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Society for Progressive Supranuclear Palsy

PSP Advocate

Official Newsletter of the Society for Progressive Supranuclear Palsy, Inc. (SPSP)

David and Reba Saks, Founders

EYE MOVEMENT STUDIES IN PROGRESSIVE SUPRANUCLEAR PALSY

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There are cells in the brain called extraocular motoneurons which have long nerves connecting them directly to the eye muscles. When these motoneurons are activated the eyes move. Over the last 25 years, brain research has been able to demonstrate several different regions of the brain which have fine nerve connections with the extraocular motoneurons and generate eye movements by activating the motoneurons. The pathways in the brain controlling eye movements are comparatively well understood. In human beings, there are at least 5 different types of eye movements. Each type is controlled by different parts of the brain, and relatively separate neural networks, which eventually all project onto the extraocular motoneurons to move the eyes. This means that one type of eye movement can be affected by brain damage leaving the others intact.

The different types of eye movements are: rapid jumps of the eyes, called saccades, where the eyes move rapidly from one fixation point to another: these are used during reading, or looking downwards when you go down stairs. There are another type of eye movements which are used when the eyes follow a moving object, called smooth pursuit. Slow automatic adjustments of the eye position when the head moves are called vestibulo-ocular reflexes: and there are similar so-called optokinetic-reflexes when the whole field of vision moves, as is the case when one is on the train, or even walking along the street. Finally, there are vergence eye movements which move the eyes in opposite directions and are used to focus on a near object.

In progressive supranuclear palsy (PSP), the rapid eye jumps (saccades) become slowed or impossible, particularly in the downward direction. The other types of eye movements remain normal at early onset. This is why persons with PSP often complain that they have difficulty walking downstairs or reading. Several studies on the saccade pathways in cases of PSP have been carried out and others are still in progress. One fact that seems clear from these eye movement studies is that the degeneration of nerve pathways in PSP spreads along the chains of nerve

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BEHAVIORAL PROBLEMS IN PSP

By Irene Litvan, M.D.
Chief, Neuropharmacology Unit
Defense and Veteran Head Injury Program
Henry M. Jackson Foundation

Studies show that persons suffering from progressive supranuelear palsy (PSP) frequently have alterations in mood and personality. These changes, particularly if unrecognized, may influence the burden that caregivers experience. In fact, it has been shown that neuropsychiatric disturbances predict caregiver depression and burden. Although study of this aspect of PSP has been neglected, we believe that the identification, treatment and understanding of the behavioral abnormalities patients experience may improve the quality of life for both PSP persons and their caregivers.

To evaluate these problems we administered the Neuropsychiatric Inventory, a tool with established validity and reliability, to assess the behavioral symptomatology of 22 patients with PSP, who kindly came to the NIH for testing and compared them to 50 patients with Alzheimer's disease, and 40 controls. Almost all the PSP patients we examined exhibited apathy (91%). Disinhibition and impulsive behavior occurred in one-third of the PSP patients, anxiety in 18%, but rarely (< than 9%) patients exhibited irritability, abnormal motor behaviors, or agitation. The apathy of PSP patients was manifested by decreased spontaneous activity (91%), initiation of conversation

The Board of Director's honors Dr. Irene Litvan and her husband, Dr. Jordan Grafman, (Cognitive Neuroscience Section, National Institutes of Health) for all their efforts in organizing the First International Brainstorming Conference on PSP.

Continued Page 4

SOCIETY FOR PROGRESSIVE SUPRANUCLEAR PALSY, INC. (SPSP)

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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. The Society, Director, and staff are under the administration of the Johns Hopkins School of Medicine, Department of Neurology.

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PSP Advocate

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(In memory of Henry and Jane Ogiba)

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The Director's Doings . . .

It takes a village...

As I consider all the love and resources necessary to raise a child into a happy, self fulfilled and productive adult, I see parallels for our organization. The Society for PSP, just as a child, is totally dependent on those persons who are committed to its success. We depend on donors who believe in our mission so that it can sustain our educational and research programs as well as our operations. We depend on vendors and other community resources to recognize our mission and to provide quality services to PSP families. We depend on governmental policies to protect our non-profit status. Most importantly, we look to our Board of Directors and a growing body of volunteers for their innovative guidance and oversight including their time and talents. All of these resources have catapulted our organization over the past ten years.

We need teachers and mentors, too! How do board members and staff learn the most innovative technologies for managing our organization? Fortunately, we have a "village" of resources, to guide us in ways to promote our organization's mission.

As a member of the Maryland Association of Non-Profit Organizations (MANO), we take courses on non-profit fiscal and organizational management as well as board development and board excellence.

The Johns Hopkins University provides us with human resource and benefit administration as well as computer technology classes and career education.

The National Organization for Rare Disorders, an organization representing 1200 of the over 5000 rare diseases, provides board development and technical assistance as well as making others aware of PSP through its data base and informational activities.

Goucher College of Continuing Studies provides me with courses on fundraising, board building and program development expertise. In June, 2000, I will receive my "Certificate in Fund Raising Management," a two year, ten course program.

The National Society of Fund Raising Executives and Baltimore Public Relations Council provides local and national resources and training in development and external relations

Yes, it takes a bevy of people—volunteers, staff, board, allied organizations, teachers, and mentors to help the Society thrive. "Our Village" has built our success! As we grow, we will need a " Country"' of resources. WATCH US GROW!

Ellen Pam Katz
Director, SPSP

The Society for PSP Thanks Walter Welch

Walter Welch has been recently recognized by The Society for PSP for his many years of service as a member of the Board of Directors. Walter has been vital in promoting the mission of the Society since 1991. He created the original computer data base for the Society's informational and business mailings. Walter was asked, "What advice would you give to others on how to raise awareness of PSP?" He replied, "I would encourage everyone to use every opportunity to spread the word about PSP. I try to use every chance. For example, I persuaded my local police department to include PSP in their training of new officers. Each time you tell a person about PSP, they tell two or three other people. I have continued work with our local Parkinson's group and do their data base. From time to time, I am invited to talk to a group about PSP. Be sure to tell people about The Society for PSP, which provides information, education, support and advocacy to persons with PSP, their families and caregivers. The Society also educates physicians and allied health professionals about PSP and how to improve patient care and promote research in finding the cause and cure for PSP. We must all share this information, join a support group and support the Society. But, most of all - DO NOT GIVE UP!" Walter lives in Florida and continues to serve his community by volunteering in elementary schools keeping their computers in repair, teaching several computer classes and organizing computer clubs. The Society thanks this dedicated volunteer for his many years of service and knows Walter Welch will always remain a "Special Friend" of The Society for PSP.

Walter Welch is presented a gift in honor of his years of service by Joanne Armstrong, SPSP Vice Chairman and George Jankiewicz, SPSP Chairman.

PROGRESSIVE SUPRANUCLEAR PALSY AND CORTICO-BASAL DEGENERATION

Huw Morris, Research Fellow
Institute of Neurology
Queen Square
London, England

Cortico-basal degeneration (CBD) is probably the most closely related disease to PSP and some doctors argue that they are variants of the same condition. Like PSP, CBD attacks areas in the base of the brain which control eye movement and balance and complaints of difficulty with vision and of falls are common in the early stages of both conditions. Unlike PSP, CBD also affects areas of the brain which control 'higher function' related to movement and sensation, usually asymmetrically. Commonly, persons with CBD complain of difficulty in controlling or using one hand, although the strength and sensation in the hand are normal. This appears to result from breakdown of the semi-automatic motor routines that we use in everyday life to put many complex individual muscle movements together into a highly skilled movement like writing or tying up a shoelace. Damage in closely related parts of the brain can cause irregular muscle jerking called myoclonus or very occasionally the loss of control of the hand can appear to make the hand have a mind of its own. Similar phenomena can occur in the legs. The type of nerve cell damage in the brain is very similar and the type of abnormal tau protein laid down is identical to that seen in PSP.

Not all persons with CBD have these very typical features outlined above and similarly persons with PSP can often have some of the CBD type features in a mild form. Studies of the process of making diagnoses by expert neurologists indicated that CBD and PSP are the conditions which are most likely to be confused. While it is important to have the most accurate diagnosis possible, usually the treatment of both of these conditions involves attending to 'symptomatic' problems - difficulty with tasks around the home, poor safety with walking, swallowing and so on. Working out the relationship between CBD and PSP is very important in investigating the disease process and this work is very much advanced by examining brain tissue after death. We would encourage all patients and their carers to consider becoming brain tissue donors in order to improve the knowledge and treatments available for future generations and to help resolve the types of symptoms and nerve cell damage seen in these conditions. *(Reprinted from the Europe PSP Bulletin/Fall 1999. Both sister PSP organizations have reciprocal permission for reproduction of information.)*

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.

Behavioral Problems in PSP continued from Page 1
decreased spontaneous activity (91%), initiation of conversation (86%), and interest (64%) and was not associated with the duration of the disease. Some caregivers noted that their relatives became less active and less likely to initiate a conversation even before motor or ocular-motor problems were evident.

In practice, PSP patients' apathy is often mistaken for a depressive disorder and they are frequently but unsuccessfully treated with antidepressants. Differentiation of apathy and depression may help focus therapeutic interventions in PSP. The apathy PSP patients experienced was significantly associated with specific neuropsychological problems, suggesting that both are caused by abnormalities of the frontal lobe or frontal-subcortical connections and that apathy is part of the disease. The presence of high apathy and low agitation and anxiety scale scores correctly identified with PSP patients 85% of the time. This study suggests that evaluating the behavioral abnormalities of people with PSP will aid diagnosis and facilitate better management.

Sue Dagert, SPSP Development Consultant, Carol Marchi and Dale Ferris, Society Board members, attend a dinner in honor of Irene Litvan, M.D.

Stan Levin, Society Board member, with his wife, Isabel, and Albert Katz, dedicated Society supporter and devoted husband to the Society's Director, Ellen P. Katz.

REMEMBER THE SOCIETY FOR PSP IN YOUR WILL

Extend your support of the Society's programs beyond your lifetime. No matter what size, large or small, your gifts will continue to support our programs of education, service, support, advocacy and research.

To make a bequest of cash or other property to The Society for PSP, your will or supplemental codicil should state: "I give and bequeath to The Society for PSP, Inc., a non-profit corporation, organized under the laws of the State of Maryland, and having its main office at Woodholme Medical Building, Suite 515, 1838 Greene Tree Road, Baltimore, MD 21208, the sum of $_____ or _____ percent of the residue, rest and remainder of my estate to be used for the general purposes and mission of the organization."

A bequest to the Society is fully deductible for estate tax purposes. To learn more about opportunities for giving, consult your attorney, accountant, estate planner or call our office. Thank you for the gift that keeps giving.

MORE 1999 SOCIETY FOR PSP RESEARCH GRANT RECIPIENTS

See The Advocate, 2nd Quarterly, 1999 for additional 1999 Research Grant Reviews

Ultrastructural and Biochemical Heterogeneity of Paired Helical Filaments in PSP

Hanna Ksiezak-Reding, Ph.D.
Albert Einstein College of Medicine
Bronx, NY

Progressive supranuclear palsy (PSP) is one of the neurodegenerative disorders characterized by the presence of abnormal protein aggregates, or clumps, in the brain. These aggregates are made of tau protein and are designated as "paired helical filaments". In normal brain, there are six forms of tau protein present. They are necessary for transport of organelles and nutrients in cells. Under pathologic conditions or with certain genetic abnormalities, normal functions of tau are disturbed and tau becomes aggregated. In our studies, we will determine which of the six forms of tau are preferentially aggregated in the brain cells of PSP patients. We propose that the forms of tau most likely to aggregate into clumps are unique for each type of the brain cells. In order to prove or disprove this idea, we will examine various regions of the brain where tau aggregates in PSP, using the electron microscope to study the shape, size and twising pattern of the tau filaments in the aggregates.

We postulate that these features will depend on which of the six forms of tau aggregate in a given cell and on the type of cell where the aggregate occurs. This could help understand what goes wrong in the production of tau protein to produce damage in some brain cells but not in others and could therefore point to ways of preventing such defects.

Supported by the Dorothy and Jerome Blonder PSP Research Fund and the Harold and Barbara Fox PSP Research Fund ($20,000)

PROBLEMS OF CELL DEATH IN PROGRESSIVE SUPRANUCLEAR PALSY

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The causes of brain cell loss in PSP and related neurodegenerative disorders are unknown. Recent studies have raised the question whether "apoptosis", a specific form of gene-directed programmed cell death, represents a major mechanism in the selective degeneration of specific nerve cell populations. This type of cell death can be detected under the microscope in brain tissue by recently invented methods that demonstrate fragmentation of DNA and the production of cell-death-regulating proteins. Recent studies in Parkinson' s disease (PD) and Alzheimer's disease (AD) suggest an increased vulnerability of certain brain regions to apoptosis. In AD, increased DNA fragmentation has been demonstrated in neurons affected by neurofibrillary tangles, one of the pathologic hallmarks of AD, formed by pathologic tau protein aggregations in neurons. In PSP, another type of tau protein is deposited in many brain cells, but it is still unclear whether these tangles of protein in the brain cells actually contribute to their death or are just products of the process of cell death.

The present study will examine the incidence and distribution pattern of DNA fragmentation involved in brain areas in autopsy-confirmed cases of PSP and will check for the presence of apoptosis-related proteins and stress proteins that are known to be involved in cell death. To examine the relationship between DNA fragmentation and the tau protein deposits, we will look for differences between brain cells with deposits of tau protein and those without such deposits. This could shed light on the mechanisms of brain cell death and the distribution pattern of increased brain cell vulnerability independent of whether tau deposits are present. If the tau deposits prove to be necessary to the degeneration of the cell, then treatments that dissolve the deposits may be useful in preventing PSP. On the other hand, if cells without the deposits show signs of DNA fragmentation, then dissolving the deposits would not help PSP significantly and other methods of preventing apoptosis would have to be sought.

Supported by the Eloise H. Troxel Memorial PSP Grant and Fellowship Program ($18,000)

MUTATIONAL ANALYSIS OF THE TAU GENE IN PSP

Joseph J. Higgins, M.D.
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Abnormal forms of tau protein are present in the brains of individuals with several neurodegenerative diseases including progressive supranuclear palsy (PSP), Alzheimer's disease, Pick's disease (which produces a different sort of dementia than Alzheimer's disease that is closer to the type of dementia found in some cases of PSP) and corticobasal degeneration (a degenerative movement disorder very similar to, but even rarer than PSP). Recently, mutations in the tau gene were found to cause familial Pick's disease. In our investigations to find a genetic cause for PSP, we demonstrated that a variation in the tau gene was common in a group of unrelated individuals affected by PSP. These results suggested that mutations in the tau gene, or in a gene in close proximity on the same chromosome were responsible for causing the disease. We have looked carefully at certain regions of the tau gene and found areas of the gene that may have an important role in predisposing individuals to develop PSP. These preliminary findings are being confirmed in

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Mutational Analysis of the Tau Gene in PSP
Continued from Page 5

a larger patient population and further studies are being conducted to determine exactly what effects these genetic alterations have on the expression of the tau gene. The goal of this research is to conclusively identify mutations in the tau gene in patients with sporadic PSP by molecular analysis. The results of this research may help us understand how tau causes neuronal degeneration. These efforts may refine the diagnosis of PSP and aid in the development of new treatment strategies intended to alter how brain cells work with tau protein.

Supported by the Eloise H. Troxel Memorial PSP Grant and Fellowship Program ($20,000)

ACTIVITY AND EXPRESSION OF ANTIOXIDANT ENZYMES IN THE PSP BRAIN

Sarah Jane Augood, M.D.
Massachusetts General Hospital/Harvard Medical School
Boston, MA

Although the cause of PSP is unknown, genetic studies have identified variations in the gene that makes tau protein. In the PSP brain, the abnormal deposits of tau protein contain a form of tau that has too much phosphate attached. Normally, this happens as an old or defective protein is being prepared by the cell for disposal. The normal cell removes excessive phosphate from normal protein. The excessive phosphorylation of tau in PSP suggests that there may be a defect in that process in people with PSP. One theory that has been proposed to explain excessive phosphorylation of tau is that excessive oxidation ("oxidative damage") to fatty constituents of the cell (called "lipid peroxidation") renders tau resistant to removal of phosphate. This finding coupled with our recent biochemical finding of a marked increase in lipid peroxidation in the PSP brain links an oxidative event to hyperphosphorylation of tau. Thus, in this study, I will investigate whether the brain cell loss in PSP is associated with impairment of the cell's normal ability to counteract oxidation. I hope that this work will provide further insight into the way brain cells degenerate in PSP and may suggest treatments, as with antioxidant drugs, that may retard the progression of this disease.

Supported by the Margaret Parker PSP Research Fund ($20,000)

ARE IMPAIRMENTS OF ENERGY METABOLISM CONTRIBUTORY IN PSP?

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Boston, MA

The mitochondria are sub-units in most cells of the body, including the brain, that have the job of producing energy from oxygen and sugar. A growing body of evidence implicates defective function of mitochondria in a number of neurodegenerative diseases, including Parkinson's disease, Alzheimer's disease and Huntington's disease. Although the cause of PSP remains unknown, recent data from our laboratory suggests an "oxidative stress," (a chemical imbalance that can result from defective mitochondria) contributes to brain cell loss in PSP. There are a number of possibilities that might explain why increases in oxidative damage occur in PSP - one possibility is that mitochondrial defects increase production of free radicals, a group of very damaging chemicals that the body normally produces as byproducts but disposes of quickly. The type of free radicals we suspect as having a role in PSP are called "reactive oxygen species." Thus, we propose to examine in detail the function of mitochondria in brain tissue from persons with PSP and also in cells growing in the laboratory that have been genetically engineered to act like brain cells from people with PSP. This study should shed important insight into the mechanisms of cell death in PSP and may facilitate the development of new, improved therapies to treat this debilitating movement disease.

Supported by the Eloise H. Troxel Memorial PSP Grant and Fellowship Program ($20,000)

Sarah Augood, M.D. and David Albers, M.D.

Grant Announcement:

The Society for PSP announces:
The Annual Eloise H. Troxel Memorial Grant and Memorial Fellowship, each of $50,000 for research in PSP. Deadline, October 1.

Regular Grant Program to $20,000
Deadlines are April 1 and October 1.

For information contact:
Dr. Lawrence I. Golbe,
Chairman of the Medical Advisory Board
at golbe@umdnj.edu or Fax 732-235-7041.

Eye Movement Studies In Progressive Supranuclear Palsy
Continued from page 1

brain region called the superior colliculus - a structure essential for orienting the eyes, head and body towards any startling sight or sound - and that this could be the route through which the saccadic eye movement system becomes affected in PSP.

In PSP, eye movements are always affected and these changes are relatively easy to measure. In addition, the nerve pathways responsible for eye movements are well known. Therefore, studies of eye movements may be particularly helpful in working out why only some nerve pathways, but not others, are targeted by the disease; or whether the damaged pathways have a common chemical characteristic (e.g. neural transmitter), or how the disease travels along the pathways. Measuring eye movements could provide a sensitive test for research into new medications that may prevent its' progress.

Congratulations to Dan Lake, member of the Society's Board of Directors, and Bonnie Barker, former Society's Administrative Assistant, on their recent marriage in September

CONGRATULATIONS!!

The Society for PSP congratulates our Director, Ellen Pam Katz, for her appointment to the Board of Director's for the National Organization for Rare Disorders. This prestigious appointment will give Mrs Katz the opportunity to serve thousands of individuals affected with rare disorders through a federation of over 140 not-for-profit voluntary health organizations. Congratulations, Ellen!!

National Organization for Rare Disorders (NORD) and The National Institutes of Health Office of Rare Diseases 1999 Annual Conference

Ellen Katz, SPSP Director, and Nancy Brittingham, SPSP Editor, attended the NORD Annual Conference that was held September 30-October 3, 1999 in Arlington, VA. "NORD is the only organization of its kind, a unique federation of more than 140 not-for-profit voluntary health organizations serving people with rare disorders and disabilities. Thousands of affected individuals and their families, as well as support groups, health care and human service professionals, and advocates for people with rare disorders and disabilities rely on NORD's assistance and leadership. The National Organization for Rare Disorders' mission is to help people with rare "orphan" diseases and assist organizations that serve them. NORD is committed to the identification, treatment and cure of rare disorders through programs of education, advocacy, research and service."

What is a Rare Disorder?

"A rare or "orphan" disease affects fewer than 200,000 people in the United States. There are more than 5,000 rare disorders that, taken together, affect approximately 20 million Americans. One in every 12 individuals in this country has received a diagnosis of a rare disease. Since its inception in 1983, NORD has served as the primary non-governmental clearinghouse for information on over 5,000 rare disorders. NORD also provides referrals to additional sources of assistance and ongoing support."
Internet:www.rarediseases.org/welcome.htm)

The conference was directed for two tracks:

Track 1 addressed the concerns of individuals, families and friends affected by a rare disease. "How can I effectively communicate with my health insurance company? How can I cope with my health condition while dealing with the daily battles of family relationships, caregiving, social isolation and all the non-medical aspects of living with a rare disease?"

Track 2 provided training for leaders of voluntary health agencies to learn how to be more effective, conform to the rules and regulations of non-profit organizations and ways to avoid wasting precious resources by reinventing the wheel. Providing mutual support and learning how to raise funds for research was discussed.

NORD President, Abbey S. Meyers, stated, "Together we will learn new skills, empower ourselves, inspire each other, make new friends and return home knowing that we are not alone. NORD is committed to making the world a better place to live by ensuring that the medical and social progress of the 21st century will eradicate the obstacles that people with rare disorders still face in their daily lives."

Change In Membership Dues

The revised SPSP bylaws state that there will no longer be membership dues. As a nonprofit health organization, SPSP is solely dependent upon the financial contributions of our friends and supporters to sustain our research, education, and outreach programs. Your contribution is tax deductible.

If you wish further information about the SPSP bylaws, please call the SPSP office at 1-800-457-4777

Actor, Composer and Pianist Dudley Moore Receiving Treatment for Progressive Supranuclear Palsy

Dudley Moore, age 64, is being treated for PSP by a team of doctors including Dr. Lawrence Golbe of UMDNJ-Robert Wood Johnson Medical School, New Brunswick, NJ; Dr. Stephen Reich of the Johns Hopkins University School of Medicine, Baltimore, MD; Dr. Martin Gizzi of the NJ Neuroscience Institute at JFK Medical Center, Edison, NJ; and Dr. Thomas Galski at Kessler Institute for Rehabilitation, West Orange, NJ.

Mr. Moore said, "I have come forward to tell my friends and the public that I am being treated for a disease closely related to Parkinson's. I hope that by revealing my illness today, I can bring attention to this rare malady that afflicts thousands of people, many of whom remain undiagnosed. I wish to raise public awareness of the critical need for medical research and education on behalf of all those with this disease who struggle to continue leading productive lives. I would also like to thank my dedicated physicians who are working to help slow the progression of my symptoms."

At this time, Mr. Moore is able to walk unassisted but prefers using a cane for stability. He is maintaining a regular daily routine with normal mental functioning and a positive attitude. Under the supervision of Dr. Thomas Galski, Mr. Moore is undergoing a comprehensive program aimed at improving physical and cognitive functioning. He is also participating in an experimental drug therapy program.

Comments about Dudley Moore from Dr. Stephen Reich include, "I admire Mr. Dudley Moore for having the courage to go public with the diagnosis of progressive supranuclear palsy. By doing so, he not only brings attention and additional support to his own plight, but also brings wider attention to the orphan disease, PSP. I saw Mr. Moore for the first time in January of 1998 at which point it was clear that something neurological was going on but that something was not clear. By the time I saw him in follow-up in Feb. 1999, the diagnosis of PSP was apparent." In the meantime, the most important clue about the diagnosis came from Drs. Martin Gizzi and Michael Rosenbrerg at the New Jersey Neuroscience Institute. Using a technique known as infrared video oculography, they were able to measure the speed of Mr. Moore's eye movements. This demonstrated that his vertical eye movements were very slow and this is one of the earliest features of PSP but often difficult to appreciate clinically.

Dr. Lawrence Golbe stated that Mr, Moore has been seeing him for care of his PSP since May, 1999. Mr. Moore is currently enrolled in a double blind trial of the drug pramipexole, which is suspected of being able to slow the rate of progression of the brain cell degeneration that occurs with PSP. This study is being performed in collaboration with Robert Wood Johnson Medical School in New Brunswick and Yale University School of Medicine where an experimental type of brain scan called "beta CIT SPECT" monitors the function of the brain cells that are affected in PSP.

Dudley Moore was first seen by Dr. Martin Gizzi in Feb. of 1996 after he was experiencing balance problems. It was later that he was referred to Dr. Reich at Johns Hopkins for treatment and monitoring for progression of the disease.

In a lighter moment, Mr. Moore commented that "I understand that one person in 100,000 suffers from this disease and I am also aware that there are 100,000 members of my union, the Screen Actors Guild (SAG), who are working every day. I think, therefore, it is in some way considerate of me that I have taken on the disease for myself, thus, protecting the remaining 99,999 SAG members from this fate."

GIVING A GIFT OF SECURITIES

The Society for PSP is a non-profit 501-3(C) organization that exists to promote and fund research into finding the cause and cure for PSP. The Society is exempt from income taxes in the United States. We are able to sell donated securities and use every dollar to enhance our research funding, services for people with PSP and their families, educational programs, and advocacy for all affected by PSP

Transferring listed securities to the Society for PSP is quite easy. You simply have to mail the stock certificate or bond to our office. In a separate envelope, you must mail us the executed stock or bond power. Your generous gift will be valued on the postmarked date for tax purposes. If the stock or bond is with a brokerage account, inform the broker that you want your securities on an account for the Society for PSP. The broker must then call our office and the securities will be transferred by him/her. This usually occurs the same day that you instruct the broker to make the transfer.

Please consider a gift of securities. Each dollar will help people with PSP. We are the largest network of individuals dedicated to helping find the cause and cure for PSP and improving the quality of life for persons with PSP. Please join us in this challenge! Contact our office at 1-(800)-457-4777. Thank you friends of the Society and "ADVOCATES" for those suffering through the hardships of progressive supranuclear palsy.

PSP Golf Tournament in Memory of Frank Panunto

Under skies streeped with soft pink and gray clouds and wild geese gracefully soaring, Tim O'Gorman spon - sored his first golf tournament to raise funds for the Society for PSP. The perfect weather and great comradery among Tom's friends and coworkers contributed to a turnout of 120 persons at the Chantilly Golf and Country Club in Rising Sun, MD. They came to honor the memory of Frank Panunto who died of PSP. Tim, whose best friend is Frank Pamunto, Jr., watched the progressive degeneration of his best friend's dad and wanted to do something special for the family. Frank's Sr.'s wife, Teresa, and son Frank, Jr. were on hand when Tim of O'Gorman's Battle Caps Bar and Restaurant of Wilmington, Delaware, presented a check for $1800 to Joanne Armstrong, vice-chairman of the Society. The funds are designated to help underwrite the November symposium. Many thanks, Tim, for your splendid gift made under such splendid skies. The Society appreciates that you wish to make this an annual event!

THE STORIES OF PEOPLE AND PSP

Dear Friends,

I am hoping to compile a broad cross section of personal stories that encompass the family of progressive supranuclear palsy. 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 take this opportunity to share and care. Each of our stories will be filled with courage, creativity, and perseverance.

Please send your "stories" to me via: email:103301.640@compuserve.com OR 6 Bramston Drive, Hampton, VA 23666

Praying for a cure,

Nancy Brittingham, Editor, The Society for PSP

Dear Nancy,

I just ran across something in my husband's room that I thought worth sharing. My grandaughter, 15 years old at the time, was assigned a paper to do at school and decided to do it on her grandpa. She submitted it as her lesson but also sent it to him on Father's Day a few years ago. We, of course, saved it. It follows. I wanted to share it. We thought is so lovely.

Grandpa Bowers

In the spring of 1981, my family, including my dad and mom, my twin brother Kyle, and my grandparents, took a vacation up to our lovely log cabin in Vial. That week I saw my grandpa's inner beauty. During our stay, I was 4 years old and I loved to climb to our loft on the ladder. On one occasion, I suddenly lost my grip and hit my head on the ladder cracking my skull. I can remember vividly my grandpa caring for me. His strength and his reassuring words helped me through my accident. After this time of comfort, I always believed in him.

"Let's go catch some fish, grandpa!" my twin brother and I pleaded while pulling on his arm. My brother and I always loved when our grandpa visited us. It meant he would teach us his secrets of fishing. He was the best fisherman in the world.

"Be quiet kids, or you'll scare the fish", my grandpa warned us firmly. We untied the rope and started to push off the dock. My brother and I realized we were venturing off into our own little world. A world of peace known only to us. As we steadily took off into the midst of Grand Lake, our eyes brightened with anticipation. The excitement increased when we put our bait on the hook, casting with our fishing pole and finally reeling our lines in. Most of all, I liked the attention we got from him helping us. At that moment, I respected my grandpa with all my heart. I knew that when we came back without fish he would not care and would still believe in us no matter what. He was so smart and I knew he loved us tremendously.

Years passed and he had long since retired. He told me of his heroic deeds of saving lives during rescues and putting out fires. My grandpa was a humble fireman for all of his life. I am so proud of my grandpa, a person who does not need gratitude, who is not famous or on the television and has such a fulfilling life. He has made a difference and had an obvious purpose in life.

Although we live far away from each other, our strong bonding is recaptured on our short, yet meaningful visits. Such little things as teaching me how to cook a Mexican pizza or our joking about him pulling a wheelie in his wheelchair means so much to me. He has shown me a wonderful outlook on life. My grandpa has taught me that I do not have to be famous to be a worthwhile individual who makes a difference in the world.

Now my grandfather has progressive supranuclear palsy. It is a rare, progressive, neurological disease that has rendered him nearly helpless. He has strength and perseverance as this disease progresses. Throughout the years it has been persistently detrimental to my grandpa. It has made this man take many steps backward in the process of moving forward. My admiration for him is growing stronger than ever. It comforts me on our recent visits because we have become closer. The phone calls hurt me to no end. This hurting starts when I hear my grandpa, who rarely showed strong emotion, break down and cry. I have learned to comfort those who need comforting from my grandpa, who has always been my comfort. I love you, Grandpa Bowers.

Your loving granddaughter, Hailey

"AND THERE WE WERE!"

It was the first week of August; we were at Washington Dulles Airport boarding our United Airlines plane headed for San Francisco. Like many others on our non-stop flight, we were eager to leave the summer heat of Washington and spend some vacation days in the Bay Area. In particular, we also had the special occasion of the wedding of one of our sons, and, in turn, being together with all of our geographically distant "kids" for the first time in six years.

However, unlike others, my husband, Tom, a tall, sixty-nine year old with a sense of humor and an active mind, was in a wheelchair, with a feeding tube carefully coiled under his blue canvas LL. Bean shirt. I carried a portable suction machine (neatly contained in a shoulder strapped case) along with two cans of Pulmocare, his complete nutritional drink, and a syringe (for his "lunch", to be discreetly given). Along with our suitcases, we had a cardboard box with a ten day supply of things my husband would need for his nutrition, safety, hygiene and comfort. Tom is in the advanced stages of PSP and is receiving hospice care; he is unable to eat, walk, dress himself, write or type, read, and has great difficulty speaking. Nevertheless, we were both determined to make this trip. Although I faltered briefly twice between the early planning stages in April and the actual trip in August, I realized I could not give up in the face of Tom's positive attitude and enthusiasm.

I can't say the trip was without considerable effort and planning. So important for each of us were the encouragement, support, and practical suggestions from our family, friends and the hospice team. The Holy Cross Hospice social worker contacted three Bay Area

Continued Page 10

Continued from Page 9
hospice groups and made arrangements for us in case of emergencies (blessedly, there were none). Tom's nurse gave us practical suggestions and kept our senses of humor alive. The hospice chaplain repeatedly shared her faith and deep conviction that "God could not let this trip fail to happen." Our California family and friends took turns visiting and driving us, respecting Tom's need for morning and afternoon naps, as well as early bed times.

No, we weren't able to stay for the entire rehearsal dinner or wedding reception, nor did we eat any of the specially prepared foods during the events. (However, I was given samples to have myself later in the evening and to share a few pureed and strained spoonfuls for Tom to taste the next day). We did get to the informal poolside rehearsal dinner/picnic to meet family and friends of the bride and to spend time with our "kids". And, most importantly, we did get to the marriage ceremony; no video tape or photographs could substitute for being there. And there we were!

Not only did we plan enough time to participate in wedding events, we also decided, since we had flown 3,000 miles, to indulge our mutual passion for the northern California Mendocino Coast; with a daughter and her husband, we traveled north for two over nights. Finally, we also spent two nights in Marin County with a dear friend of Tom's.

Were we crazy to plan a ten day trip 3,000 miles away under the circumstances? Were we incautious? No. The trip was a wonderful goal for us for many months; the joy and sense of accomplishment we felt being there, and returning safety, have left us with feelings hard to describe. We have expressed thanksgiving and gratefulness in our daily prayers. Both Tom and I hope that others with PSP who might have a goal, special event, or wild ideas for travel will find encouragement from our experience and decide to follow their passions and realize their dreams.

Carolyn and Tom Peirce

P.S. My Theme Song is Elton John's "I'm Still Standing"

It was requested in a recent edition of the PSP Advocate to "take this opportunity to share and care" by relating personal experiences with PSP. Well, I have PSP. No one knows how I got this disorder, or why I got it. On top of that, as most of you know, there is currently no known cure for the disease. My association with PSP began in the fall of 1993. The following is my story:

My love in the working world was flying. This love affair began in college and until the time I was forced to quit because of PSP. I had amassed over 5,000 hours of flight time in a variety of airplanes and helicopters. After a number of years with my employer, I was able to work my way into a position where flying was my principle duty. I even managed to rise to the rank of aviation coordinator for my division. After several years in this position, I needed to go into the hospital for some major surgery. It was during my recovery from this surgery that I began to notice a problem with my eyes - they would not go where I wanted them to go. What followed was almost 12 months of trips to various doctors and specialists in futile attempts to find out what was wrong with me. During this time, my speech began to deteriorate and my balance became suspect. Unfortunately, I was unable to work this entire time.

About half way through this ordeal, I used up the last of the sick leave I had accumulated over the years. At this point my fellow employees, some of whom I had very little work experience with, began donating their sick leave to me. We all hoped that a reason for my disability would be found and that I could then be cured. All was in vain, however, when I was finally diagnosed with PSP. One of the main reasons that it took so long to diagnose was that I was only 43 years old at the time the symptoms first began to appear. Shortly after my diagnosis, with over 16 years of service (the last 8 as a full time pilot), I retired.

This is not the end of my story, however. In February of 1997, I was diagnosed with aspiration pneumonia. I was placed in our hospital's intensive care unit where I remained for about 3 weeks. My prognosis was not all that encouraging, but I pulled through - with an addition. I had a tube installed in my stomach through which I was to be fed. Now, my "meals" consist of about 8 cans of a high-calorie liquid food daily. I am allowed to eat "normally" as I see fit, but only for gustatory pleasure. This time I did not need "sick leave", but the number of get-well cards I received was truly amazing. It has become apparent to me that God is not finished with my life on this planet.

I've learned a lot from this illness. While it's true that I've lost the ability to do a lot of the things that I have enjoyed doing (especially flying), I've come to really appreciate those things that I do have in life. I have a beautiful and loving wife, three beautiful and loving daughters, caring family and friends, and a lovely home, to name just a few. I have the ability to enjoy going to church, to events at school and college involving my daughters, to visit family and friends, to movies, to sporting events, to Broadway to see a show, occasionally out to eat, woodworking, swimming, and working with my computer. This list is not all-inclusive either.

The most important thing that I have learned, however, is that you need to develop and maintain a sense of humor. Don't be afraid to smile a lot. Don't be afraid to laugh at yourself. Be a role model. These qualities make it much easier for those people around you. They will not be afraid to approach you, to speak with you, or to learn from you. One other thing - whenever you get to feeling sorry for yourself, just think of all those people who have it a lot worse than you do. Would you rather trade places with them? In closing, let me leave you with this broad variation of a somewhat famous quote - which sums up my way of life - "Some people look at what has happened to them in their lives negatively and wonder, "why?". I look at what can happen to me in my life positively and wonder, "why not!".

Gregg M. Forry
(P.S. My theme song is Elton John's "I'm Still Standing".)

Helpful Hints

Dear Nancy Brittingham,

Thank you for the newsletters. We have used ideas offered in The Advocate. We are so grateful for helpful suggestions. Our son picked up on Dan Lake's grab poles and installed one in our kitchen next to the table where we eat. It seems to be a comfort to Rush who hangs on to it throughout his meal.

Your reading audience should consider checking with their personal neurologist about these ideas. These things have worked for us and under doctor's permission, they may work for others. Our allergy physician prescribed a medication called Guaifenesin to help Rush with his throat congestion and coughing. If offers good relief. We could not make it without a prescribed medication called Lorazepam taken for anxiety. *(From the editor-This medication was also prescribed for my father to help relax his muscles when he went into a coughing or choking spell. It worked quickly in calming the muscular spasms and was our lifeline at times in extremely distressing situations.)* Our neurologist just started Rush on Mirapex. Rush was starting to lunge forward as he walked. Yesterday, I realized that he is no longer doing that. I wonder if it is the Mirapex? He has been taking it for about a month. His walking is by no means normal, though.

The best undergarments I have found are made by Kendall out of Marietta, GA and are called Assurance Premium Slip-On undergarments. Yet, they may not work best for bedridden persons.

We are looking for better ways of helping Rush. I will try to quickly share any discoveries I make. We are enclosing a check for the Society. Bless you all for a wonderful service.

Sincerely,
Dottie W.

Dear Mrs. Brittingham,

Enclosed is information on an extremely valuable bath chair I purchased for my mother. Perhaps other readers of the PSP ADVOCATE would be interested. The company's name is:
ACCESS INDUSTRIES, INC
4001 East 138th Street
Grandview, MO 64030-2837
Phone (816) 763-3100/ 800 925-3100
Fax (816) 763-4467

Best regards, Linda W.

"The Tubmate chair gently lowers you into the water for a relaxing bath (unlike a bath bench). The Tubmate chair swivels to make getting in and out of the tub easier. It comes ready for installation-including a standard shower diverter or optional tub spout with diverter. The lightweight Tubmate attaches to your bathtub with four suction cups. To attach firmly, the tub's surface must be smooth and not have grooved or anti-skid surfaces. It uses simple, reliable household water pressure to raise and lower the chair. There are no electric parts. Water pressure of just 20 psi from your shower head or tub spout provides all the power needed to lift a person in and out of the tub."

Nancy,

My dad has PSP and I am writing so that your readers will be aware of a portable ceiling lift that is available and is not widely known about. Mom and Dad have been using it for 5 years now to lift Dad from his bed to the wheelchair and wheelchair to his recliner chair and back again. Without it, Mom would not have been able to care of Dad by herself at home for so long and -now that he has round-the-clock home health aides-it makes it possible for him to remain home with one aide who is able to move him by herself.

I am enclosing a picture of the ceiling lift which appears on some of the promotional literature I requested from the distributor so that your readers can see what the lift is and how it works. Basically, there is a portable battery-powered motor that hangs from a track in the ceiling and Dad is lifted in a "sling" that is attached to this motor. (You can install the track in however many rooms you want to use and move the portable "motor" from one room to the other.)

The name of the company that manufactures the lift is Barrier Free Lifts, Inc. and the toll free number of their home office in Virginia is 1-800-582-8732. Someone at this number can provide the name and phone number of a distributor/dealer in every state. Their website address is http://bfl-inc.com

The equipment might seem expensive, but this lift has been INDISPENSABLE to Dad's care at home.

Sincerely,
Ed K.'s daughter, Linda

Dear Nancy,
My mother has recently begun using a thickening agent. I checked back to the 2nd quarterly ADVOCATE newsletter and discovered many other types. I am buying a brand called Thicken Up. It is mailed directly to me through a distributor called TAD Enterprises. It costs $3.50 plus shipping for an eight ounce can. I bought a case for $42.00 plus $8.10 shipping. This works out to approximately $4.18 per can and it is delivered to your door. I hope this is of help to someone.
Thank you,
Sue S.

Editor's Note: This information is provided as a service. The Society for PSP does not endorse these or other products and neither the Society nor its staff have financial interests in these products. Information is offered with the intention to inform others about products that may help to maintain independence and improve the quality of life.

If you have any helpful hints, medical devices, equipment, or services you can recommend to other PSP families and caregivers, please write:
Nancy Brittingham, Editor
PSP Advocate
Woodholme Medical Building
Suite 515
1838 Greene Tree Road
Baltimore, MD 21208

or
Fax: 757-838-6086
email:
103301.640@compuserve.com

CAREGIVER INFORMATION

Family Caregiver's Guide:
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By Joan Ellen Foyder

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By Sefta Kobrin Pitzele

This book offers practical strategies and inspiration to people with chronic illness.

708 Broadway, New York, NY 10003
(212) 254-5900
ISBN: 0894801392 $10.95

A letter in response to the publication of Alice Kitchen's article "A Good Death" in the 2nd Quarterly PSP Advocate, 1999, Vol. 10, No. 2

Dear Alice,

The last line of your essay "A Good Death" in the second quarterly 1999 edition of the PSP Advocate struck me and I felt the need to write to you. My husband Cal, who had PSP, died on June 9, 1996, exactly one year earlier than your Ron. As in Ron's case, Cal also refused the feeding tube when it was suggested by his doctor. Cal had just turned seventy and we had been married for forty years. He struggled valiantly with PSP for seven years.

I was moved by your concept of a "good death" as meaning that you and your family were with Ron, at home, attending to his final journey. Our family felt the same way and managed to be with Cal in a home setting during his final days. This was a great challenge for us because Cal and I lived in Florida and our children and grandchildren were in Colorado. I made arrangements for Cal to be in a Colorado Veteran's Hospital for a few months so that our children could visit him and I commuted from Florida until the last month of his life. Hospice then helped us bring Cal into our son's Colorado home. We are all grateful that we were able to be with Cal in a home setting during his final days. I agree that dying alone in the hospital environment can sometimes lack humanity, dignity and meaning.

Thank you for your article,
Lee G.

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Videotape: Society for PSP/NIH Brainstorming Conference

I wish to order the March 18-19, 1999 videotape "Highlights of the SPSP/NIH Brainstorming Conference" featuring Irene Litvan, M.D. and John Steele, M.D. The tape contains a layman's review by Dr. Litvan of the research topics discussed at the Conference. Patient/family issues are presented by Dr. Steele during his visit to Baltimore on March 20, 1999.
COST: $25 + $3 postage US and $5 outside US.

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Support Group News

The Society would like to thank the following Support Group Leaders and Communicators who take their time and show their concern by sponsoring support groups, phoning and visiting PSP families. Please reach them at:

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Christina Watts, Asst. Coord.
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Myrtle Beach, SC 29577
843-445-1647

Continued Page 14

"Special Letters"

My grandma was diagnosed with progressive supranuclear Palsy about 2 years ago. The thing that kept her alive was my Bat Mitzvah on May 29, 1999. But when it came, she was too weak to make it to the services. She passed away about two weeks later on June 15, 1999.

I have seen the effects of this illness up close and personal. My grandma was as strong as she could be but she was not strong enough to overcome this terrible disease. Watching her die from this was one of the saddest and hardest things that has ever happened to me.

Enclosed with this letter is a check for $300. It is to help find a cure and to prevent others from dying. I earned this money from my Bat Mitzvah and I thought it would be best if it went to finding a cure. I hope this can help you with your research.

Sincerely,
Mandy Benardout
Age 13

Mandy and her grandfather

SACRAMENTO VALLEY PSP SUPPORT GROUP

The Sacramento PSP Support Group had its first meeting in January, 1999. We had 4 people attending our meeting. We now have grown to 16 members. We meet every four to six weeks. We are making every effort to let everyone know that we are here for support and information. For more information or questions, please call: Carol Platt (916) 332-6041 or FAX (916) 332- 6606.

Support Groups Continued from Page 13

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THE SOCIETY FOR
PSP
Progressive Supranuclear Palsy
1990-2000
A Decade of Caring

Keep a careful watch as you await the 1st Quarterly PSP Advocate for the Year 2000!! We are celebrating a "DECADE OF CARING 1990-2000" with a new Society look and Society logo. It will be printed on WHITE (not the usual yellow) paper so make sure you keep a look out for it. We would not want you to miss it!

!

Yes! I wish to be included on the Society for PSP's mailing list.

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Thank you for your TAX-DEDUCTIBLE contribution!
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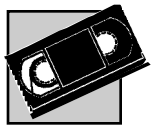
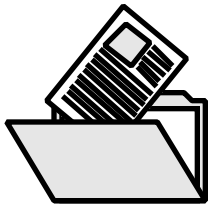


"The Diagnosis of PSP" (#2)	Made for and sold only to neurologists, neuroscience nurses and similar professionals. The tape depicts presentations on diagnosis of PSP at the International Scientific Conference in Barcelona. Recommended for clinicians and faculty. VHS format, U.S. $30, prepaid.
1999 Symposium (#17)	Captures the presentations at SPSP's 1999 symposium for patients, family members and caregivers. See and hear Drs. Steele, Golbe, Reich, Zee, Litvan, Riley, Laura Verdun and several other experts discuss various aspects of PSP. Call the office for information.

Pamphlets



"PSP: Some Answers" (#1)	This is a highly regarded, widely circulated discussion of PSP by Dr. Lawrence I. Golbe that is easy to read, and easy to understand. Recently revised, and printed in booklet form.
"The PSP Advocate" (Newsletter) (#4)	PSP Advocate, the popular quarterly published by SPSP to chronicle its activities, keep you up-to-date on PSP research, provide a support forum, inform readers on participation in research studies, and tell you about support opportunities through advocacy.
"PSP: Swallowing Problems" (#6)	This pamphlet deals with one of PSP's most critical problems. It offers recommendations for managing the symptoms and suggestions for avoiding its dangers.Written by Laura Purcell Verdun, M.A., CCC (Research Speech Pathologist).
"Personality Changes in PSP" (#7)	Some PSP patients undergo changes in personalty and behavior that bewilders family members and caregivers. This pamphlet discusses the problems and offers suggestions.
"Helping The Helpers Who Care For People With PSP" (#8)	Dr. Stephen Reich discusses the vital role of the caregiver in PSP. He offers important advice for self care in the interests of the patient.
Eye Movement Problems in PSP (#9)	Dr. David Solomon explains how PSP affects the eye motor system and suggests some treatments.
PSP Fact Sheet (#11)	8 1/2 x 11 easy guide to PSP can be copied and distributed.
"Baltimore Sun" Article (#12)	Reprints of feature PSP article in Baltimore Sun written by Diana Sugg.
Brain Bank Information (#14)	Packet of information about the PSP Brain Bank. Details how to make preparations to make brain donations and help in the search for the cure for PSP.
Physician Referral Cards (#15)	
Giving Envelopes (#16)	Keep on hand to send gifts to SPSP, Inc.

ON LINE SERVICES

Website: www.psp.org
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Questions: Parkinson's Web http:/pdweb.mgh.harvard.edu
e-mail: SPSP@erols.com

Please e-mail the addresses of any sites relating to PSP or other neurological disorders, cargiving issues, etc. to SPSP@erols.com and we will list them in the next *ADVOCATE*.

PSP EUROPE

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

Michael Koe
The Outbuildings, The Old Rectory
Wappenham, Nr Towcester, Northamptonshire
NN12 8SQ
Telephone 00 44 (0)1327 860342
E-Mail 10072, 30@compuserve.
Website Http//pspeur.org.uk

1999 ANNUAL GIVING CAMPAIGN

Our Annual Giving Campaign is underway. The Society has strived to provide you with information, advice and support. The Society keeps you informed of the latest information through our newsletters, brochures, symposia, and other types of mailings. We were able to provide these valuable services because of your generosity. We must continue our work! To do this, we need your continued gifts of time, expertise and money! We are supported entirely through your tax-deductible gifts. Our 1999 campaign goal is $100,000. Please help us reach our goal so that we can continue to help others. Complete the following form and include it with your gift and mail to the Society office. Thank you for your support.

Yes, I/we wish to support the Society for Progressive Supranuclear Palsy in its mission to fund meaningful research and develop significant educational programs and outreach services to persons with PSP and their families.

Enclosed is my tax-deductible gift of:
Sponsor $50 o Patron $100 o Silver Patron $250-$499 o
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__ Yes, I wish to volunteer to help the Society for PSP. Please contact me.

__ I am interested in learning how I can make a planned gift to the Society.

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Gifts of $100 and over will be recognized in the newsletter, Please print your name as you wish it to appear. _____

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email: SPSP@erols.com
website: www.psp.org

AG99

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 / E-mail: SPSP@erols.com/ SPSP, Inc. Woodholme Medical Building, Suite 515
1838 Greene Tree Road, Baltimore, MD 21208

ADVOCATE MAILING LIST UPDATE

PLEASE RETURN TO OUR OFFICE BY JANUARY 30, 2000

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