

## Benefit Salute To Dudley Moore

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*From left to right: Eric Idle, Mary Tyler Moore, Jimmy Fallon, Michael Tucker, Jill Eikenberry, Bo Derek, John Dankworth, Dame Cleo Laine, Lauren Bacall, Miranda Cuckson, Barbara Walters, Rena Fruchter, Robert Mann, Brian Dallow, and Tony Adams*

### INSIDE

**The Denny Nagle  
Celebrity Golf  
Classic  
Nov. 18 & 19**

**53rd Meeting  
American Academy  
of Neurology  
PSP Presentations**

On April 16, 2001, Carnegie Hall was filled with well wishers honoring Dudley Moore as he celebrated his 66th birthday. The evening's program was titled "Music for All Seasons: Benefit Salute to Dudley Moore: A Man for All Seasons." In November of 1999, Mr. Moore revealed that he had been diagnosed with progressive supranuclear palsy. This event raised funds to support one of Dudley's favorite non-profit organizations, "Music for All Seasons." This organization provides music to nursing homes, hospitals, geriatric centers, etc. Funds were also raised for the Dudley Moore Research Fund for PSP. The Society for PSP has been appointed to be partial administrators of this fund.

Tony Adams created a presentation of super celebrities paying tribute to Dudley Moore. Adams stated of the performers that, "I've never worked with celebrities who were so moved by an honoree." Barbara

Walters welcomed the audience and introduced the all star cast. The cast included Bo Derek, Mary Tyler Moore, Tony Randall, Robert Mann, Eric Idle, Jimmy Fallon, Chevy Chase, John Ritter, Christopher Cross, Jill Eikenberry, Lauren Bacall, Michael Tucker and John Dankworth. At the end of the evening's program, the Carnegie Hall audience rose and sang "Happy Birthday." Dudley, hair thinned and face gaunt and pale, stood up and applauded the generous cast.



*Ellen Katz, Executive Director, presents Dudley Moore a special gift from the Society for PSP.*

A dinner party at the Essex House followed the tribute. Many members of the Society's Board of Directors as well as special friends of the Society attended the evening's events. Ellen Katz, the Society's Executive Director, and George Jankiewicz, Board Chair, gave the special presentations to Dudley Moore and Music for All Seasons.

# The Society for Progressive Supranuclear Palsy

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Reba and David Saks

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

The Society for Progressive Supranuclear Palsy, Inc. (SPSP) 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. SPSP provides information, education, support and advocacy to persons with PSP, their families, and caregivers. SPSP educates physicians and allied health professionals on PSP and how to improve patient care.

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(In memory of Henry and Jane Ogiba)  
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(In memory of Lois Croft Davis)

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## Director's Doings



**D**ear Friends,  
When Barbra  
Streisand sang "People,  
people who need people are the  
luckiest people in the world," she  
reaffirmed how important it is to  
interconnect with others. At the  
Society, I see every day the  
importance of these classic lyrics.  
PSP is a disease that will isolate  
families and loved ones only  
if we let it. By sharing your

experiences and taking advantage of the Society's outreach activities, you can keep hopes high and feel that you are not alone.

Here's how:

1. Become a PSP Communicator which means you give us permission to release your name to other families in your state with PSP when asked. Just call the office and asked to be placed on the Communicator's List.
2. Ask for a Communicator's List for your community. You can contact others whether or not you add your name to the list.
3. Form a support group. We have a manual on how to do it and offer additional help from Janice Clements, the Co-Chair of our Outreach and Education Committee.
4. Join a support group. Find helpful hints and peer support.
5. Attend and/or help plan a regional symposium in your area. The next one is in the Boston area on September 29, 2001.
6. Join the listserve. This on-line support group has over 300 subscribers and is most helpful and supportive.

Don't be alone with PSP. Others are waiting today to hear from you and to share experiences.

Sincerely,

*Ellen Sam Katz*



*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*

## Deepest Sympathy to the family of Pearl and Erwin Poizner

The Society for PSP regrets the passing of Erwin Poizner, and his wife, Pearl Poizner, on May 1 and May 2 respectively. Erwin, a victim of PSP, died after his health kept failing. His wife's passing of a stroke the following day was unexpected. Steve Poizner, their son, expressed, "My parents were totally devoted to each other. They fought PSP together, and in the end, it killed them both."

We feel the shock and sense of loss of Steve and Carol Poizner and their siblings, Sharon Cooper, Howard and Jerry Poizner and their families. The Society deeply appreciates Steve and Carol Poizner's second installment of \$225,000 on their pledge of \$600,000 to fund PSP in their parents' names. The fund has been sadly renamed "The Pearl and Erwin Poizner Memorial Research Fund for PSP."

### NOTE TO THE EDITOR

Dear Nancy,

I have just been reading the Fourth Quarter issue of the Advocate 2000, which came recently. My husband, Ken Olson, died from PSP in July 1999. We were not aware of the Society until shortly before that because he had previously been diagnosed with Parkinson's. I listed the Society in his obituary as a place where gifts could be sent in his memory. Eventually, over \$1000 was sent. I'm writing just to say how interesting the recent issue is and how much it would have helped Ken and me—the article about swallowing problems, the one that explains what PSP is, and the personal stories from several people, as well as the one on brain tissue donation. We received our very first issue 10 days before Ken died, and we read it all. He was especially influenced by the article in that issue called "A Good Death" by Alice Kitchen, since we were in the process of going through the same good death. I wrote to you later, after you received many comments about her article. Anyway, I just want to let you know what a good job you are doing. I'm sure it is a great help to many people. One thing I am sorry about is that we didn't arrange for brain tissue donation. I did write earlier to Dr. Dickson and received some information from Mayo. But there wasn't time to make the careful arrangements—15 months in advance as Mr. R.L. Mellers described in the last PSP Advocate. However, by his request, Ken did donate his body to the Colorado Anatomical Society and I have signed up to do the same. Thanks again for such a fine periodical.

Sincerely,  
Jane Olson

*Note from the Editor:*

*Thank you, Jane, for your kind words and communicating with me once again. I would like to share this letter of appreciation with Mr. Jay Troxel and our readers. Mr. Troxel, in memory of his beloved wife, Eloise, finances the production of the PSP ADVOCATE. He is a generous friend and guardian of all those impacted by PSP. He supports the PSP Brain Bank and many research grants. I would encourage all of us to thank him for his most generous gifts and continued efforts.*

*Nancy B.*

# SPSP - A Look Inside

## Meet Members Of The PSP Board of Directors (PART II)

**BRUCE BARNETT, Ph.D.**

Bruce Barnett grew up on a farm 25 miles from Cincinnati. He attended Harvard University, where he majored in physics and played in the band. After graduating from Harvard in 1965, he attended the University of Maryland, where he obtained his Ph.D. in 1970 with a research specialty in elementary particle physics. He joined the faculty of the University of Maryland and in 1976 moved to Johns Hopkins University, where he continues to be on the faculty today.

Among Bruce's other interests is singing bass with The Handel Choir of Baltimore. He is on the Board of Directors for a local homeowners association, where his primary responsibility is to direct the operations of a seven-acre public park. This includes responsibility for 80,000 tulips, 20,000 annuals, plus lots of trees, shrubs and grass!

Bruce became involved with the Society in 1999 when his wife, Dorothy, was diagnosed with PSP. It had been clear for quite awhile prior to the diagnosis that she had some neurologic problems, but neither Bruce nor Dorothy had ever heard of PSP. He joined the Society's Board of Directors because, as he states, "I would like to do whatever I can to eradicate PSP because it does such terrible things to its victims."

**ROBERT BARNETT**

Robert Barnett, an engineer, is the Executive Vice President of Motorola and President of the Commercial, Government, and Industrial Solutions Sector. This sector's business products and services include missions critical to communication for police, fire, utility, hospitals and others. The sector is also involved with communication and infrastructure systems for military and space agencies.

Bob became involved with the Society after a family member was diagnosed with PSP. His other volunteer activities include working with the United Way and serving on Advisory Committees to the Dean of the McCormick School of Engineering, Northwestern University. He also serves on the Board of Directors for Johnson Controls, USG and Central Vermont Public Service.

**ELIZABETH BRISSON**

Elizabeth Brisson works for New England Financial in Boston as an officer for Product Management and Sales, providing health insurance to small businesses. Liz became involved with the Society in an effort to raise money for PSP research during the time that her aunt, Margaret Parker, was struggling with PSP. Elizabeth, along with her husband of 20 years, Roger, and Dale Ferris, Margaret's daughter, were instrumental in establishing The Margaret Parker Research Fund in 1997. Liz is Chairman of the Development Committee and the National Symposium Committee. She is also Vice Chair of the Society Executive Committee.

"If there is something good that can come out of this dreadful disease, it is the power of all the people it has brought together," Elizabeth says. "Whether it be families, friends, caregivers or just concerned individuals wanting to contribute their talents and financial gifts, it is bringing people together, and

that is good. I know for myself, personally, I felt helpless when I realized the magnitude of this disease and what it does. I have found purpose in my life by volunteering my time and abilities to the Society as a Board member. It is something I do because I can, and it keeps the memory of my aunt alive. I will continue to communicate the Society's mission until the cause and cure for PSP is found."

**JANICE H. CLEMENTS**

Janice Clements is a retired University of Vermont College of Medicine research administrator, co-author of several journal publications on low back pain, and former caregiver for her husband, John, who died from PSP in January 2000.

Janice was appointed to the Society Board in January 2000 and is co-chair of the Outreach and Education Committee, a member of the Human Resource Committee, and coordinates support groups until the new Director of Outreach and Education is hired.

Janice is an active community volunteer, facilitating two neurodegenerative disease support groups in Vermont—one for couples and one for caregivers. Janice is a member of the Champlain (Vermont) Long Term Care Coalition. She has coordinated two Vermont regional Parkinson's Awareness Day conferences

and was the Vermont representative on the Committee to Pass the Udall Bill. She is active in her church and sings with the Burlington Choral Society. Janice is also proud grandmother of ten, an active gardener and would-be watercolor artist.

**DALE FERRIS**

Dale Ferris lives in Fall River, Mass. with her husband and two children. She is Executive Manager of Ferris Realty. She is on the Bristol Community College Foundation Board, currently serving as Vice President. She is a member of the Friends of St. Anne's Hospital, the Order of St. Sharbel, and the Home for the Aged, Inc. serving on several of their boards and various committees.

Dale became involved with the Society for PSP after her mother, Margaret Parker, was diagnosed with PSP at the age of 60. In 1998, Margaret passed away at the age of 66 after a long and courageous battle and, as Dale says, "She will always be an inspiration of strength and dignity." Before she passed away, the Margaret Parker Research Fund was established. Dale, Elizabeth (Margaret's niece) and Elizabeth's husband, Roger Brisson, organized a mountain climb to raise funds for research in her name. Almost \$80,000 was raised for research along with awareness of PSP. It is Dale's hope, along with all who know someone with PSP, that a cure will be found.

**STEPHEN HAMER**

Stephen Hamer is a financial advisor and fund manager at Thompson Kernaghan in Toronto, Canada. He graduated with a political science degree in the 1970s from Sir Williams University in Montreal. Stephen lives in Toronto with his wife, Jean. His hobbies include woodworking, hiking, Tai Chi and canoe tripping.

"I became involved in PSP after my father was diagnosed with this illness several years ago," Steve says. "My main interest is to work on the Strategic Plan of the Board of Directors with a particular focus on improving the support group network available to those families and individuals with PSP. I believe this priority is important due to the aging of our population and the lack of services available to most members of our population."



*Michael Koe, Chief Executive of PSP Europe Association, with Board Members Joanne Armstrong and Bruce Barnett*

# SPSP - A Look Inside

HOWARD HURTIG, M.D.

Dr. Howard Hurtig was born and raised in the Mississippi Delta and attended college and medical school at Tulane University in New Orleans. His post-graduate training was in internal medicine at New York Hospital-Cornell Medical Center in NYC and in neurology at the Hospital of the University of Pennsylvania. He joined the faculty of the University of Pennsylvania in 1973 and his present position is Chair of Neurology at the Pennsylvania Hospital, an entity within the Penn Health System and Professor and Vice Chair of the Department of Neurology, University of Pennsylvania Health System.

"I accepted an offer to serve on the Board because I am a movement disorders neurologist and I take care of patients with PSP," Dr. Hurtig says. "I saw the opportunity as a chance to support research into the mechanisms of causation and the search for new treatments, since we currently have none."

KENNETH ALAN MCKUSICK M.D. FACNP, FACR

"My first and only known experience with PSP has been with my medical colleague, John Clements, M.D., of Burlington Vermont," Dr. Kenneth McKusick says. "Even from afar, the frustration of early misdiagnosis that led into the years of an uncertain future that culminated in incredible challenges of care management were only too vivid. When asked to serve on the Board of the SPSP, I was grateful for the chance. Perhaps some skills learned over the past several decades in organized medicine would be helpful to the goals of the SPSP, and eventually to a better understanding of this illness."

Dr. McKusick is certified by the American Board of Internal Medicine and the American Board of Nuclear Medicine. He is a Fellow of the American College of Nuclear Physicians and the American College of Radiology. He is also a retired Associate Professor of Radiology from Harvard Medical School. Now retired from active nuclear medicine practice at Massachusetts General Hospital in Boston, Dr. McKusick is currently president of the Society of Nuclear Medicine Education and Research Foundation, whose mission is to improve health care through the use of radioactive products.

Having developed some experience with governmental health policy, he continues to be active nationally on those matters that affect the nuclear medicine community. He lives on Cape Cod, where he and his wife have become very involved in water resource, health and long-term planning issues.

PATRICIA A. MUELLER

Patricia Mueller became affiliated with The Society for PSP when she saw a TV special on Dudley Moore in November 1999. She contacted the Society via email and was stunned to learn about the organization. After several visits to neurologists, her mother had finally been diagnosed with PSP in 1989. All anyone told her about the disease was that it was extremely rare and there was no treatment. Her mother passed away in 1995.

Until Dudley Moore announced he had PSP, Patty had never heard about this disease again. After watching the news one evening and learning about another individual who had PSP, she learned about the Society. She volunteered to do anything she could. Her professional background and education is in Human Resources. The Society needed an individual to help transition from Johns Hopkins University to a non-profit agency.

For eight months, she worked with other Society Board members on job descriptions, compensation, benefits, policies and procedures etc. to support the newly structured organization. She became the Human Resource chairperson and a Board member.

"The Society for PSP has brought new meaning to my life; I have met other individuals who lost loved ones to this disease and I have hope the work the Society is doing will help others find a cure for PSP," she says.

Patty has lived in St. Louis, Missouri most of her life and has been married to her husband, Paul, for 13 years. They have two children: Joey, 11, and Curtis, 7. Patty and Paul spend most of their free time going to children's activities or boating.



*Sue Dagart, Society's Development Consultant with Stephen Hamer*

JENNIFER BUDGE SHATTUCK

Jennifer Budge Shattuck is the Executive Director of Ladew Topiary Gardens in Monkton, Maryland. A certified public accountant by training, she has served as a trustee of various schools and environmental non-profit organizations. Jenny earned a B.A. in history from Williams College in 1975 and an M.B.A. from New York University's Graduate School of Business in 1978. She lives in the Baltimore area with her two college-age children.

Jenny's mother has been diagnosed with PSP, and she and her family have been striving to meet the challenges of PSP for several years. This compelled Jenny to become involved in the Society shortly after moving to the area. She has been a Society trustee since 1997 and serves on the Society's Development, Human Resources and Finance committees.

GWYN M. VERNON, MSN, CRNP

Gwyn M. Vernon is a neurology nurse practitioner in private practice with physician colleague, Stephen M. Gollomp, MD, at the Lankenau Hospital near Philadelphia, PA. Gwyn has 25 years of nursing experience, 14 of which have been in neurology and movement disorders.

In addition to nursing practice, Gwyn is on the faculty of the Graduate School of Nursing at the University of Pennsylvania. She has authored or co-authored over 20 articles published in the nursing and medical literature on care of patients with neurologic disorders and related research projects.

Gwyn's outside interests include tennis, swimming and singing in a local chorus. She also enjoys sailing on the Chesapeake Bay with her husband, Mark.



*Board Members Janice Clements and Ken McKusick*

## Research

# Presentations about PSP at the 53rd Meeting of the American Academy of Neurology

by Lawrence I. Golbe, M.D.

The 53rd Annual Meeting of the American Academy of Neurology was held May 5-11, 2001 in Philadelphia. This is the single most important annual meeting for clinical neurological researchers from around the world to present preliminary results. In most cases, the researchers incorporate comments from their peers at this meeting to improve the work before formally submitting it to a journal. There were 10 presentations on PSP.

### MRI STUDIES

Yan Rolland and colleagues from Rennes, France, looked at the findings on routine MRI in PSP using a more careful, standardized technique than had been used in previous published reports. They found abnormalities in all 12 cases with PSP. Compared to 12 patients with Parkinson's disease, those with PSP showed atrophy (shrinkage) of the midbrain and gliosis (scarring) in the periaqueductal gray area and upper midbrain (both parts of the brainstem) and medial globus pallidus (part of the basal ganglia deep in the cerebrum). These results show that routine MRI is adequate to distinguish PSP from PD, although the authors were able to distinguish the two groups by other means.

Another MRI study was performed by Michael Hutchinson and Ulrich Raff of New York University. They used a special MRI technique called "inversion recovery" to delineate the precise boundaries of the remaining portion of the substantia nigra (an important part of the brainstem that produces dopamine) in patients with PSP and PD. They found that their technique was very sensitive to degeneration of the substantia nigra in both disorders. It also demonstrated progression of the loss from medial (near the middle) to lateral (at the sides) in PSP and in the opposite direction in PD.

### PATHOLOGY

Roberta Vitaliani and colleagues from Padua, Italy and London, UK examined the spinal cords removed from five patients with PSP at autopsy. They found greater involvement than had been suspected in the past. Neurofibrillary tangles (the characteristic microscopic feature of PSP) involved all levels and layers of the spinal cord. This may explain some of the gait and bladder problems in PSP. Furthermore, there was some loss of the anterior horn cells, which are the same cells that break down to a more severe extent and for a different reason in amyotrophic lateral sclerosis (Lou Gehrig disease). The latter change may explain the muscle weakness and wasting that occurs in some cases of PSP.

### GRANT ANNOUNCEMENT:

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

Deadline, October 1.

Regular Grant Program to \$50,000 - Deadlines are April 1 and October 1.

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

### A BLOOD TEST

The neurofibrillary tangles that appear in the dying brain cells of PSP are made of tau protein. James Tetrud and colleagues from Sunnyvale, California found that antibodies to tau protein were present in the blood of 7 of 10 patients with PSP and in only 2 of 13 healthy people. These antibodies are not the cause of PSP, but a reaction to the accumulation of tau in the brain. Their presence may eventually be useful as a diagnostic blood test, just as tests for other antibodies are routinely used to test for other diseases.



James Tetrud, M.D., at the 53rd AAN meeting

### CLINICAL SIGNS

Uma Nath and colleagues from Newcastle, UK, have collected 187 living patients with PSP from northern England. This is the first large-scale study to use the "NINDS-SPSP" diagnostic criteria formulated by an international effort supported by the National Institute of Neurological Disorders and Stroke (part of the US Government's National Institutes of Health) and the Society for PSP. They are planning to use these and other patients in a series of epidemiological studies aimed at identifying potential causative factors. For now, they have reported that the median age of symptom onset was 66 years, that Parkinson's disease (PD) was the most common mistaken diagnosis (in 27%) and stroke was next (in 10%). The most frequent symptoms at the time of referral to a neurologist were falls (in 89%), speech or swallowing problems (74%) and intellectual loss (56%). Double vision occurred in 39%, light sensitivity in 20% and difficulty lifting the eyelids in 17%. At some point, 19% of the patients responded at least modestly to levodopa (the active ingredient in Sinemet).

The diagnosis of PSP often relies on a subjective impression by an experienced neurologist. In an effort to identify specific points that comprise such an impression, Sandra Kuniyoshi and colleagues from Cleveland and Baltimore (including SPSP Medical Advisory Board members David Riley, David Zee and former SPSP Chairman Stephen Reich) quantified the ability of seven tests easily performed in the examining room to differentiate PSP from PD. They found that in cases where slowing or restriction of vertical eye movement does not occur, PSP can often be distinguished from PD by the inability to stop blinking when a flashlight is repeatedly shone in the one eye, by a persistent turning of the head after the patient is spun slowly in an office chair for 45 seconds, and by an inability to inhibit hand clapping after 3 claps, as demonstrated or verbally requested by the examiner.

### TREATMENT

Pramipexole (Mirapex) is one of 4 "dopamine receptor agonists" presently available for treatment of PD. Mark Guttman of Toronto and colleagues from several centers in the US and Canada performed a study of pramipexole in PSP, hoping that it would ameliorate the symptoms or perhaps slow the progression of the underlying brain cell loss. It was sponsored by Pharmacia & Upjohn, the manufacturer of pramipexole. Fifty-one patients with PSP received pramipexole up to 6 mg per day or placebo tablets. Unfortunately, at no point in the study was there a difference between the two groups in tests of movement, activities of daily living, mood, intellectual performance or PSP Rating Scale score. The search for a truly effective treatment for PSP continues.

*Continued Page 7*

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# Research

## GENETICS

A large collection of male US World War II veterans who are twins has been analyzed for the presence of parkinsonian disorders by Caroline Tanner and colleagues from Sunnyvale, California. That study reported in 1997 that PD was concordant in both members of twin pairs less frequently than would be expected for a genetic disease. Since then, a similar study using positron emission tomography (PET), a more sensitive test for PD than the routine personal examination used in the Tanner study, found evidence that genetics in fact is important in the cause of PD. The Tanner study now reports their results for PSP. In the original group of 350 twins whose telephone interviews gave evidence for some kind of parkinsonism, 4 proved on examination to have PSP. None of them were members of the same pair. The twin brothers of the 4 with PSP were each examined and found to be neurologically normal. Two of the twins were from identical pairs and 2 were from fraternal pairs. This study fails to provide evidence for a genetic component in the cause of PSP, but a much larger group of twins would be necessary to answer the question with certainty. Perhaps a PET scan in the 4 outwardly normal twin brothers would be helpful as well.

## EYE MOVEMENTS

Richard Leigh and colleagues from Cleveland, Houston and Munich, Germany sought to determine which of two groups of cells in the brainstem, when damaged by PSP, is responsible for the slowing of vertical eye movement that is an important component of the disease. They tracked eye movements in response to flashing targets in 5 patients with PSP, 6 with other parkinsonian conditions and 7 healthy people of the same age. They found that loss of the "burst neurons" rather than of the "omnipause neurons" accounts for this deficit in people with PSP. This finding could eventually provide a clue to treatment of the eye movement problem in PSP.

## DEMENTIA

It has been known for many years that when dementia occurs in PSP, it resembles that of disorders in which the frontal lobes of the brain are damaged. Michael Geschwind and colleagues from San Francisco sought to determine whether the mental decline in PSP is related to degeneration of the frontal lobes themselves or from a loss of connections of the frontal lobes with the deeper parts of the brain, parts that are known to degenerate in PSP. They therefore gave detailed psychological tests to 10 patients with PSP and performed MRI in those patients using "voxel-based morphometry," a technique that precisely measures the amount of brain tissue in a specified area on the scan. They found that the patients displayed significant deficits on the psychological test of frontal lobe function, but that there was only a little loss of frontal lobe brain tissue. Rather, the performance loss correlated better with loss of tissue in the midbrain, which is in the brainstem. This experiment is only the start of a larger inquiry by these researchers into the cause of frontal lobe function in PSP—an inquiry that could provide valuable clues to treating or preventing intellectual decline in PSP.

### DISCLAIMER

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

## Of Mice and Monkeys

Lawrence I. Golbe, MD  
Chair, Medical Advisory Board

Two unusual developments in the past few months have improved the prospects for understanding the cause of PSP.

A team headed by Michael Hutton, Ph.D., of the Mayo Clinic, Jacksonville has created a mouse that develops neurofibrillary tangles (NFTs) in its brain. NFTs occur in the brain in people with PSP and several other disorders, including Alzheimer's disease, Pick's disease (a dementing illness similar to Alzheimer's), corticobasal degeneration (a movement disorder similar to PSP) and frontotemporal dementia (an often hereditary disorder featuring intellectual loss similar to, but more severe than, that in PSP). The lead author of the paper, which appeared in the prestigious journal *Nature Genetics*, was Jada Lewis, Ph.D.

The technique involved inserting a mutant version of the tau gene into embryonic mice. Tau is the protein that accumulates abnormally to form NFTs. Proteins are chains of amino acids in a specific order that determines the function of the protein. The mutant form of tau that the researchers used is one that is known to cause tau to form neurofibrillary tangles. It was found by analyzing the tau gene in human patients with hereditary frontotemporal dementia. This mutation causes a substitution of the amino acid leucine for the proline that normally occurs at position 301 of the tau protein molecule. The original mouse with this mutation was able to pass it on to its offspring, creating a colony of mice with neurofibrillary tangles and brain cell loss. By 10 months of age, 90% of the mice with this gene have developed neurological abnormalities.

The resulting "transgenic" mice can now be used to conveniently, cheaply and quickly test treatments that prevent or reverse the formation of NFTs. Such a treatment could prevent or treat PSP and other NFT disorders. PSP now joins the long list of disorders that stand to benefit from creation of transgenic "animal models."

Another animal model for PSP appeared by chance in a cynomolgus monkey (a type of macaque similar to a rhesus monkey) living in a zoo in Thailand. Dr. Wijit Kiatipattanasakul and colleagues noticed that an elderly male monkey was moving more slowly than expected for its age of 35 years, with drowsiness and a mild tremor. When the monkey died of natural causes 18 months later, autopsy showed changes in the brain very similar to those of human PSP.

The authors of the paper, which appeared in the journal *Acta Neuropathologica*, state that this is the oldest monkey of this species ever autopsied with this level of detail. They suggest that if large numbers of such monkeys can be kept alive to advanced old age, a certain number of them may develop the same illness. They could then be used to test treatments that could benefit PSP sufferers, but that may be too risky to try in humans.

### 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:

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# The Genetic Aspects of PSP

Dr. Huw Morris  
Research Fellow  
Institute of Neurology, London

## WHAT IS GENETICS?

Genetics involves the study of the inherited factors which control human biology. We each inherit one copy of each gene from our mother and father and our set of genes (about 80,000 pairs of genes in humans—the human “blueprint”), made up of DNA, influences every aspect of our bodies’ functions. While the majority of the genes are identical in humans, there is some variability, occurring about 1 every 1000 DNA “letters.” The majority of this variation has no detectable effect, although some variations may contribute to human differences, like height and hair color, and an even smaller number of DNA variations may contribute to the development of disease.

Why is studying genetics useful? Disease-causing gene changes may have either a major or minor effect. Gene changes with a major effect will cause a disease in individuals who inherit the change, for example in Huntington’s disease. In these cases, disease may seem to “run” in families. Gene changes with a minor effect only cause disease when they are inherited with a number of other minor gene changes or in conjunction with environmental factors. The effect of these minor gene changes may not be detectable within families. Identifying these gene changes can allow us to understand how the disease develops, make animal models for the disease, and attempt to develop new treatments.

What is the evidence for the role of genetics in PSP? Families with PSP are very rare, so a major gene effect does not seem to be an important factor. However, one common variation in the tau gene is present more commonly in patients with PSP and so seems to increase the risk of developing the disease. Furthermore, a similar disease, fronto-temporal dementia may be caused by rare changes in the tau gene, suggesting that tau is important in the development of PSP. These rare changes have been used to make a mouse model, which may be helpful in designing new treatments.

How should the study of the genetics of PSP proceed? Fully understanding the genetics of PSP will involve the following:

1. Further detailed study of the clustering of PSP with other neurological diseases.
2. The search for further genetic risk factors.
3. The identification of the responsible genes in the rare families with PSP.
4. Analysis of the changes that occur in the brain tissue of patients with PSP.

All of these studies depend on the cooperation of patients with PSP and their caregivers in donating blood samples for DNA analysis and in some cases agreeing to brain tissue donation. Hopefully, the development of animal and cell models based on this work will allow new treatments to be developed in the future.

*(Reprinted with permission from the PSP Bulletin, The Official Newsletter of the PSP Europe Association, Winter 2000, Volume 7, No.20)*

## “Visions and Job Opportunities”

Thanks to the expansion of the Society through its dynamic strategic plan, the Society has created the following two new positions. Each position will be located in the Society’s national headquarters in Baltimore, MD. Each position offers the opportunity for skilled professionals to make a meaningful contribution in the quest for a cure for PSP while helping persons with PSP and their families.

### DIRECTOR OF DEVELOPMENT:

The Society seeks a dynamic fundraiser who can coordinate and implement the goals prioritized in the strategic plan. Candidate should have a broad knowledge of various fundraising strategies with a concentration in major gifts, planned giving, corporate and foundation giving, identification and cultivation of donors and direct mail. Bachelor’s degree, five years experience. Ability to travel is essential.

### DIRECTOR OF OUTREACH & EDUCATION:

The Society seeks an innovative and resourceful professional to establish a strong national organizational presence through the development of support groups, informational, referral and networking services to persons and families affected by PSP, the production of educational materials in various media, medical and professional education, the presentation of PSP symposia throughout the country and the development of a marketing and communication program to enhance awareness of PSP. Bachelor’s degree and five years experience in educational programming, outreach or volunteer services and communications. Ability to travel is essential.

All of these positions are newly created, will be located in Baltimore and will include a generous benefits package. For more information, contact Ellen Katz, Executive Director at 1-800-457-4777 or e-mail cover letters and resume to [epkatz@psp.org](mailto:epkatz@psp.org).

## Society for Progressive Supranuclear Palsy Brain Donation Program

For Diagnosis and Research on PSP  
Society for PSP Brain Bank  
Supported by the  
Eloise H. Troxel Memorial Fund  
Mayo Clinic Jacksonville • Jacksonville, FL 32224

The purpose of the Society for PSP Brain Donation Program is:

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](mailto:SPSP@psp.org)  
SPSP, Inc. Woodholme Medical Building, Suite 515  
1838 Greene Tree Road, Baltimore, MD 21208

## **THE DENNY NEAGLE CELEBRITY GOLF CLASSIC**

**ON SUNDAY, NOVEMBER 18<sup>TH</sup> AND MONDAY, NOVEMBER 19<sup>TH</sup>  
OVER 30 WELL KNOWN MOVIE, TELEVISION AND SPORTS STARS  
WILL DONATE THEIR TIME TO PARTICIPATE IN TWO FUN AND  
EXCITING CELEBRITY ACTIVITIES WHICH WILL BENEFIT  
THE SOCIETY FOR PROGRESSIVE SUPRANUCLEAR PALSY.**

**A LIMITED NUMBER OF PLAYING SPOTS AND CORPORATE  
TEAMS ARE AVAILABLE FOR THIS SPECTACULAR GOLF EVENT  
AT BEAUTIFUL MOUNTAIN GATE GOLF CLUB.**

**INDIVIDUAL GOLF PACKAGES AT \$1,500.00 PER PERSON\*  
AND SPECIAL  
CORPORATE GOLF TEAMS AT \$6,000.00 PER TEAM\***

**IF YOU ARE INTERESTED IN JOINING US IN LOS ANGELES  
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HOLLYWOOD ALLSTARS CELEBRITY SPORTS  
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MARINA DEL REY, CA 90295  
or call  
(310) 845-9455**

**FOR AN INFORMATION BROCHURE.**

- \* Individual golfers receive two invitations for our Sunday Evening Pairings Party. One playing spot on Monday with a celebrity, a nice gift bag, breakfast, lunch and drinks on the golf course and our post Golf Awards Cocktail Party.**
- \* Corporate teams include 12 invitations for our Sunday Evening Pairings Party Five playing spots with one celebrity, gift bags, breakfast, lunch, signage, drinks on the golf course and our post Golf Awards Cocktail Party.**
- \* Special airline and hotel rates are available to those individuals who are interested in traveling to Los Angeles for our celebrity golf classic.**

# Glamour and Glitz!

## Donors and PSP Guests at New York Tribute to Dudley Moore



*Phillip Gratz with Bo Derek*



*Albert Katz, Kelley Harrison, George Jankiewicz, Joanne Armstrong, Dick Janney, Ellen Katz and Elizabeth Brisson*



*John Steele, M.D., Marcy Todd, William Hermann, II and William Hermann, Sr.*



*Barbara Fox, Lorraine Bieser & Doris Amory*



*Carolyn & Amy Mandlman*



*Randy Todd, D.D.S., Ilia and Charles Hinckley*



*Barbara & Douglas Bloom*



*Debbie & Wayne Berger*

*George S. Jankiewicz  
and Joan Riefler,  
Society Development  
Committee  
Chairperson*



*Eric, Virginia  
and Phillip Gratz*

## What is Dysphagia?

Dysphagia is a difficulty in swallowing. Impairment may occur in any of the stages of the swallow. There are three stages in a normal swallow. Food is prepared through chewing and shaped into a "bolus" during the oral, or initial, stage of the swallow. During the second, or pharyngeal stage, of swallow, the bolus passes over the base of the tongue through the pharynx (the canal which connects the mouth to the esophagus) and onto the esophagus entrance. The bolus passes through the esophagus during the third, or esophageal, stage of swallow. This complex and efficient process takes less than two seconds. The airway to the lungs is closed and protected, as the entry to the esophagus is open during this brief period of time.

As with many neurological diseases, dysphagia can become a significant problem for persons diagnosed with PSP. Swallowing thin liquids or tough foods can become difficult due to throat muscle weakness or incoordination. The swallowing muscles have difficulty creating the watertight seal that is necessary to separate the path to the stomach from the path to the lungs. This increases the risk of aspiration (food or liquid, material or saliva enter the lungs instead of the esophagus or go down the "wrong" pipe).

Repeated, minor episodes of food and liquid entering the lung can cause pneumonia. (Pneumonia is an inflammation of the lung caused by an infection of bacteria, viruses or other organisms.) A person's mouth harbors a mixture of bacteria that is harmless in its normal location. But, it can cause a serious condition (aspiration pneumonia) if it reaches the lung.

When swallowing problems develop, the pleasures of eating are sometimes replaced with discomfort and anxiety for the affected person as well as the caregivers. In order to maintain adequate nutrition, intervention or a change in diet may be necessary. The risks of aspiration are decreased by modifying the texture of foods and fluids. But, it is important that the modifications in consistency and texture conform to an individual's swallowing needs. Consult your health care professional for a swallowing assessment.

A soft or pureed diet may become necessary. Pureed foods are smooth and have a mashed potato consistency. Most foods can be pureed in a blender or food processor. Tough peels and seeds must be removed from fruits and vegetables prior to blending. Foods can be thickened or thinned to meet individual requirements.

### TO THICKEN LIQUIDS AND FOODS:

- Add potato flakes, flaked baby cereal or mashed potatoes to hot liquids such as soup, gravy or sauce.
- Add unflavored gelatin, pureed fruits, or a commercial thickener (such as Thick and Easy or Thicket) to cold liquids.
- Add mashed potatoes, thick sauces or gravies, canned pureed or strained meat (baby food), or a commercial thickener to pureed soups.
- Add cooked cream of rice or wheat cereal or a commercial thickener to pureed fruits.
- Add mashed potatoes, sauces, or commercial thickener to pureed vegetables.
- Tofu and banana flakes can also be used as thickeners

### TO THIN FOODS:

- Add bouillon, broth, juice, liquid flavored gelatin, melted hot butter or margarine, milk, plain yogurt or strained pureed soups.

THE FOLLOWING ARE GENERAL STRATEGIES FOR SAFER SWALLOWING. ALL OF THE GUIDELINES MAY NOT APPLY TO EVERY PATIENT.

- Take small bites—1/2 to 1 teaspoon at a time
- Eat slowly
- Do not talk as you eat
- Try bending the head down, tucking the chin to the chest and bending the body forward. Sometimes this provides more ease in swallowing and helps prevent food from entering the airway.
- Do not mix liquids and solid foods in the same mouthful.
- Sit in an upright position (90 degree angle) for 30 to 45 minutes after each meal.

### RECIPES:

#### CREOLE CLAM SOUP

1 can clam chowder soup  
1 can chicken gumbo soup  
1 soup can of milk  
Heat, stirring until smooth. Puree and serve

#### CABBAGE SOUP

1 small head of cabbage  
1 can cream of celery soup  
1 tablespoon horseradish  
1 dash black pepper  
1 dash celery salt  
water from cooked cabbage  
Steam or boil cabbage until tender and save water. Add remaining ingredients and heat. Put into blender and puree until smooth. Add the hot cabbage water gradually until you have the consistencies you like.

#### FRUIT COTTAGE CHEESE

1/2 cup cottage cheese  
2 tablespoons of fruit of any type, drained  
Put all ingredients in blender and puree

#### STRAWBERRY MILKSHAKE

4 oz. skim milk  
1/2 teaspoon of milk  
3-4 ice cubes  
3/4 cup of fresh or frozen strawberries  
Put all ingredients in blender. Blend at high speed until frothy and smooth. Instead of milk, you can use 1/2 cup of vanilla or strawberry ice cream.

#### HIGH-PROTEIN SMOOTHIES

In a blender, mix 1 cup fruit-flavored yogurt and 1 cup fortified milk with soft, fresh, peeled fruit or soft, canned fruit and 1 cup of cottage cheese. Blend until smooth.

#### JELLO RECIPE FOR JELLO LOVERS

2-1/2 cups boiling water  
1-cup vanilla Ensure  
1 package vanilla instant pudding  
2 pks. (8 serving size) or 4 pks. (4 serving size) Jello gelatin (any flavor)  
Mix Jello gelatin and water until dissolved, Let cool about 30 minutes at room temperature. Combine pudding and Ensure and beat with wire whisk for one minute. Add the mixtures together and stir. Refrigerate for 2-3 hours until firm.

#### BAKED STEAK WITH MASHED POTATOES AND GRAVY

Round Steak tenderized and cut into individual size servings  
1/2 cup flour  
Durkee or French's Brown Gravy Mix (3-4 packages)  
Flour and brown the steak in oil (not fully cooked). Follow directions on the gravy mix and pour into a cake pan. Put steak in the gravy and bake at 350F for 1-1/2 - 2 hours until tender. When meat is done, mix gravy and meat in the blender. Serve with mashed potatoes. *Continued Page 12*

## Education

### MEATBALL PLUS

4 meatballs cooked  
1 small carrot cooked  
1/2 can beef gravy cooked  
Put all into the blender and puree

### COOKBOOKS FOR SWALLOWING DIFFICULTIES:

- **MeALS**  
The ALS Clinic  
Department of Neurology, Neurosensory Center  
6501 Fannin, Houston, TX 77030
- **Non-Chew Cookbook** by J. Randy Wilson  
P.O. Box 2190, Glenwood Springs, CO 81602  
800-843-2409
- **The Puree Gourmet**  
J. William Richman  
American Institutional Products, Inc.  
2733 Lititz Pike, Lancaster, PA 17601  
800-866-7757
- **Puree & Fancy**  
Milani Foods/Diafoods Thick-It  
2525 Armitage Avenue, Melrose Park, IL 60160  
800-333-0003
- **Pureed Foods with Substance & Style**  
Imaginart Communication Products  
307 Arizona Street, Bisbee, AZ 85603  
800-828-1376
- **Good Looking, Easy Swallowing**  
Janet Martin & Jane Backhouse  
FC Foundation  
618-373-2577  
800-866-7757
- **Puree Pizzazz**  
Becky Dorner, RD, LD  
Interactive Therapeutics  
800-253-5111

### SUPPLY RESOURCES:

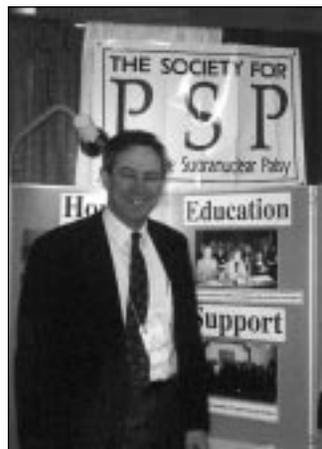
- **Imaginart**  
800-828-1376  
flexi-cut cups, dysphagia cup, nosey cup, maroon spoons
- **Speech & Language Rehabilitation Products**  
800-225-2610  
dysphagia cup, maroon spoons, nosey cup, glossectomy spoon, gravity assisted drinking cup, people feeder, flexi-cut cup
- **MenuDirect**  
888-MENU123
- **RESOURCE**  
800-438-6153  
Dairy thick, sugar-free thickened drinks, instant thickened coffee, thickened drinks, thickened juice, thickeners
- **AliMed Dysphagia Management Products**  
800-225-2610

### LIFE QUALITY PRODUCTS

- **Enabling Waters**  
831-637-6830

*(From the editor: If you have "special needs" recipes to share, please forward them to me. My email and mailing addresses are on page 2 in the Editor's block.)*

## PSP is prominent at the 53rd Annual Meeting of the American Academy of Neurology (AAN)



*Howard Hurtig, M.D.,  
Society Board of Directors*

The 53rd Annual Meeting of the American Academy of Neurology was held May 5-11, 2001 in the Pennsylvania Convention Center, downtown Philadelphia. The Society for PSP's informational booth exhibit educated neurologists about progressive supranuclear palsy. All our educational materials were on hand as well as an electronic retrieval system that allowed neurologists to be placed immediately on our mailing list and receive our physician's information packet. An edited version of Dr. Lawrence Golbe's video, "The Diagnosis of PSP" (for physicians only) was continually presented for neurologists visiting our exhibit. Specific information was also distributed discussing the neuropathological criteria for the diagnosis of PSP, sensitivity and specificity of ocular motor abnormalities in early PSP, optimal criteria for the clinical diagnosis of PSP and differentiating PSP from other parkinsonian syndromes.

The Society thanks Howard Hurtig, MD, (Chair of Neurology at the Pennsylvania Hospital) for his assistance in expanding on our neurologist/physician educational materials. The exhibit also educated these health care providers about the existence of the Society for PSP and the importance of early referral of persons diagnosed with PSP and their families to this organization.



*AAN President Francis I. Kittredge, Jr., M.D. and Mrs. Kittredge  
visit the exhibit with Ellen Katz and Nancy Brittingham.*

## Ask A Doctor

Lawrence I. Golbe, M.D.  
Chair, Medical Advisory Board

**1. "Is the nicotine patch beneficial for persons diagnosed with PSP?"**

No. I tried it in about 30 patients and it helped no more often than placebo usually does. Also, the only benefit was in the general energy level, not in the stiffness, speech, swallowing, eye movements or balance—the things that really count in PSP. A few patients had important side effects such as dizziness or nausea. I don't prescribe it any more.

**2. "I read again that someone again referred to the incidence of PSP as one in 100,000, 20,000 in the US and 3-4,000 still not diagnosed. Aren't these figures obsolete? Can we get some statement that updates what is now known about the incidence of PSP and get it out in the Advocate?"**

You're talking about prevalence ratio, not incidence. The new figure is 6.4 per 100,000. If the population of the US is now 284 million (as of today, from the Census website), then the absolute prevalence (the number of people with PSP in the whole country) is 18,176. But the 6.4 figure is only an estimate because it was based on a sample of a population of only 121,608 people. The degree of uncertainty in such figures is expressed in terms of a "95% confidence interval," which in this case is 2.3 to 10.6. That means that the true prevalence ratio has a 95% chance of being within that span. So . . . the absolute prevalence of PSP in the US has a 95% chance of being between 6,532 and 30,104 people.

As for how many have been accurately diagnosed, we have very little by way of hard data to go by, but most of the studies show that in patients in whom PSP is eventually diagnosed, it is not diagnosed until half of the disease course has passed, on average. So you can divide the 18,176 figure in half. But a large fraction of those with PSP are NEVER accurately diagnosed. I'd estimate half at best. So at most, a quarter of the 18,176 people with PSP have actually received that diagnosis.

Bear in mind that the 6.4 per 100,000 figure was derived from clinical examinations of people whose medical records mentioned something vaguely parkinsonian or PSP-ish. So even that may have missed some people with PSP whose doctors' records had nothing hinting at that diagnosis.

**Mark The Date!**  
**MASSACHUSETTS REGIONAL  
PSP SYMPOSIUM**

PSP Awareness Day  
Saturday, September 29, 2001  
Crowne Plaza Hotel  
Woburn, MA

***In Memory of Jerome Blonder***

## PSP FAMILIES URGENTLY NEEDED!

The Society for PSP is growing. Public awareness of PSP has increased, most notably with the 1999 announcement by Dudley Moore that he is among those suffering from this disease. Dudley's announcement triggered the largest wave of media coverage PSP has ever seen.

More recently, Denny Neagle, now pitcher for the Colorado Rockies, has joined the team of those working to solve the many challenges of this disease. His activities will generate a great deal of financial support and media interest.

Nonetheless, we have a long way to go regarding public awareness of PSP. There are many reasons it is needed. Greater visibility of PSP does much in the search for its cause and cure. Patients still incorrectly diagnosed have a better chance of realizing they are dealing with PSP. This in turn increases involvement with The Society for PSP. Increased involvement brings more volunteers into the organization, leading to further ideas and activity. Greater numbers working together cultivate larger research dollars. The more of us giving voice to those struggling with PSP, the more likely we will be heard and helped.

Many media outlets are interested in running a PSP story. The missing part of the equation is the families needed to relate their struggle. These family stories have great impact, especially on viewers unaware of what this disease does to the lives of those battling it every day. Who knows who else is out there, willing and able to help but unaware of PSP.

Please offer your family for a local story. You will be connected with a medical reporter who will come to your home. Some great stories have been printed and aired, but we need many more.

To help or to ask questions please contact:

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Sherman Oaks, CA 91403  
T: (818) 343 3259 Fax: (818) 343 3258  
medianet@earthlink.net

**The Society For PSP Announces  
THE SIXTH BIENNIAL PSP  
SYMPOSIUM FOR PERSONS  
WITH PSP, FAMILIES &  
CAREGIVERS**

May 17-18, 2002  
Baltimore, MD  
More details to follow

# 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:*

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# News From Support Groups

## MICHIGAN



Please find enclosed a picture of the West Michigan PSP Support Group, which meets at the beautiful Senior Center in Holland, MI. We had our third meeting with 15 people in attendance including three men and two women diagnosed with PSP. If you would like to join us to share information and fellowship, please email me at Smiths5@eglnet

Thanks, Sally Smith

## MINNESOTA

The Minnesota Support Group for PSP meets at the Struthers Parkinson Center, 6701 Country Club Drive in Golden Valley on the second Thursday of each month, 1:00-3:00 PM. Respite care is available at a day program in the center, while you attend the support group, for no charge. Reservations need to be made ahead of time. We meet together with folks whose family members have Parkinson's for a time of sharing daily experiences and information sharing. There are professionals from the center who come in from time to time to talk on speech and swallowing issues,

exercise benefits. Sandra Varpness, the social worker from Struthers who leads the group, can give help with accessing community services.

We are interested in possibly starting a second group on the east side of St. Paul in the Maplewood–Woodbury area for Parkinson's and PSP carepartners. Please let me know of your interest in attending a group in this area.

We are always looking for new families to join us in our group at Struthers and encourage anyone interested to call Charlotte Tripet at 763-546-1694.

## VIRGINIA



Allen Rohlfling of Virginia Beach organized the first meeting of the Tidewater PSP Support Group. Seven people came together and shared their ideas and suggestions. Nancy Brittingham, editor of the PSP Advocate and resident of Tidewater, happily accepted Mr. Rohlfling's invitation to attend this first meeting and join the group.

It was a learning experience for all. If you would like more information about upcoming meetings, please call Al at 757-426-5281.



## Note from Kathy Small

Hello to everyone -

I haven't yet thanked all who responded to the news of my Mom's death this week, but I will. The service was today, and while it is all still with me, I thought I would pass on some thoughts I have learned about PSP, hoping maybe they would be helpful to some. They include things we did, things we did not do and things we learned. This was such a novel course, mistakes were inevitable, but if some-

one else can benefit from them, they weren't in vain. For new folks—you may not want to read these now—it may just be too sad and overwhelming. Tuck it away, because as things move along, your need for information will broaden and change, and you may find some of this useful.

I remember early on feeling angry at the casualness of others who were more comfortable with all the complications and accommodations with this disease while the hair on my neck was standing on end. What I have learned is we are all

at different stages, and our comfort or acceptance reflects those stages. Take in information as you can, and know you are not alone.

### SOME THOUGHTS:

The most reliable physician to diagnosis PSP is a neurologist who is a Movement Disorders Specialist (MDS). General neurologists have not seen many clinical cases of PSP, and PSP is diagnosed by a clinical evaluation.

Find a support group on PSP if you can. In our support group, we learned about the disease, met other people with the same struggles, got literature, and met other PSP professionals through the group. We traveled over an hour to attend—well worth it.

Prepare to accommodate your loved one at home early on so you can be prepared as they decline. For example, thinking about a future ramp to your home may be sad, but when the time draws near, your load will be lighter. Learn about lifts like a Hoyer lift, or floor to ceiling poles for your loved one to use. We learned from experience—we would see a problem and frantically try to address it, having hoped my Mom wouldn't be burdened with certain features of PSP. Then

*Continued Page 16*

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## Kathy Small

when she was, we had to scramble to figure out what to do next. Now I look back and wish we had ANTICIPATED, been a little more proactive—rather than often responding to a crisis—being reactive. What we did was how most of us behave, but I now see there might have been a better way.

Keep an uncomplicated journal of medications, so you can refer to what was happening at the time when certain medicines were being used. You'll be traveling down the road of experimentation, and you may be disillusioned at times as we were. You will have to learn what works best for your loved one by trial and error—not by proven practices.

Make a folder of information on PSP and put it in a pack that can go with your loved one—to the hospital for example, or any situation where an understanding of PSP would be helpful. You can also make some folders for the health care folks that will be coming into your home—OT, PT, Speech Therapist, etc. This wonderful idea came from someone on the listserv who had all the info about PSP, and with each hospitalization would pass out folders at the nurses station, to the physician on duty, anyone who dealt with her loved one. It was well received. I did this recently and the nurses appreciated it. In the folder, I put the fact sheet on PSP from the Society for PSP (1-800-457-4777), a list of PSP resources, a description of my Mom as she was before PSP, and the Questions and Answers I downloaded from Jim Barron on the PSP listserv.

Contact the Society for PSP. This will connect you to conferences, newsletters, information about the disease, and support the work related to PSP.

When swallowing or choking problems begin, get a good and thorough evaluation from a Speech Pathologist referred by your neurologist. If your loved one can learn ways to reduce choking or aspirating early on, that may prevent aspiration pneumonia, which they are at great risk for with PSP. Because PSP is "progressive," your loved one's needs will change, and what works at one time will need to be reevaluated at another time.

Referrals for occupational therapists and physical therapists helped but we should have used them more. I'd encourage anyone to set up home visits with OT/PT on referral, for home support, adaptive equipment, etc.

We hired a friend who did massages to come to my Mom's home for a weekly massage. It helped with her stiffness and circulation and was a pleasant experience.

Discuss sensitive issues while your loved one can be a part of the decision-making process. Issues like permission to resuscitate, feeding tubes and other serious decisions will be decided for them unless provisions are made to honor their wishes. We did not want to even think about such issues because we hoped they would not be necessary—it is a lot to take in upon learning of a diagnosis. Give yourself time, and when you have settled into some reality, begin to consider what your loved one's needs may be.

The best to you all -  
Kathy Small, daughter to Bette McDowell (died 4/1/01)

## The Caregiving Years (PART II)

(Part I is in the PSP Advocate First Quarter, 2001)

By Denise Brown

*I am still helping my relative or friend!*

Who are you? You've been caregiver for more than five years. You've been through it all: hospital admission and discharges; short-term rehab stays in nursing homes; a vast array of community services. You may appear to doubt the advice given by health care professionals; you've just been through the health care system long enough to know that sometimes health care professionals may not seem to have your best interest in mind.

Some family members and health care professionals worry about your ability to find humor in situations they find offensive. They view your attitude as "calloused" and "uncaring." Far from it, you have a very practical, very realistic approach toward your caregiving role—and your sense of humor has been a critical tool for your survival. Without your sense of humor, you would have given up a long time ago.

Your Keyword: Welcome. Welcome the joys of your relationship; welcome forgiveness (of yourself, of your care recipient, of other family members and friends); welcome shared activities.

Your Purpose: To gain a better understanding of yourself and your care recipient. You've settled into your role and your routine; now is your opportunity to step back and reflect. The first three stages laid the groundwork for this stage, your period of personal growth.

As a "pragmatic caregiver," what can you do?

1. Work on finding joy in your relationship with your caregiver. The biggest joy-killers are your hands-on duties: bathing, dressing, incontinence care. But these duties bring you together; this is your time together. Add some fun to your hands-on care: sing songs, tell jokes, share goals and dreams.
2. Work on forgiving your care recipient for past hurts. Resentment toward past wrong and injustices will make your present caregiving role very difficult. Let go of what was and concentrate on making what is healthy and productive.
3. Develop a habit of enjoying shared activities. Develop a routine of time shared as husband-wife, mother-daughter, father-son rather than as just caregiver and care recipient. Releasing the roles of caregiver and care recipient allows you to enjoy each other.
4. Begin to think about your future.

What goals have you yet to achieve? How can you achieve them? Can your care recipient help you achieve them?

*My role is changing.*

Who are you? You've been a caregiver over a period of several years and have recently made a decision about your role as caregiver. Or, your care recipient's condition has taken a turn for the worse and you know his time is very limited.

As a result, you've changed your role—or are just about to.

Your Keyword: Allow. Allow time to mourn and grieve; allow remembrances to remain; allow reflections of your experiences.

Your Purpose: To walk with your care recipient during his last months and weeks, implementing his or her decisions

## Support

about end-of-life care that you both discussed during Stage 1.

This stage is about loving and feeling good about the shared journey. As you both feel the journey end, this is also a time to mourn and grieve. As you mourn, you might find yourself questioning what will be the next chapter in your life. You've been a caregiver for so long, how can you possibly do anything else?

As a "transitioning caregiver," what can you do?

1. Allow yourself time to mourn and grieve.

A nursing home placement may have been as painful a loss as a death. Both experiences are tremendous losses—and need to be respected with time to process, and then heal, the emotions.

2. Remember your care recipient.

You don't have to give away clothes or remove pictures—until you want to. When family and friends seem hesitant to talk about your care recipient (they worry they will upset you), assure them that sharing memories, laughs and stories brings you great comfort.

3. Reflect back on your caregiving responsibilities and decisions with pride.

Find comfort in knowing that you did the best you could.

4. Review your journal.

How are you different today than you were on the day you first started writing in your journal? How will you use this experience to enhance your future relationships?

*My caregiving has ended.*

Who are you? Your role as caregiver ended more than two years ago. You find yourself compelled to make a difference in the lives of other caregivers. You share information readily with caregivers in the earlier stages, or you start a business dedicated to helping family caregivers, or you find a job in which you assist family caregivers. And, you treasure each relationship you have in your life, recognizing that each day, and your health, should never be taken for granted.

Your Keyword: Treasure. Treasure your dreams; treasure your opportunities to share lessons learned; treasure memories of your care recipient.

Your Purpose: To implement your lessons learned from your role as caregiver, from your care recipient and from your family members and friends. During this stage, which can last as long you wish—even your lifetime—you reap the benefits of your efforts.

As a "Godspeed Caregiver," what can you do?

1. Follow your dreams.

Make your goals your achievements.

2. Family caregivers will look to you as a mentor and leader.

Allow caregivers in earlier stages the same freedom to stumble and steady themselves that you had. All worthwhile journeys have trips and wrong turns; the journeys become meaningful as we learn from our mis-steps.

Share your experiences with expectant caregivers, fresh-man caregivers, entrenched caregivers and pragmatic caregivers. They can learn from you! (Many of the books, web sites, audio tapes and videos which helped you along your journey were developed by Godspeed Caregivers.)

3. Treasure the memories you have of your care recipient. Continue to remember your care recipient regularly through rituals, such as enjoying an ice cream cone in her honor on her birthday, or by planting trees in her name. Reading and reviewing your diary will be a great way to remember.

Of course, your best memorial to your care recipient's memory is a life you build for yourself filled with healthy relationships, productive careers,, and joy and laughter.

*Denise Brown operates The Center for Family Caregivers and owns and operates Tad Publishing Co., both based in Park Ridge, Ill. Through her organizations, Denise helps persons who care for an aging relative. Through Tad Publishing Co., Denise publishes Caregiving newsletter; authors books and manuals for family caregivers and health care professionals; writes a monthly advice column for Chicagoland's Senior News; and maintains the Caregiving.com web site. In addition, she is Executive Director and Founder, The Center for Family Caregivers. The Center is a non-profit organization dedicated to helping persons who care for chronically ill or disabled family members.*

# OCTOBER IS PSP AWARENESS MONTH

*Now is the time to start planning a special event for October. Think about a dinner, walk-a-thon, sports event, concert etc. Contact your local media about these events and together we can raise awareness about PSP across the nation. All it takes is one person to get the event started and you will be surprised to see how it grows!*

### What A Shock To Find Out Ken Did Not Have PSP

Dear Nancy,

Our journey with Ken's disease may help others to realize the importance of brain donation and receiving a final diagnosis, to say nothing of the benefit it may be to those suffering in the future. We first noticed what we recognized as symptoms about 1988 when Ken complained that when he got up out of a chair, he felt like he was going to keep going forward. Shortly thereafter, he complained of a frequent slight tremor in his leg and arm. I was not too concerned, as those never seemed too serious. However, when he began to lag behind in our frequent walks and hikes, and not swinging one arm, we became more concerned. He had a strong heart, good blood pressure and no apparent other health problems. He never smoked, was a firefighter for 30 years, drank only socially, worked out and was a strong, athletic man before this disease. However, in retrospect, we have wondered if a severe bout of depression and stress which he went through in 1981 was connected with this disease or just a mere coincidence. That was the cause of his retirement from the fire department when he was in his early 50's.

#### A VISIT TO THE NEUROLOGIST

We started out with a visit to our family doctor (an HMO GP) who diagnosed him with PD. We took him to another neurologist on our own. He also stated it was PD and put him on Sinemet. We noticed no cessation in the progression of his disease; in fact it seemed to be progressing very rapidly. They kept increasing the dose of Sinemet and trying Parlodel, and other enhancers, but the progression continued. He began falling, freezing steps, stuttering steps, and dragging a foot—all sorts of mobility problems. His voice became very soft, handwriting illegible and impossible after a while. Impotence and incontinence followed. After a fall in which he broke his hip and needed a total hip replacement, and another one six months later resulting in a shattered femur on same leg, he was never able to walk again unaided. He went into a wheelchair in 1993. I took him to Barrows Neurological Center in Phoenix when they were doing Parkinson's drug trials and he was turned down the first day of trial because they said he did not have Parkinson's. They did MRI, PET, and some other tests, and knew something was wrong, but couldn't make an exact diagnosis. Our home neurologist, was not in agreement with that diagnosis and insisted he did have PD, as he had plenty of PD patients just like that. Later, I wondered how many he misdiagnosed.

We went to Loma Linda where they diagnosed Ken with either PSP or Multiple System Atrophy (MSA) which they explained were different but hard to differentiate neurological diseases. They advised taking him off all medication for PD as it was not helping and could conceivably cause harm.

#### OUR MOVE NEARER TO FAMILY

His condition was worsening so rapidly that I needed to move to Ohio where I had some family, as he was no longer able to travel. I bought a van equipped with a ramp and drove him from CA to Ohio in his wheelchair, as he was unable to

get on a plane. No fun! Getting him in and out of hotels, motels, restaurants for 5 days, but we made it.

Ken was examined at Ohio State University and diagnosed as having PSP. He was now taking no meds, except BP meds. I connected with the PSP online group and the Society for PSP to learn more about the disease. He followed right down the line with others in their symptoms and problems. It never really occurred to me that we had not reached the final diagnosis. He "fit" with this group of people. There were some differences, but so many similarities. Ken never complained much of pain, even when he had falls. He lost his ability to speak. He could no longer focus his eyes to read or watch TV and became very light sensitive. We had to keep the room dark. He developed aspiration pneumonia from silent aspiration and was hospitalized for 2 or 3 weeks. He began losing weight. He lost 50 pounds before the bout with pneumonia, and they then inserted a peg tube. He never ate again. He received all food, water and meds by peg tube. He became very rigid. Since 1995, I had to use a Hoyer lift to transfer him from bed to wheelchair, where he would sit the biggest part of the day. We went through all different types of physical therapy early on and again later. Also speech therapy, all helped minimally and temporarily. He slept a lot during the day in his wheelchair, but he never complained. He did gain his weight back on the peg tube, but had to have an indwelling catheter, and had serious bowel problems ranging from diarrhea to bowel impaction.

#### THE LATER YEARS

By the time of his death in 2000, he was rigid, but his mind still appeared to be intact. He knew everyone; it was obvious, and attempted to let you know he understood by a slight squeeze of the hand or a blink. We talked to him a lot, read to him, played music for him. I was his sole caregiver and rarely left the house for the last 5 years of his life. As we looked back over the years, we remembered several tell-tale signs that seemed to lead up to this before the first symptoms he complained of, like his stumbling in our square dances and ballroom dancing. At the time, we didn't connect all this.

We had discussed brain donation long before his death. He wanted to do that. To say I was surprised when they concluded from the autopsy that Ken did not have PSP after all but MSA is a gross understatement. I was absolutely stunned. I couldn't even comprehend it for a while. I had identified with all the other caregivers of PSP for so long, and compared all like symptoms, that there was no doubt in my mind that was his disease. I had spent so many years learning about PSP, and living with it (I thought) that I needed a period of time to adjust. I now am going forward now learning all I can about MSA. It was very important to our children to have an exact diagnosis. It was also important to me.

Bernice Bowers  
caregiver and spouse of Kenneth Bowers  
age 73 dec. 06-23-00

## PSP: The Quest for Hope

One hot and muggy afternoon, my dad, Malcolm P. Olivier, fell to the ground under his favorite Magnolia tree. We were baffled as to why he fell. It was as if his body had just collapsed. He had been previously diagnosed and treated for Guillain-Barre' Syndrome, and maybe this fall was an aftermath of this disease. The doctors could not answer this question. Daddy was continuing to fall, so we brought him to the hospital for more evaluation. After running more neurological and blood tests, Daddy was diagnosed with Parkinson's disease (PD).

We now had a diagnosis, but was it the correct one? We did not notice the shaking tremors usually found with PD patients. Daddy started to complain of his vision being blurry. He could not move his eyes in vertical position. We brought him to an ophthalmologist, who diagnosed him with having cataracts in both eyes. Surgery was scheduled and performed. The doctor seemed to feel it was a successful operation, but Daddy still could not see clearly. This particular doctor questioned the PD diagnosis.

One day while at a family function, Daddy expressed, "My feet are not doing what my brain is telling them to do." My family realized that something serious was wrong with Daddy. We again questioned the PD diagnosis. His falls were multiplying. Over the course of eight years, Daddy had fallen over 250 times. For safety reasons, he started using a wheelchair with a seat belt.

Slowly other symptoms began to surface. Daddy tried to speak, and his voice sounded weak; his strong voice now only a whisper. He also began to have trouble swallowing food and liquids, which necessitated our having to puree his food and help him to eat and drink. He also began to drool excessively, and we had to carry towels wherever we went. Eventually, he could not swallow and had to have a feeding tube.

One evening, Daddy, who promoted the symptom of stubbornness, was determined to stand in the kitchen and make a turkey sandwich. He lost his balance and fell across the opened dishwasher door. My Momma tried to pick him up and couldn't. Daddy was in excruciating pain. Momma called the ambulance to have him brought to the hospital for an examination. In the ambulance, Daddy, who was still holding on to his turkey sandwich, proceeded to eat it. After his X-rays proved he had broken his hip, the doctors scheduled immediate surgery. Well, due to Daddy's stubbornness in eating the sandwich, the operation had to be postponed until the next day.

While he was in the hospital, he began to suffer other symptoms. He was having hallucinations due to the medication Sinemet, which was prescribed for the PD. We immediately had the medication stopped. He then began to experience complete kidney failure. After he recovered from this near death experience, he had to be rushed into emergency gallbladder surgery. His recuperation from all of this trauma was lengthy because he then developed pneumonia. After being in ICU for a few days, we began to realize that after each episode, Daddy progressively lost strength in his hands, legs, and muscles.

Finally, the doctors were convinced that Daddy did not have PD but something else. He was then referred to a neurologist

who diagnosed Daddy with Progressive Supranuclear Palsy (PSP). What? We were told PSP, but we were not given any information about the disease. We had a name, but no symptoms or treatment. My family spent the next few years caring for Daddy with a disease we knew nothing about. We did not know what the next symptom would be, how much Daddy would decline, or how long he had to live. Neither did the doctors. We asked questions, but received no answers.

Everyday Momma had to turn him to prevent bedsores, feed him through the feeding tube, and administer medication that was not helping. Daddy was a prisoner within his own body. He fought bravely in World War II to save others, but he could not fight to save his own life. PSP was a war he could not win.

The night before he passed, Daddy mustered up enough strength to call each of his children that night to say the words, "I love you." He passed on May 18, 1997. The world had lost a wonderful, caring man to a horrible, debilitating disease.

I have since started a grass roots advocacy group through which I help families who have loved ones diagnosed with PSP. With the help of the Society for PSP, I provide more information to

them than most doctors have available. Many patients are misdiagnosed, and some have been told to "Go home and die!" I have even had families call after finding their loved ones abused and starved in nursing homes. The employees did not know how to care for someone needing constant monitoring and medical attention. This is a sorrowful shame, but where does one find an appropriate care facility and knowledgeable medical professionals? Most medical personnel need to become educated about PSP.

I propose that PSP be included in the terminology of future medical students. There are many misdiagnosed cases of PSP, and the patients are not receiving proper care or treatment. If more people were educated about the disease, then maybe the patients could begin a quest for hope. Serious research and funding is needed to discover the cause, cure, and treatment of PSP. Some research has been established, but not enough to properly help the families who have to deal with the disease on a daily basis.

I appreciate your time and attention with this matter. The families are crying out for help and support, so maybe together we can find a cure for this debilitating disease. The families of PSP deserve a fighting chance and a glimmer of hope.

Brenda Olivier

Maybe together  
we can find  
a cure for this  
debilitating disease.

### NOTE FROM THE EDITOR

If you would like to share your "PSP Story" with others, please send it to me via - email: NancyB501@cs.com or "snail mail": 6 Bramston Drive, Hampton, VA 23666. There will be similarities throughout all the stories yet each story will also be unique.

What may help one with the disease process may also help another. Please limit stories to 400 words and send a photo if possible.

### Mom Never Lost Her Beautiful Smile

Dear Nancy,

When my mother was still alive and struggling with PSP, the "PSP Advocate" was invaluable to me. It helped me to understand what was happening to Mom. The articles and helpful suggestions were really appreciated, as were the personal experiences of others with PSP. The following is my tribute to my wonderful mother.

Sincerely,  
Jeanne Simmons

My mom, Joyce Day, was a vibrant, talented and loving person all her life. Her home, family, and faith meant everything to her. On March 31st, it will be a year since she passed away (at age 77) and five years since she was diagnosed with PSP. Shortly before her diagnosis, she had fallen and broken her hip and was having therapy with hopes that she would walk again. Unfortunately, after the surgery Mom had a stroke, which slowed her recuperation. With that and the symptoms of PSP, she never did fully regain her ability to walk again.

Before she fell, we had been noticing that Mom would stumble when walking. Her personality, too, seemed to be changing quite drastically. She was apathetic and let things go at home—things that used to mean a lot to her. When eating she would choke a lot. We requested that a neurologist look at her to give us some idea of what was happening to Mom. The diagnosis of PSP didn't mean much to us since we had never heard of it before. We were to find out how devastating it would be for Mom and how difficult for the family to see our loved one slowly deteriorate.

Mom tried to do her therapy, but her heart just wasn't in it. In time she had to start kidney dialysis, because she had end-stage renal failure, also. Through all the trips to dialysis and the trips to the hospital because of infections and complications with shunts, she tried her best to cooperate and to cope with all these things happening to her. As a family we took care of her physical needs at home and visited her every day when she was in the hospital. Arrangements were made for aides to come to the house for a few hours a day. My father, 14 years her senior, would be with Mom through the night. We took advantage of all the wonderful health care equipment that was available. It helped us with lifting, transporting, feeding, bathing—all making the daily routines so much easier.

During the time Mom was home we tried to make her as comfortable as possible. She liked to look out the front door and watch the neighborhood activities. We took her for walks in the wheelchair to get fresh air and to have a change of scenery. Any reading or looking at pictures was difficult for her so we would read to her.

We kept talking to her and included her in conversations and family happenings even though she could no longer talk on her own. Just because she wasn't speaking didn't mean she wasn't listening and trying to communicate. We would try all kinds of things to try to find out what Mom wanted. Sometimes we were successful. When we weren't, at least Mom knew we were trying.

My mother was in a nursing home for the last 4 months of her life. Between her needs for dialysis, the actual physical

care needed and the use of a feeding tube, the hospital recommended she be admitted to a nursing home. This was a very difficult decision for the family to make. We were fortunate, however, to find a home with in-house dialysis that was close enough that we could visit her almost every day. The staff was very caring and seemed to attend to Mom's every need.

Her smile said it all when family members came from far and near to visit. Mom never lost her beautiful smile that would light up the room. It is something I will never forget; nor will I forget the wonderful person that she was. She loved and cherished us as children, and as adults her love and support were ever present. We surely do miss her and will honor her forever.

## A Poem

*What do you see, what do you see,  
what are you thinking when you're looking at me?  
A crabby old woman, not very wise,  
uncertain of habit, with faraway eyes.  
Who dribbles her food and makes no reply  
when you say in a loud voice, "I do wish you'd try?"  
Who seems not to notice the things that you do,  
and forever is losing a stocking or shoe.  
Who, resisting or not, lets you do as you will,  
with bathing and feeding, the long day to fill.  
Is that what you're thinking? Is that what you see?  
Then open your eyes, you're not looking at me.  
I'll tell you who I am as I sit here so still,  
as I use at your bidding, as I eat at your will.  
I'm a small child of ten with a father and mother,  
bothers and sisters, who love one another.  
A young girl of sixteen, with wings on her feet,  
dreaming that soon now a lover she'll meet.  
A bride soon at twenty — my heart gives a leap,  
remembering the vows that I promised to keep.  
At twenty-five now, I have young of my own  
who need me to guide and a secure happy home.  
A woman of thirty, my young now grown fast,  
bound to each other with ties that should last.  
At forty my young sons have grown and are gone,  
but my man's beside me to see I don't mourn.  
At fifty once more babies play round my knee,  
again we know children, my loved one and me.  
Dark days are upon me, my husband is dead;  
I look at the future, I shudder with dread.  
For my young are all rearing young of their own,  
and I think of the years and the love that I've known.  
I'm now an old woman and nature is cruel,  
'tis jest to make old age look like a fool.  
The body, it crumbles, grace and vigor depart,  
there is now a stone, where I once had a heart.  
But inside this old body, a young girl still dwells,  
and now and again my battered heart swells.  
I remember the joys, I remember the pain,  
and I'm loving and living life over again.  
I think of the years; all too few. Gone too fast,  
and accept the stark fact that nothing can last.  
So open your eyes, open and see,  
not a crabby old woman; look closer — SEE ME!!*

# The Society for PSP Survey

## How Are We Doing?

Please take a few moments to update our records and share your ideas with us.

Date \_\_\_\_\_

Name \_\_\_\_\_

Person with PSP  Family member caregiver to (name) \_\_\_\_\_

Physician  Other \_\_\_\_\_

Address \_\_\_\_\_

City, State, Zip \_\_\_\_\_

Phone \_\_\_\_\_ Email \_\_\_\_\_ Fax \_\_\_\_\_

Please evaluate our programs and services by marking the appropriate answers.  
(1=Unsatisfactory 2=Satisfactory 3=Very Good 4=Excellent)

Benefits and Services	Know About	Use	1	2	3	4
Toll Free Communication with Society office	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Quarterly Newsletter	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reporting and Funding of Research	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Communicators List, Physician Referral List	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support Groups	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Biennial and Regional Symposiums	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Brochures/Educational Material	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Videotapes	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Web Site/Internet	<input type="checkbox"/> yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
List Serve	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Brain Bank Donations	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Acknowledgement and Receipt for Contributions	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Suggestion to improve current programs and services listed above.

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Suggestions for new programs and services.

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What medical devices, equipment or services can you recommend to other PSP caregivers?

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OPTIONAL:

Please tell us about the person with PSP

Name \_\_\_\_\_

Age \_\_\_\_\_ Previous Occupation \_\_\_\_\_

Present condition \_\_\_\_\_

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VOLUNTEER BANK: Consider me as a future volunteer in the following areas:

- Board of Directors                       Communicator                       Lead a support group
- Legislative                                   Public Relations                       Newsletter
- Fundraising                                 Computer                               On-Line Services
- Other \_\_\_\_\_

Please describe any expertise you have in these areas: \_\_\_\_\_

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FUNDRAISING:

- Would you help raise funds for the Society and PSP research?     Yes     No
- Would you approach your employer to make a contribution?     Yes     No
- Does your company have a matching gift program?                 Yes     No
- Do you belong to any organizations, or foundations that could make a contribution to the Society?                       Yes     No
- Would you consider beginning a named research fund?             Yes     No

Thank you for taking the time to fill out this valuable survey. We value your input and guidance.  
SPSP Board of Directors

Please return to:                      The Society for PSP, Inc.  
1838 Greene Tree Road, Suite 515  
Baltimore, MD 21209

# 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.

Helpful Hints from Ken Hodges

## LIFT CHAIR FOR CAR

I had a special seat installed in my minivan—the seat made by Braun Co. It is called The Braun Companion. It mounts in the passenger's position, swivels outward and extends outboard about 24" enough for the liftee to be lowered onto the seat cushion. The seat retracts and then swivels around to face forward. The extension/retraction is electric-motor driven. This special seat is not installable in sedans and is only compatible with the Ford Windstar, Chrysler Town and Country Dodge Caravan and Plymouth Voyager minivans. The seat cost \$1695 installed in our Windstar, and took them one day shift to install it. Ford rebated me \$1000 under their Mobility Motoring Program.

The Companion Seat utilizes your van's original seat, but replaces the existing base with a unique power base. When not needed, it functions exactly as the passenger seat—making it perfect for active families with only one member needing assistance.

## WHEELCHAIR ADAPTATIONS

My pwps had a problem with slipping down in the wheelchair seat because of lack of friction between smooth surfaces of the chair's seat, 2) the inflatable seat cushion, and 3) the lift sling. I wrapped around the inflatable seat cushion one layer of the rubbery non-slip shelf paper used aboard boats and RV's (available in rolls from Wal-Mart and elsewhere). This has greatly reduced the slipping-down tendency.

## WALKER ADAPTATION

Our front-wheeled walker was delivered with 3" diameter wheels. Uneven sidewalk joints, carpet edges, misjudged unevenness, etc. tended to foster a "toe-stubbing" effect, disquieting to the user. I found that 5" diameter wheels were available, attached to the walker's adjustable lower front leg tubes, and could be quickly installed in place of the smaller ones. They were installed and proved more operationally suitable during the period of walker use.

## COMMUNICATION

Caretakers cannot always be within sight or earshot of the pwps. Wireless plug-in intercom or baby-monitoring units can be used for monitoring and receiving patient calls. When the pwps has limited or reduced verbal capability, low-cost signaling devices we've used at one time or another include:

- A small sports-type whistle on a long ribbon, worn around the neck (cost \$1- \$2 range)
- A bicycle horn, squeeze-the-bulb type, can be mounted on bed rail or wheelchair armrest (cost less than \$4)
- A battery-powered remote door chime—the small push-button unit was glued to a long cord and worn around the neck and the chime unit can be taken wherever the caregiver is, within the home - but be sure to test it before use since there might be dead spots just like with cell phones. (cost about \$10 when on sale in hardware stores; cost in the \$30 - \$60 range when sold as "Personal Pager" via mail-order catalogs)

## FINANCES -(California residents only)

Beginning with taxable year 2000, California will allow a

\$500 non-refundable long-term care credit (per applicable individual) that can be used by State income taxpayers against the net state income tax. It's available to filers whose adjusted gross income is less than \$100,000. Ground rules are published in Form 3504 "Long Term Care Credit," available from the California Franchise Tax Board by snail-mail or e-mail.

## OTHER

I needed to raise a recliner (chair) seat about 4" so my pwps could seat herself more gracefully and arise more easily. A length of 4"x4" redwood was purchased and, after careful measurements and sawing, an open wooden rectangle was nailed together upon which the recliner would rest. Shallow depressions were countersunk in the wood surface to accommodate the recliner's four "feet" for stability. Incidentally, I found the raised recliner more comfortable, too!

Later, I found it necessary to raise our dining room, kitchen, and computer area tables to accommodate my pwps seated in a wheelchair. Blocks about 3" to 4" high to raise the tables' legs were cut from a length of 4"x4" redwood and, where necessary, holes were countersunk in the top surface about 3/4" deep to accommodate the legs "feet" for stability. For appearance's sake, the edges could be rounded and the blocks painted.

*On Sunday, May 20, 2001, Ken's beloved wife, Kathleen Patricia Hodge died. The Society extends its sympathy to Ken and his family.*

## HELP WITH "HELPFUL HINTS" NEEDED

Dear Friends,

This editor needs your help! In addition to the "Helpful Hints" featured in the PSP Advocate, I would like to put together a pamphlet of "Helpful Hints" for future distribution. Persons with PSP, their families and caregivers are very creative and adaptive when it comes to meeting the challenges of PSP. Several of these challenges are listed below. Please take the time to share your ideas, advice, possible solutions and accommodations with other families affected by PSP. Send your ideas to me on a separate sheet of paper and mail it to Nancy Brittingham, 6 Bramston Drive, Hampton, VA 23666, Fax (757) 838-6086 or email NancyB501@cs.com. Many times families impacted by PSP feel isolated and helpless. This is a positive opportunity to assist others and make a difference! I look forward to hearing from all of you and will put together all of your ideas so that you can share them with one another.

## CORRECTIONS

FINGERWEIGHT CORPORATION - 877-734-6437

Fingerweight offers progressive weight resistance training and rehabilitation for the fine motor muscles of the hands with patented "one size fits all" weighted finger rings. Ideal for computer users, arthritics, musicians, and athletes.

TRADEMARK MEDICAL - 800-325-9044

In addition to their Silent Speaker laminated cards used to facilitate communication with those unable to speak, Trademark Medical also offers the Plak-Vac oral hygiene suction device used in nursing homes and in other venues to promote oral hygiene among those unable to maintain a regimen of personal oral hygiene.

# Report Of Gifts - February 1 thru May 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 its difficult challenges.*

## SPECIAL GIFT FOR RESEARCH - \$225,000 STEVE & CAROL POIZNER TO THE ERWIN & PEARL MEMORIAL RESEARCH FUND

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Grady Gafford in memory of Myrtice Gafford  
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# Report Of Gifts

## DONATIONS - PATRONS \$100 AND OVER continued

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# Report Of Gifts

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Ginny Smith in memory of General Clarence Jackson  
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The Society for PSP, Woodholme Medical Building, Suite 515, 1838 Greene Tree Road, Baltimore, MD 21208  
1 (800) 457-4777 1 (410) 486-3330

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 (NEW)
- #22 Challenges in the Management of PSP (NEW)

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

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PSP Advocate, Second Quarter 2001 .....

You Can Help By Becoming A Volunteer

## VOLUNTEER PROFILE

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

Spouse or Significant Other's Name: \_\_\_\_\_

Home Address: \_\_\_\_\_

Home Telephone Number: \_\_\_\_\_ Fax: \_\_\_\_\_

E-Mail Address: \_\_\_\_\_

Business: \_\_\_\_\_ Title: \_\_\_\_\_

Business Address: \_\_\_\_\_

Business Telephone Number: \_\_\_\_\_ Fax: \_\_\_\_\_

Your occupation and job responsibilities: \_\_\_\_\_

Board Memberships & Professional Organizations: \_\_\_\_\_

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Personal Interests/Hobbies: \_\_\_\_\_

Areas of Experience or Expertise:

- |   |   |   |
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THE SOCIETY FOR  
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Progressive Supranuclear Palsy

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