walking wheeled their father (-in-law) over the 2-mile loop of the 6-mile walk. Another couple wheeled their one-year-old around the loop. Many of the walkers completed both the 2- and the 4-mile walks to finish the entire 10K (6-mile) walk. One of the non-walking supporters used his photographic skills to record the event on film.

After the walk, the participants and helpers made short work of a monster sub sandwich complete with chips, cold drinks, cookies, and farewells, with the expectation of doing it again next year. Special thanks to Biotene, Mom's Home Health Catalogues and Neutrogena for their support of this event.

MARYLAND

Hats off to the walkers and their sponsors in the 2001 Maryland Walk-A-Thon organized by Jodi Da Roja and family in memory of William Da Roja, who passed away on Aug. 13, 2001 of PSP. On a beautiful spring-like day in Westminster, the walkers came out 80 strong. The donations totaled \$7,000.



Mid Point at the Walk-A-Thon in Westminster

Also a special thanks to the vendors - Metro Food Markets, Innovative Gourmet, and Dotty and Phil Poniatowski.

Let us post your support group news and announcements in the PSP Advocate. Deadline dates are Feb. 10, May 10, Aug. 10, Nov. 10. Please send your support group news/photos to The PSP Editor at NancyB501@cs.com or to the Society office.



The Da Roja Family

BALTIMORE SUPPORT GROUP MEETING

The Baltimore PSP Support Group met at 7p.m. on Sept. 25, 2001 at the Society's National Headquarters. These meetings are held regularly on the last Tuesday of each month. The meeting was led by Ruth Goldstein and Bruce Barnett. Nearly 20 caregivers and the Society's office staff attended.



The main attraction was a guest neurologist, Prof. Paul Fishman, M.D., Ph.D., from the University of Maryland Medical School. Prof. Fishman has worked with several local persons diagnosed with PSP. He is the recipient of one of the recent research grants awarded by the Society. He spoke about recent progress in understanding neurological diseases and progressive supranuclear palsy in particular. He described his proposed research program, which was discussed in some detail in The PSP Advocate, Volume 12, Number 3.

He discussed how neurofibrillary tangles composed of abnormal forms of the tau protein are a major feature in the pathology of PSP. Mutations in the tau gene can result in inherited human diseases. One of the genes involved in inherited forms of Parkinson's disease, called parkin, can help eliminate abnormal and potentially toxic proteins. His research group proposes to see if parkin can reverse the effect of production of abnormal tau proteins in culture cells. If parkin is able to eliminate abnormal tau production it could be particularly important in fighting PSP.

TEXAS

The PSP Network of Houston has raised \$2,000 to mark PSP Awareness Month. We would like to thank Karen Kennemer for organizing this fundraiser and members of her support group for dedicating these funds in memory of their loved ones.

Gifts were made in memory of: Vivian Branch, Marybell Buchanan, Mary Cheslak, William Drake, Thomas Haywood, Harold Lipp, Artie McMahan, Jr., Gene McBride, J.P. Parks, John Robbins and Meredith Teel.

News From Support Groups

SPOKANE PSP SUPPORT GROUP

by Jim Barron

Member Society Outreach and Education Committee

October 26, 2001

The first meeting of the Spokane PSP Support Group was held October 26 with 15 people in attendance. Four persons attending were diagnosed with PSP.

Jim Barron convened and moderated the meeting. He described the handouts available, welcomed everyone to the meeting and extended an invitation to future meetings to anyone interested. He encouraged people to share as much as each is comfortable discussing. It was made clear that discussions within the group are confidential.

The meeting began with people introducing themselves and saying a few words about their PSP experiences and suggesting their expectations for the support group. Expectations mentioned were to share information, learn from each other, meet others with PSP, learn how to educate healthcare providers, break out of the isolation PSP brings, lend support to caregivers, learn what PSP is, learn about PSP research findings, learn what to expect as disease progresses, deal with feelings resulting from loss/anticipated loss and learn what local M.D.s are doing for their patients.

The bonding process was very fast and a quick rapport developed within the group due to the common experience of dealing with PSP. This was followed by opening the floor to questions and concerns of participants, which were answered to the best of anyone's ability to provide information from their own experiences or that gained from contact with others dealing with PSP. The group decided to meet monthly and developed a list of some topics to be addressed in coming meetings. Except for three participants, no one else had ever seen a person with PSP or a family member in person, although some had talked on the phone to others.

QUESTIONS ASKED BY PARTICIPANTS:

- Is there any cure?
- Does Congress know about PSP?
- Is stem cell research promising for PSP?
- How is PSP related to Parkinson's?
- Does sinemet help?
- What is amantadine?
- Did physical therapy help?
- What kind of walkers help PWPSP?
- Do doctors tell you when it's time to begin taking new steps to prevent injuries as the disease progresses?
- Does anyone help make your house safe for a PWPSP?
- Do symptoms change from day to day?
- What was the progression of symptoms?



FUTURE MEETINGS:

We'll hold monthly meetings (dodging holidays and Wednesdays). The next meeting will be on Friday, December 7. We'll meet in the same room and begin at 11:00 a.m. Paula will arrange to have someone talk with us about mental health. She will try to find someone with PSP experience.

Topics of discussion for other meetings include:

- Occupational therapy
- Physical therapy
- Speech therapy
- Recreational therapy
- Diet
- Massage therapy
- PSP From a Neurologist's Point of View

The Society extends its sympathy to Jim and his family for the recent loss of his beloved wife, Miriam.

SACRAMENTO, CA WALK-A-THON

The Sacramento Valley PSP Support Group hosted a Walk-A-Thon in honor of PSP Awareness Month on October 20 at Fair Oaks Park in Sacramento County. Lunch and T-shirts were provided for everyone walking. Carol Platt organized the event, which raised \$1,000.



Meet David Konigsberg and his grandmother, Wanna Hinchee. This photo was taken at David's Bar Mitzvah on June 30, 2001. David donated \$500 of his Bar Mitzvah gifts to the Society for PSP in honor of his grandfather, Don M. Hinchee, who died Dec 13, 2000.

Thank you David and we are honored to have this photo included in the *PSP Advocate*.

Massachusetts Regional PSP Symposium

There was a terrific turnout (over 80 persons attended) for the MA. Symposium held on September 29, 2001 at the Crown Plaza in Woburn, MA. The half day program provided current information about PSP, including clinical presentation, symptoms, and management. New research efforts in PSP were also presented. People diagnosed with PSP, as well as family members and professional caregivers, also enhanced their awareness of resources available. Four of the Society's board members attended and supported the event, as well as two staff from the Society's headquarters in Baltimore.

Speakers included:

- Kenneth A. McKusick, M.D., FACNP, FACR
• Society for PSP Board Member
Fellow of the American College of Nuclear Physicians and the American College of Radiology
- Paula Ravin, M. D.
• Associate Professor of Neurology
Director of Movement Disorders Clinic
University of Massachusetts Memorial Medical Center
Worcester, Massachusetts
- Janis M. Peyser, PhD
• Director, Psychological Services
Clinical Psychologist University of Vermont
Fletcher Allen Health Care
Burlington, Vermont
- Heather J. Cianci, PT, GCS
• The Dan Aaron Parkinson's Rehabilitation Institute
Philadelphia, Pennsylvania
- Mary Noyes, Speech and Language Pathologist
• Partner's Home Care Visiting Nurse Association
Rockland, Massachusetts
- Janet Edmunson, M.Ed.
• Product Manager, Prevention and Wellness
Blue Cross Blue Shield of Massachusetts
Caregiver for husband Charlie

Special thanks to Janice Clements, Society Board member and Chair of the Outreach and Education Committee, for organizing the event.



Kelley Harrison, Society Board Member; Heather Cianci, Speaker, and Janice Clements, Society Board Member

The Society for PSP thanks all our corporate sponsors for their support in helping to present the PA Symposium. When calling these companies for information and placing orders, please mention that you learned about them through the Society for PSP & the MA Symposium.

Advanced Respiratory 800-426-4224	LiftVest USA 800-300-5671
AlliMed 800-225-2610	Luminaud 800-255-3408
Allergan (Refresh Tears) 800-347-4500	Medical West Healthcare Center 800-489-1888
Assistive Technology 800-478-2363	MOMS Catalog 800-232-7443
BIOTENE 800-922-5856	Nova Ortho-Med 800-557-6682
The Brookfield Reader 888-389-2741	Sage Products 800-323-2220
Calmoseptine 800-880-3405	Saltillo Corporation 800-382-8622
Crestwood Communication Aids 414-352-5678	The Shirley Walker Company 800-848-9255
Healthcraft Products 888-619-9992	Today's Caregiver Magazine 800-829-2734
Inglis Drink-Aide 800-336-7022	Trademark Medical 800-325-9044
Intelligent Meetings 888-909-6543	U-Step Walking Stabilizer 800-558-7837
Lifeview Resources 800-395-5433	

PSP FAMILIES NEEDED

Families needed with living persons diagnosed with PSP for local media stories to help increase awareness of PSP.

Please offer your family for a local story. You will be connected with a medical reporter who will come to your home.

To help please contact:

Ceri Williams
15445 Ventura Blvd., #46
Sherman Oaks, CA 91403
T: 818 343 3259
medianet@earthlink.net

Support

Become A PSP Communicator

Become a PSP Communicator which means you give the Society permission to release your name to other PSP families in your state when asked. Just call the office and ask to be placed on the Communicator's List. Ask for a Communicator's List for your community. You can contact others whether or not you add your name to the list.

Nancy,

I became involved in PSP when by husband's niece, who is a neurologist, diagnosed him in 1989. Never having heard of the disease, she gave me the address of the *PSP Advocate* and suggested we find out as much as we could on our own. We immediately started reading what little material was available at that time. We didn't have the internet to go to at that time. It was discouraging to learn that there wasn't much that could be done.

We have four children who all live out of this area and at that time we had four grandchildren, since his death two more have been born.

I did find a Parkinson's support group here in Walla Walla and in attending it, we learned there was one other man in town who had PSP. Byron didn't like to attend the meetings, and I'm not sure why. Maybe he felt it was too discouraging. Anyway, the group disbanded during the summer and never started up again.

When Byron died in 1993 I felt led to become a telephone contact person, and was listed in the *PSP Advocate* as a group leader. I've tried to explain that out here in the West it is miles and miles from one patient to another, so by using the phone, we can "talk" and give support to each other. I share others addresses and phone numbers and it helps the caregivers to hear from someone else who is going through the same thing, or in my case, who have been there. I know first hand what they are going through-isolated as they may be from others and not knowing where to turn. Each case may be different in symptoms, but the disease destroys just the same.

I would encourage former caregivers to get involved and help someone by phone. I had my niece to call when things got rough especially with the falling and choking.

Hope this will help.

Robertta Hunt, Washington

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

SPSP, Inc. 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!

Thank You!



 Ellen and Albert Katz thank Carol, Rebecca and Steve Poizner for their generous gifts to research in memory of Steve's parents, Edwin and Pearl Poizner.

 In appreciation to Gloria Matero whose letter writing campaign in honor of her mother, Alda Mocogni, yielded \$7375.00 from 100 gifts.

 Thanks to Josh Meisel who made a donation from his bar mitzvah gifts in honor of his grandfather, Alfred Berger. We regret that Alfred has since passed away.



 Thank you to Mort and Marian Epstein whose \$5,000 gift to research was made from the sale of Marian's art collection. Marian, an artist from Cleveland, Ohio, has PSP.

PSP and MJR - My Story.

PSP and Michael J. Rabalais by Polly Rabalais

Sometimes an event occurs and you know it will change your life forever. Mike's violent vehicle accident on 9/10/97 was one of those events. While he survived miraculously and recovered quickly from the effects of the accident, the symptoms that were subtle prior to that time intensified. He had more difficulty getting up from a seated position, more vision problems, more balance problems and the beginning of the debilitating dizziness which would make it necessary for him to retire sooner than he would have chosen. At the same time all the symptoms were accelerating, we found ourselves in the same predicament as most people with PSP: the problem of getting a diagnosis. We went through the usual trail of different doctors—the eye doctors (three of them), the ear doctor (thinking there may be inner ear trouble), the internists (diabetic-related? or high blood pressure-related?), the neurologists (three of them). A year later, a tentative diagnosis of PSP was confirmed.

We were advised that the treatment consisted of using Parkinson's medications and that the benefits would be modest at best. How true. We were also told that it was important to maintain a positive outlook. That advice became our motto. We were determined to keep that positive outlook. We tried to keep life as close to normal as possible and that was not easy because of the progression of the disease. When people asked, "How is Mike doing?" my response was always a brief description of how things were going. I ended up by saying, "He is still walking and still talking." His ability to do either of these was deteriorating steadily. The last year and a half of his life, he could walk only with a lot of help—a walker plus a person holding onto him because of the potential of falling.

Here was a most social person who was a public speaker for 20 years in addition to his career as a college administrator; who, for the last year of his life, was understood only by me. People would visit him and leave (in tears) and tell me how amazing it was to them that I could understand him. This was the most frustrating part of all. He echoed the sentiments of other PSP patients that he was "trapped" in his own body. This is where his sense of humor was most helpful. I think the things that sustained us through this ordeal were our sense of humor, our loving and supportive family and our faith. We knew we had friends and family praying for us daily and that gave us what we needed to carry on.

Mike did not want to go to a nursing home if it could be avoided. Dealing with PSP was an all-consuming challenge for both of us, but with one really great helper who came in 16 hours a week, I was able to keep him at home until he entered the hospital on July 10, 2001 with aspiration pneumonia. He died on July 12. Although each day was an ordeal, staying at home was truly an answer to a prayer. Our son and grandson spent every Sunday with us. Our daughter and her family visited as often as possible. There were occasional visits from friends. The funeral service provided a time for people to say a few words. Both our daughter and our son had moving and heartwarming tributes to Mike. Following are excerpts from each of them.

Karen's . . .

Dad was a remarkable man. I have watched my dad handle his PSP with incredible grace and dignity, never being bitter or angry or complaining that he had this disease. For the past few years, his life has been a daily struggle and yet just a few days ago my dad was telling my mom how much they had to be thankful for. In the midst of his suffering, he had a remarkable perspective. I know it was because of his faith in God and his dependence on the grace of God.



Karen R. Gill, Kevin Rabalais, Polly Rabalais with Mike Rabalais

Kevin's . . .

Although I want to cry for my father, the tears I cry are of joy, not of sorrow. No individual in the world deserves the pain that my father went through, but through his pain he made me a better man. When my father lost his ability to walk, he gave me a cane, and I'll have that cane forever. When his vision failed, he gave me light. When he lost his ability to speak, he spoke through me. His wisdom will live forever in my sister and me. Mom, Karen, Trevor, Brittany, J. T., Caleb, Sarah and Jack, I want you to know that I'm going to do my best to fill those big shoes that he left me.

During his years of public speaking Mike realized the magnitude of "Anonymous" works, the scope of which covered practically every subject and provided guidelines for almost every situation. He began to compile a collection of "Anonymous" quotes and anecdotes. When his failing health prevented him from doing the things he would normally have done, his thoughts turned to publishing "The Wisdom of Anonymous." We received the first printing November 2000. So many people came back for more books (for gifts) that the first printing was exhausted in a few months. Mike wanted any proceeds from this book to go to the Society for PSP. I have ordered a second printing and the books are available.

(From the Editor: Ellen Katz, Society Executive Director, and I have both read "The Wisdom of Anonymous." We both agree it is a charming and delightful book. The author, Mike Rabalais, wanted to donate all proceeds from this book to the Society for Progressive Supranuclear Palsy. Polly Rabalais has ordered the 2nd printing of this book. If you are interested in ordering this book, please fill out the form below and mail to Polly.)

"THE WISDOM OF ANONYMOUS"

I support the Society for PSP.

Please send _____ copies of "The Wisdom of Anonymous" @ \$10.00 each.

Enclosed check for \$ _____ made payable to Polly Rabalais.

Name _____

Address _____

Mail directly to Polly Rabalais
PMB 10378 HCC
P.O. Box 1100
Raymond, MS 39154

My Husband John

Mary Boullion, Dexter, MI

I believe it was the winter of 1991 and we were at our usual recreation and favorite pastime, dancing in Texas at a senior citizen recreation room, and John missed a step. We always danced very well together and never missed a step. I laughed at him and asked if he was getting old or something. Before the night was over he had missed three or four steps. Jokingly on the way home, I asked him if maybe he needed dance lessons.

Before spring, when it was time to go back to Michigan, he was tripping once in awhile. Back in Michigan he started hesitating before the first step, but nothing else. Several falls occurred and when we headed back to Texas some of the neighbors noted his walk and questioned us. He was only 67, so age was not a factor, however his gait just kept gradually getting a little worse. In March, we flew home to see our grandson wrestle in the State tournament in Kalamazoo, Michigan, and rented a hotel room. Around midnight, John got up to go to the bathroom and fell. When I tried to help him, I had to call some of the children who were staying in the same motel. We took him to the emergency room. They kept him for 8 hours and he appeared to be fine in about an hour. We flew back to Texas and I took him to the physician that he had seen before. The doctor examined him and asked when was he diagnosed with Parkinson's disease. I was shocked but immediately knew he had all the symptoms.

For the next 5 years, he was treated for Parkinson's disease. Nothing was working. We took him to Mexico for 25 chelation treatments. There was a steady decline in John's health. He could barely walk and fell frequently. The blepharospasms in his eyes began. In the next few years, he had Botox injections 8 different times; each time the effect lasted shorter and shorter until the last 2 times, the injections were of no benefit. They did nothing and his eyes were closed tight almost all the time. By now he had gone from a walker to an electric cart. With his eyes tightly shut and his determination to proceed on with his life, he ran the electric cart into literally every wall in our home.

One evening while I was watching television, I watched Dudley Moore as he spoke about his diagnosis of PSP. I immediately called the Society for PSP's toll free number and requested all their information. I made an appointment with his neurologists and left one some of the PSP information at the office. I wrote a note on the cover asking him to please read it before we came in for our appointment. Immediately, he agreed John's diagnosis was progressive supranuclear palsy.

We were almost ready to return to Michigan, and my Texas neighbor's son was a neurologist at the University of Michigan hospital. She called and made an appointment with him for when we got home. After a thorough exam, he definitely agreed John has PSP. He discontinued all the Parkinson's meds. The facial distortion disappeared but that was the only physical improvement. He gradually became more and more disabled.

I am writing this from a Hospice hospital where he is bedridden and suffering through the last difficult stages of PSP. It has been a long and rough road and is now coming to an end. No one has tried harder than my dear husband, John, to fight this debilitating and horrible disease. He is now 77 and tomorrow we will be married 57 years. All eight children, sixteen grandchildren and two great-grandchildren will be here with us.

“How One Person CAN Make a Difference”

Louisiana's PSP Support Group Leader, Brenda Gremillon, Attends A Congressional Luncheon Meeting on Capitol Hill

Dear Nancy,

You asked me to share with the *PSP Advocate* readers some history on how I ended up on Capitol Hill. I must first say that I am part of this support group in memory of my Daddy (who died from PSP) and I feel God is the reason that everything falls into place. I started the LA support group because friends of my family were also diagnosed with PSP. They did not know anything about progressive supranuclear palsy. When my Mom would meet a person diagnosed with PSP or their family members, she would tell them to call me for information and support. So, the LA PSP Support Group began. I would notice that when I became tired and frustrated due to being a full-time student at LSUHSC plus working an internship (field work) part-time job, working part-time at a paying job and most of all, raising 3 teenagers, I would pray to stop for awhile because I did not feel like I was helping in a good way. This would not last long because every time I felt like quitting, I would get a phone call from someone new with a loved one diagnosed with PSP. I figured this is something I am supposed to be doing.

One day Ellen Katz, Society Director, emailed me and asked if I would like to go to a breakfast with the Society for Neuroscience Annual Convention which was being held in New Orleans, my hometown. I was to review what research was going on and see who exhibited at the Convention meeting. I told her I would, but since I did not have all the meeting information, I personally contacted the Society for Neuroscience (SFN) to get the particulars. I told someone at the SFN office about my father and his journey with progressive supranuclear palsy. After a few phone calls, and to my surprise, I was called and asked to present a speech in front of 120 neurologists from around the world to educate some doctors about PSP. I agreed to do it. I gave the speech very nervously—but I gave it from the heart, not all medical facts.

After it was over, I was approached by some physicians who were on the Board of Directors for SFN. They told me how much they liked my talk especially because it was from my heart. I then was contacted by the SFN to write an article for their newsletter—again a way to spread awareness about PSP. My article, “Progressive Supranuclear Palsy: A “Common”



Brenda and Jerry

Support - Our PSP Stories

Rare Disease," was published in their Neuroscience Newsletter (July-August 2001).

A few months later, I was asked by the SFN if I would be interested in attending one of their events called "Brain Breakthroughs: Delivering Results" on June 13, 2001. When I learned of the cost of the airline ticket I had to decline the invitation because it was too expensive. I was shocked and flattered when I was called back and told that the Society for Neuroscience would pay for my expenses. I could not believe it! I accepted their invitation with great appreciation.

On the Sunday before I left for Capitol Hill, a gentleman named Jerry called the hotel that I work in to make a reservation for November for a convention he was planning to attend. We began talking and I learned he worked with the Capitol Police in Washington, DC. I told him I was coming up there and he graciously gave me his phone number in case I had a problem and promised to show me around the Capitol.

When I arrived in Washington, I called Ellen Katz to let her know I was in town and extended an invitation to her to attend the luncheon with me. She agreed to go, so together we went to the Capitol. Then we could not find the room where the luncheon was being held. I called Jerry to ask him for help and he immediately came to our rescue, and not only did he show us to the room, he gave us a personal tour of the Capitol! It was wondrous, and I actually met many more congressmen, congresswomen and senators.

At the luncheon, former heavyweight champion, Muhammad Ali, and his wife Lonnie were honored for their

work on behalf of the National Parkinson's Foundation and the Muhammad Ali Parkinson's Research Center at the Barrow Neurological Institute. Ali was diagnosed with Parkinson's disease over 20 years ago. Another guest at the luncheon was Mahlon DeLong, MD, renowned Parkinson's researcher and Ali's personal physician. Public service awards were presented to Senator Barbara Mikulski (D-MD) and Representative Michael Bilirakis (R-FL). It was a most interesting time.



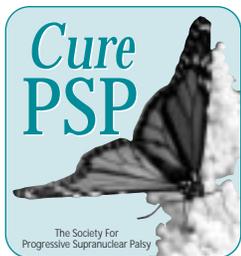
Brenda and Ali at the luncheon.

As with so many other PSP volunteers, I do not look for recognition for what I do. But, it makes me feel good when people compliment and thank me for whatever help and comfort I could give them. I recently attended a funeral for one of my PSP families and I was touched by the warmth and thanks they were sharing with me in their time of sorrow. I do what I do to help other families deal with all the challenges of this disease. I must say I admire the fighters and the caretakers of PSP as they are heroes.

As I write this article, the Sept. 11 attack on America has occurred. I am so thankful that I got to see the Capitol before this tragic event, and my heart goes out to all that were affected. I will continue to pray for all the victims of PSP and the terrorist attacks. I still cannot believe all the opportunities I have been given so far in my PSP efforts! I thank all for their help, love and support.

Peace and Angels,
Brenda Gremillon

"The PSP Butterfly Pin of Hope"



The Society for PSP is pleased to offer the "PSP Butterfly Pin of Hope." The beautiful monarch butterfly signifies HOPE and represents the Society's determination to find the cause and cure for PSP. Because of a special gift to the Society, the second offering of the "PSP Butterfly Pin of Hope" will be free of charge. Anyone wishing to order this handsomely designed pin, please fill out and mail/fax the order form below or email the Society office at SPSP@psp.org. A limit of two pins per family while supplies last. The Society is also thankful to our donors, *Barbara and Jack Kelley*, for the initial and second offering of the "PSP Butterfly Pin of Hope" given in memory of Henry and Jane Ogiba, beloved parents of Barbara Kelley and the *PSP Advocate* editor.

ORDER FORM:

Name _____
Street _____
City, State Zip _____
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Email _____

one pin two pins

Return form to:

The Society for PSP

1838 Greene Tree Road, Suite 515

Baltimore, MD 21208

or email: SPSP@psp.org

Fax: 1 (410) 486-4283

Report Of Gifts - August 16 thru November 15, 2001

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.

SPECIAL GIFTS - \$30,000 & UP

Mr. Jay Troxel - In memory of Eloise H. Troxel

Kathleen Veeh - In memory of Martin Veeh

PSP PARTNER - \$10,000 - \$15,000

Beverly Clark - In memory of Thomas Clark

Denny & Jennifer Neagle

PLATINUM BENEFACTOR - \$5,000 AND OVER

2M Management, Inc - In memory of

Paul E. Rowsey, Jr.

Marvin & Faye Glazer - In honor of Marvin's

81st birthday

Frederick Koallick

GOLD BENEFACTOR - \$1,000 AND OVER

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William R. Anderson, Jr.

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Carol Majewski - In honor of Laura Cerveny's

78th birthday

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Jan & Michael Meisel - In honor of Alfred Berger

Mary Jo Moss

Clarice Rosen - In memory of Robert Rosen

Karl Salnoske - In memory of Carlton L. Salnoske

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W I Realty I, LP - In memory of Paul E. Rowsey, Jr.

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Ronald & Paige Crosby - In memory of

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Paula John

Mary Ann Kaminsky - In memory of Joseph Kaminsky

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William Morrissey

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Computer Cabling & Telephone - In memory of

Frances C. Laird

Cheryl Conlee - In memory of Mary Van Wormer

Susan Connor - In memory of Ken Connor

Frederick D. Cotton

Joan DaRoja - In memory of William DaRoja

Anthony Dechellis

T. Herbert Dimmock

Eric Erickson - In memory of Joan Margaret Erickson

FleetBoston Financial - In memory of

Paul E. Rowsey, Jr.

Gateway Financial Group - In memory of

Mary Lois Onorato

Florence Geary - In memory of Jack Geary

John & Janet Goff - In memory of Paul E. Rowsey, Jr.

Catherine B. Grotelueschen

Stephen Hamer

Connie S. Johnson - In memory of Annis Conley

Mary Elaine Johnson - In memory of

Kenneth L. Johnson

Lifestart USA LLC

Rupert Loucks - In memory of Richard McLeod

Victor Lyon

Amy Mandlman

Mariott International - In memory of Mary Beth Clark

Matthew McClellan - In honor of

James E. McClellan

J. Michael & Melissa McGuire - In memory of

Brady Wedding

Muskogee Rotary Club - In memory of

Paul E. Rowsey, Jr.

David C. Palmer - In memory of Maria Brady

Mickey & Dwyce Ratliff - In memory of

Elsie Garland

Roanoke Orthopaedic Center

Alexann Rose - In honor of Robert Gardella

C. Alvin Sprouse - In honor of Mary S. Thomas

Texas American Shipping - In memory of

William K. Harrison

Henry Torre

Del & Dorothy Van Horn - In memory of

Delmar Van Horn

David & Susan Wedding - In memory of

Brady Wedding

Don & Doryce Wells - In memory of

Lila Jalger and Benny Lee

DONATIONS - PATRONS \$100 AND OVER

Mary K. Adkinson

Donald Agnew - In memory of Mary Agnew

Patsy Aikens - In memory of Martin Brister

AllMed Inc.

American Biosystems, Inc.

Peter K. Anastasi - In memory of William Condon

Ruth & Roger Andree - In honor of Ruth Andree

Alan Arbuse

Doris Arciello - In memory of Alfred Arciello

Robert T. Argott - In memory of William Da Roja

Helen Asarch - In memory of Ben Asarch

Assistive Technology, Inc.

ATI Industrial Automation - In memory of

Hughie Lewis

Louis Atkins

Jean & Tom Badciong - In memory of

Frances Dickinson Kelly

Mary Ann Barber - In memory of Charles Barber

Ken & Patsy Barnes

Barnett Family - In memory of Don Young

Robert Barnett

William T. Bartelme - In memory of Frances C. Laird

Richard Beal - In memory of Leora Beal

Daneil Beaumier

Anne Bendiske - In memory of William Condon

Florence Bennett

Alfred & Shirlee Berger - In honor of Wayne Berger

Morton & Miriam Bernstein - In memory of

Harris Green

Cathy Bigda

Spencer & Judy Bloch - In memory of Jack Jordan

George Blossom - In memory of David Amory

Mildred Bossart - In memory of Howard Bossart

Donald & Darlene Boyer

Sarah Boze - In memory of William R. Boze

Bozeman Daily Chronicle - In memory of Joan Kiely

Bill Bradley - In memory of Jack Jordan

Olga Fae Brand - In memory of Robert Brand

Brewsters Paint & Body - In memory of

Paul E. Rowsey, Jr.

E. B. Brooks - In memory of Joan Brooks Purnell

Noel Brown

Mary E. Browning

Ann Garside Bruckner - In memory of

Joliene Garside

Domenic Brugioni - In honor of Alda Mocogni

Harold Bryant - In memory of Earl Bryant

Dianne M. Bub

Calmoseptine, Inc.

Ronald D. Campbell - In memory of Hughie Lewis

Dominick Capaldi - In memory of Grace Capaldi

Jane E. Caputo - In memory of William Tamke

Marge & Steve Carey - In memory of Priscilla Barry

Carroll Childrens Center

Judy L. Carson

Kristen Case - In memory of Marie Jacobs

Ken & Paula Casey - In memory of Paul Saitta

Suzanne L. Casey

E. Davis Catterton - In memory of Frances C. Laird

Henry Chajet - In memory of Joan Kiely

Susan Chase

John Chiti

The Chubb Corporation

Elizabeth M. Coe - In memory of Paul E. Rowsey, Jr.

Alfred & Dorothy Coffin - In honor of Alfred Coffin

Selma Cohen - In memory of Sidney Cohen

Italia Colom - In memory of Salvador Colom

Clint Cox - In memory of Paul E. Rowsey, Jr.

E. H. Crawford - In memory of David Barr

Ted Criares - In memory of Christos Malakassis

Joan Heather Cullen - In memory of Joan Cullen

Jean Curtis - In memory of Martha D. Stratton

Dain Rauscher Investment

Linda & Bob Daleo - In memory of Louise Hartman

Jodi DaRoja - In memory of William DaRoja

Elizabeth & Mary Davidson - In memory of

Kathryn Baker

Marc & Susan Dechellis - In honor of Helen Bloom

Joseph P. Demuth - In memory of Thomas Bass, Jr.

Eileen Denihan

Louis J. DePerro - In memory of Donald Hartlein

Pat DiSisto & Family - In memory of Albert Fiocco

Vivienne Dorsch

Wallace Ducayet - In memory of Priscilla Barry

Claudia Duffield - In memory of Barbara Duffield

J. L. Dunaway - In memory of Martin Brister

Ann Dunwody - In memory of Hugh Comer

George Dupont - In honor of Esther Dupont

Maureen & Drew Durkin - In memory of

Walter Werner

Charles R. Duvall - In memory of Frances C. Laird

Francis Dwyer - In memory of Raymond Breun

Dave & Carma Easterby - In memory of

Peggy Griffith

Donald L. Edwards - In memory of Melvin Edwards

Wasim Fakhra

Family of Gerald Gehrke - In memory of

William Vonhoff

Ann Fidler - In memory of Paul Fidler & In honor of

Jane Fidler's birthday

Ed Fite - In memory of Paul E. Rowsey, Jr.

William & Adel Forsythe - In memory of

Josephine Ellen Rogers

Jeffrey & Jean Fox

Fox Management Trusts - In memory of

Joan Brooks Purnell

Delane Susan Frost - In memory of Helen Schmitt

Robert F. Gardella

Gateway Financial Group - In memory of

Mary Lois Onorato

James A. Gatton

Alek Gilbert

Jennifer Gilbert - In honor of Libby Gilbert

James & Loretta Girardot - In memory of Jack Jordan

Joseph & Vashti Goldstein

Rose Gould - In memory of George Nagin

Sharon Graber - In memory of Joanne Grant

Reinhard Graetzer - In memory of Joel Yancey

Report Of Gifts

DONATIONS - PATRONS \$100 AND OVER continued

Rose Gould - In memory of George Nagin
Sharon Graber - In memory of Joanne Grant
Reinhard Graetzer - In memory of Joel Yancey
Calvin Grafton
Arlene Graham
Diana L. Gray
Charlotte Greene - In memory of Harris C. Greene
Todd Gregory
Jerry & Margarette Griffith - In memory of
Peggy Griffith
Kenneth Grundy - In memory of Mildred Grundy
Betty Jo Gulish - In honor of Fred Gulish
Sally & Stan Hager - In memory of Joel Yancey
Michael & Mary Hales - In memory of
Henry & Jane Ogiba
Ocie Earline Hall
Walter & Marion Halpin - In memory of
Kenneth S. Hoffman
Diane L. Hamburg - In memory of Lola Hamburg
Capt. James Hamburg - In memory of Lola Hamburg
Margaret & Charles Hamburg - In memory of
Lola Hamburg
Col. Warren Hamburg - In memory of Lola Hamburg
Eugene Hamilton - In memory of Phyllis B. Hamilton
Joy Handwerker - In honor of Jan O'Rorke
Carolyn Hanson - In memory of Delores Tull
Joan Harkleroad
Alma F. Harris - In memory of Joseph Hardy
Robert H. Harrison
Virginia Hathy
Robert Hauer
Echol Hayes
Healthcraft Products Inc.
Walter Hecht - In memory of Irene Hecht
John & Claudia Hellebush
Ethel M. Hikal - In memory of Albert Kriegel
Irwin & Emily Honigberg
George Hoots - In honor of Glenna Hoots
In Step Mobility Products
Inglis House
Intelligent Meeting Corp.
David & Cher Jacobs - In memory of
Paul E. Rowsey, Jr.
Ellen M. Jeffries - In memory of Clyde M. Jeffries
Scott Jenkins - In memory of William Da Roja
Jeffrey Jennings - In memory of Sybil Jennings
Kevin Jerger - In memory of Wendell Turner
Edith Johnson - In memory of Brady Wedding
Edwin Johnson
Elizabeth M. Johnson
Fred & Connie Johnson - In memory of Annis Conley
Evelyn Jordan - In memory of Richard Jordan
Pauline Jurens
Albert & Ellen Katz - In memory of Louis Schlimer
William Kelly
Bob Kirkner
Karen Kleisner - In memory of David Barr
Frank Klimm - In memory of Miriam E. Klimm
Nancy Kliza - In memory of Donald W. DeMasellis
Frank Knowlton
Virginia Koallick
Richard Koenders - In memory of
Frances Dickinson Kelly
Frederick & Elaine Koenig
John & Fay Kovalenko - In honor of Steven Kovalenko
Melvin Kramer - In honor of June Kramer
Stephen R. Kruba - In memory of Florence Kruba
Roger Krug - In memory of Lenore Schmidt
Leland & Marilyn Kugelgen - In memory of
William E. Parker
Eugene Lai
Elizabeth J. Laidlaw
Norma Lawler
Cheri Lawson - In memory of Imogene Shively
Barbara Leon - In memory of Margaret Hollestelle
Peter Lepre - In memory of Albert Fiocco
Joseph Leto - In memory of Evangeline Leto
Diane Leva
Lifeview Resources
Susan Linde
Fred Love - In memory of James Frauenhoff
Betty Lowder - In honor of David Lowder

Ann Lucas - In memory of Marie Jacobs
Virginia J. Lucich - In memory of Donald Hartlein
Luminaud, Inc.
M & T Bank - In memory of David Barr
Louise Mahony - In memory of Jean Gray
Robert Ray Martin - In memory Frances C. Laird
Tom Martin
Connie Martini
Billy Gene Mason
John Mason - In memory of Gino Gualandi
Kymani Matthews - In memory of Brady Wedding
Donna C. McCubrey - In memory of Priscilla Barry
Darrell McDowell - In memory of Bette McDowell
Guy & Marjorie McMillan
Michelle McNutt
Medical West HealthCare Center, Inc.
Mary Anne Memminger - In memory of
Charles Memminger
Janet Mengle - In memory of
Donald Mengle & Don Rahlmann
George Merrick
Orlando Mestas - In memory of Daniel Mestas
Mile Hi Valet Service - In memory of Mary Beth Clark
Millennium Apparel Group - In memory of
Rhoda Finestone
V. David & Billie Lynn Miller - In memory of
Paul E. Rowsey, Jr.
Thomas Moran
Julia Morey - In memory Fonda Wingfield
Jacob Morrow - In memory of Joan Brooks Purnell
Isaiah & Ethel Mosby - In honor of Ethel Mosby
Sandra S. Mosteller
Robert Moyer - In honor of Frank W. Moyer
Anna C. Myers - In memory of Mary Cembalski
Mary W. Myers
Tom & Karen Myers - In memory of Dorothy S. Daum
Dean Nelson - In memory of Thomas R. McHaught
Bob & Barbara Nestor - In memory of
Lola Hamburg
R. B. Newman - In memory David Barr
Jane Ellen Nickey - In memory of William Drake
Sharon Nolen-Morse - In memory of Mildred Nolen
Nova Ortho-Med, Inc.
Amy Nurte - In honor of James Price
Mary Ellen O'Hara - In memory of William Tamke
Kathy Olsen - In memory of Frances Dickinson Kelly
H. Barry Opell - In memory of
Edith Mary Flatt-Cundy
Virginia Orr
Stacey & Craig Oshkello - In honor of
Bryan Markiet's 30th birthday
Patton Boggs LLP - In memory of Joan Kiely
Carolyn Peirce - In memory of Thomas E. Peirce
Peters Law Firm - In memory of
Louise Hartman
Philipp Morris Companies - In memory of
Sam DeFrank
Loretta Phillips - In memory of Delbert Phillips
Pogo Inc Employees - In memory of Louise Hartman
Beulah Polston - In memory of Warren Polston
Pomona IRA - In memory of Patrick J. Clarke
The Poole Therapy Group - In memory of
Troy Leonard
The Prudential Foundation
Puryear Transport Inc. - In memory of Hughie Lewis
Quarles Reunion - In honor of J.C. Quarles, Jr.
Quarles Reunion - In honor of Harold Quarles
Railey Realty Inc
Harvey Raschke - In memory of Doris Raschke
Richard Ray - In memory of Barbara R. Ray
Republic Title of Texas - In memory of
Paul E. Rowsey, Jr.
Donald H. Richmond - In memory of Richard Jordan
Raymond Rilingger - In memory of Alice Rilingger
Meg Holmes Robbins - In memory of Henry B.
Holmes & Jessianna Holmes Johnson
B. L. Roberts - In memory of Jolene Garside
W. Harold Roberts - In honor of Olza L. Roberts
Rock City Machine Co. - In memory of
Lola Hamburg
Leona Roesch - In honor of Earl Roesch
Lucy T. Rooney - In memory of Paul E. Rowsey, Jr.
Diane Harrington Roscetti - In honor of
Eilene Harrington

May Roy - In memory of Normand P. Duquette
Craig & Terri Rubenstein - In memory of
William Parker
Arthur & Mark Ruzek - In memory of Claire Rusek
Sage Products
John E. Schoenecke
Othmar Schroeder - In honor of Sally Schroeder
Barbara A. Schweppe - In memory of
Thomas Carlson
Scooter Store, Inc.
June A. Scragg - In memory of William Burke
Robert Selig - In honor of Robert Coccodrilli
Service Distributing Inc. - In memory of
Frances C. Laird
Annette Shears - In memory of Judy Shears
Shirley Walker Company
David & Karen Shore - In memory of Hughie Lewis
Alan & Lisa Shusterman
Geraldine Siegfried - In memory of
Norman Siegfried
Richard & Barbara Sielaff
Lloyd Silverman
Ruth Simon
June Simpson - In memory of Jolene Garside
Judson W. Sinclair - In memory of David Barr
Skiles Funeral Home - In memory of
William Da Roja
Paul Silver - In memory of Donald Hartlein
Esther Sloan - In honor of William H. Foster
Barbara Sorenson - In memory of Mary Hewitt
James & Marie Sparks - In honor of Marie Sparks
Mary Ann Stein - In memory of Andrew Komlanc
Joanne Stockstill - In memory of Prentiss Stockstill
Mark Strickland - In memory of Carl Strickland
Mary Striebach - In memory of John Striebach
Jill Svahn - In memory of Leigh Hanlon Weber
Elizabeth Swartzwelder - In memory of
Sanford Kaufman
Alice Tahaney
Pam Taheri - In memory of Hughie Lewis
Christine Tamke - In memory of William Tamke
Sylvia Tansey - In memory of Martin Simon
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Texas Academy Physician - In memory of
Senator Tom Haywood
John & Cynthia Thornton - In honor of
Capt. Byron Thornton
Trademark Medical
Cor Trowbridge - In honor of Lorna S. Trowbridge
Chris & Kim Turner - In memory of Kathryn Turner
Patricia Urani - In memory of Angelo Urani
Stephen J. Vaccaro - In memory of
Margaret Vaccaro
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Mitzi Van Tuyl
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Barbara & Joseph Volpicelli - In memory of
Evelyn J. Faretra
Nancy L. Wagner - In memory of
Dr. Richard Falender
Ward Transformer Sales - In memory of
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Michael Weber
Joan Weeks - In memory of George Weeks
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Patricia & Tyrell White - In memory of Benjamin
Curtis Randle
Karen & Jim Wiley - In memory of
Senator Tom Haywood
Vernona S. Willey
Mary A. Wilson
Susan Wilson
Fritz & Carolyn Witt
Ron Wright - In honor of Jan O'Rorke
Valda C. Yamada - In memory of Thomas Bass, Jr.
William Young - In memory of Louise Hartman
Paula Yudelevit - In memory of Dorothy S. Daum
Bob & Charlene Zoller - In memory of Jack Jordan

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)
- #4 PSP ADVOCATE-Newsletter
- #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.
- #11 PSP Fact Sheet (1 page summary-can be duplicated and distributed)
- #12 Reprint of feature article, Baltimore Sun
- #13 Medical Professional's Journal Review/PSP Advocate
- #14 Brain Bank Information Packet
- #15 Physician's 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 + \$3 shipping in US and \$5 outside.
- #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

Mail to: _____

Fax to : _____ Email to: _____

FOR PHYSICIAN'S ONLY:

- #2 Video "The Diagnosis of PSP" (Recommended for clinicians and faculty) \$30 + \$4 shipping in US and \$7 outside
- Medical Professional Packet (Grant Award Information/PSP Rating Scale/copies of all other info.)
- I no longer wish to receive 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:

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

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

Spouse or Significant Other's Name: _____

Home Address: _____

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Progressive Supranuclear Palsy

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