

I Have Been Diagnosed With PSP

By Bruce Sanderson

INTRODUCTION

My name is Bruce Sanderson and I am 52 years old. I was diagnosed with PSP in November of 1999. Before this time I was always declared healthy; I worked out regularly and led a very healthy life style. I have two sons with my first wife. Rohnn is 22 years old and has just finished his master's degree in finance at the University of Wyoming. My youngest son, Derrick, lives with his mother in Wisconsin. He has just turned 16 and has begun driving. He represents his school in music and the theatre as well as wrestling and soccer. I am very proud of both of them.

My current wife, Donna, and I live in California. She and I have been together for 14 years and she has added the role of caregiver in a flash. She was the first to notice the PSP, but I didn't believe her. I thought that the rest of the world was the problem. Then, in May of 1999, I noticed that I would know a song on the radio but I could not sing along because I could not get the words out. (There is a reason that I sing only in the car.) About six years before that, I noticed a balance problem, but I

thought it must be my age.

I was employed by Fleetwood Enterprises as the training manager for the motor home division when I was diagnosed with PSP. Prior to that I was in training groups with Nissan Motor Corporation in the USA and American Honda. I have been on short-term medical disability since February of 2000 and I will soon go on long-term disability.

Teaching is my passion and purpose. I have been an adjunct professor teaching business and education classes at three local universities, which means that I have been teaching part-time for about 15 years. It (teaching) has become more difficult even with help from the students in the classes. They are aware of my diagnosis and I have experienced compassion from them, my business associates, friends and management. Of course my families, Donna's in California and mine in Wisconsin, have been very supportive. Also, the many support groups, including the Listserv and the Society for PSP, have been very helpful because I am very afraid of being alone.



*Bruce and Donna Sanderson
Christmas 1999*

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INSIDE

**PSP-Related
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Presentations**

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Of PSP**

"The Road Trip"

THE SOCIETY FOR PSP RECEIVES A GIFT OF \$600,000 TO ESTABLISH "THE ERWIN AND PEARL POIZNER RESEARCH FUND"

The Society for Progressive Supranuclear Palsy, Inc announces it has received a gift of \$600,000 from Carol and Steve Poizner of Los Gatos, CA to establish a research fund in honor of Steve's parents, Erwin and Pearl Poizner of Laguna Hills, CA. The gift, to be received over a three-year period will enable the Society to expand its research efforts into the cause and hopefully a cure for progressive supranuclear palsy. The gift is made with the hopes that it will help Steve's father, Erwin, who is currently suffering with PSP, and 20,000 others who are likewise affected by PSP throughout the United States.

The Society is currently funding 31 research grants throughout the world, totalling over \$650,000 with a maximum award of \$20,000. The Poizner grant will enable the Society to raise the maximum award to \$50,000 with the hope of attracting more substantial proposals. Dr. Lawrence Golbe, Chairman of the Society's Medical Advisory Board, said, "This increase in the size of our grants should make PSP more attractive to established researchers who already have a proven record of scientific accomplishment."

Steve Poizner, the president of SnapTrack (a division of Qualcomm), established the fund with the support of his sister, Sharon Cooper, and brothers Howard and Jerry who live in Texas, New Jersey and Israel respectively.

The first award from the fund will be made to Dr. David Albers of the Weill Medical College of Cornell University. The Society is currently promoting the fund in leading neurological journals to encourage more investigators to submit proposals to study PSP. Please contact Dr. Golbe at golbe@umdnj.edu or Fax (732) 235-7041 for more information on the Society's research program.

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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.

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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.

Phone 1-410-486-3330

Toll Free: 1 (800) 457-4777, FAX 1 (410) 486-4283

Ellen Pam Katz, Director

SPSP, Inc.

Woodholme Medical Building

Suite 515

1838 Greene Tree Road

Baltimore, MD 21208

email-epkatz@erols.com

SPSP@erols.com

website-www.psp.org

List Serve: requests@hydra.welch.jhu.edu

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

EDITOR

Nancy Ogiba Brittingham

103301.640@compuserve.com

(757) 838-0777 • FAX (757) 838-6086

(In memory of Henry and Jane Ogiba)

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Director's Doings



If you are in business, you know that "time is money." If you are in the business of fighting PSP, you know that "time is life." PSP is sapping life from your husbands and wives, parents and siblings, friends and patients. What can you do to break the malicious sequence of events caused by this disastrous disease?

You can share in the work of the Society by supporting "Visions and Opportunities" - the Society's inspiring and compelling blueprint for eradicating PSP while caring for its victims.

Our goal through 2003 is to raise \$2,000,000 supporting research with \$1,200,000 and \$800,000 dedicated to raise awareness and provide educational activities that touch caregivers, support groups and health professionals.

We invite you to share your resources to invest in the plan. Please consider the "Giving Opportunities" outlined on page 4 in this newsletter. The funding of these needs will make a difference and give "LIFE."

While the needs are substantial, you might find resources easier to identify than you think. Families can pool resources in honor or memory of a loved one and companies can match gifts. Gifts of appreciated stock, bequests and planned gifts are wisdom-filled choices that can help the Society while earning you considerable tax deductions.

To ensure that your gifts are meaningful tributes to loved ones, the Society has established the "Hall of Hope" at the Society's national headquarters. Gifts of \$1,000 and over to support the plan will be recognized on beautiful commemorative plaques.

Please share our "Vision" to create a world free of misery caused by PSP. Your gifts will give "LIFE" to thousands of innocent victims already known and still unknown. To discuss your gift selection, please call me any time at 1-800-457-4777. I am always here for you.

Sincerely,

Ellen Pam Katz

P.S. On behalf of the Board of Directors, we wish to thank the 260 donors who have invested in the plan as of August 31, 2000. We have raised \$132,000. Won't you take this opportunity to make our "Vision" come true.

Congratulations to Ellen Katz who has recently been awarded a "Certificate for Fundraising Management" from Goucher College, Center for Graduate and Continued Studies. This was a two-year, 10-course program studying all aspects of organizational fundraising.

Diagnosed With PSP

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WHAT WILL HELP YOU

I want to caution you to only identify with healthy people. I think that this identification is very important for your own image, hope and possible cure. Do not give power to the nature of this disease. I have always referred to myself as having been diagnosed with it, and not that I have it because I do not want to say that I am the disease. I will continue to be me as it progresses. I am not going anywhere. I will move with this in the same way that I would move forward with any other problem or opportunity. I do not want to box myself into having it or being unable to stand it off. But again, I talk and listen to my doctor.

I also suggest that you keep doing what you are doing as long as you can. That is unless new things fit in with your wants that would create the perfect life for you. It answers the questions about "Why am I not doing what I want to do, right now?"

I have always wanted to teach and write. I had planned my retirement around these two general goals. I thought that I would move to a city where there is a state university and begin teaching. During my tenure as a teacher, I would also write. PSP has forced me to change my plans. I have dropped the idea of teaching because of the speech and voluntary eye movement problems. I have also moved things up. I am no longer working in a business position that requires teaching every day. I have started writing. It is time to write now when I can. I cannot plan on later.

You may also have to stop what you are doing because it has become too difficult and you are forced to make a life change. This disease may mean that you cannot work but it also may mean that you still have the strength for many things that you want to do. Only you can decide what you want to do.

Things usually involve more time when you have this disease. It takes me longer to do many of the things that I enjoy doing. My biggest challenge is to not become impatient or frustrated and try to hurry. I must keep working at a pace that I can take. If I forget, I usually fall or suffer some other consequence from PSP.

POSITIVE THINGS

Look at the positive things in this situation, if there are any. It is (in my life) appreciating family, friends and people more than I did in the past. My experience has shaken my comfortable foundation.

The people close to me have their burdens with this, too. PSP causes many of the people close to me to remember that I am not doing these things because I want to. I don't know how to help other than to offer others many options and then try to understand and not be self-centered or depressing to those around me. I have taken much more time to talk to and especially to listen to my family and friends. I have become more in touch with both. I no longer put off answering people.

Another positive thing is that I have moved more things that I had planned to do in the future to the present. The only day that I have is today. And really, that is true for us all. I simply want to be in the present as we all do. I want to live and make a difference. None of that has changed. But the past does not seem very important to me now and the future may never come.

MANAGEMENT

I am looking at this disease as a management problem. I know that I will have good and bad days. I also know that I will feel better in the morning or after I sleep. So, if I am going out

Continued Page 19

Strategic Plan 2000-2003

Giving Opportunities to Support the Strategic Plan

Please consider gifts in memory or in honor of loved ones.

-  Support an International Research Conference on PSP at \$75,000
-  Support the establishment of a Development Office for 1 year at \$60,000
-  Support the establishment of an Outreach & Educational Services Department for 1 Year at \$53,000
-  Fund the creation of a research fund in honor or memory of someone at \$20,000 to \$50,000 annually
-  Support a National Patient Family Symposium at \$50,000
-  Fund the development of comprehensive marketing & communication materials to reach medical and allied health professionals about PSP at \$20,000
-  Fund the development and printing of materials for caregivers and patients with PSP at \$10,000
-  Fund the production and publication of a support group manual for leaders and participants at \$10,000
-  Support the purchase and customizing of software to create a database of health professionals and their organizations at \$10,000
-  Dedicate a single issue of the PSP Advocate at \$10,000
-  Support development & expansion of Internet opportunities at \$7,000
-  Support the startup of a resource help-line at \$5,200 for one year
-  Support PSP education and information at meetings and symposiums through sponsoring guest speakers at \$5,000 (\$1,000 per speaker)
-  Support the Society for PSP's presence at meetings and exhibits at Medical Conferences at \$5,000 per conference
-  Support a Regional Patient Family Symposium at \$5,000
-  Support the purchase and customizing of software to develop a registry to identify PSP patients at \$3,000
-  Fund the establishment of an audio cassette library at \$3,000



For more information on giving opportunities, contact:

Ellen Pam Katz, Director
(410) 486-3330; (800) 457-4777

Research

PSP-Related Research Presentations from the Sixth International Congress of Parkinson's Disease and Movement Disorders Barcelona, Spain, June 11-15, 2000

by Lawrence I. Golbe, MD
Chairman, Medical Advisory Board, SPSP

EPIDEMIOLOGY

Hu et al, London UK:

Atypical parkinsonism among Afro-Caribbean and Indian UK communities: a clinical, magnetic resonance and PET imaging study.

This study demonstrated that compared with British caucasians, British people of African origin (via the Caribbean) have a three-fold greater prevalence of parkinsonism that responds poorly to levodopa. Although PSP might have accounted for many such cases, examination and PET scan results suggest that the parkinsonism in this group was not PSP, but rather was atypical Parkinson's disease. This result helps us interpret the meaning of the cluster of the PSP-like illness on the Caribbean island of Guadeloupe.

TREATMENT

Perina et al, Buenos Aires, Argentina:

Donepezil improves motor and cognitive function in patients with PSP.

This non-blinded study of 7 patients with PSP found that 6 improved and one worsened after a 6-week trial of donepezil (Aricept). Improvement was in a variety of functions, but averaged a 23% reduction in PSP Rating Scale scores. This result is contrary to most other experience with donepezil in PSP and is unlikely to influence most neurologists' prescribing practices.

Fabbrini et al, Rome, Italy:

Donepezil in the treatment of PSP.

This study, also non-blinded, involved 6 patients treated for 3 months. It showed no improvement in detailed tests of mental function and movement. Like the one above, this study used a dosage of 5 mg daily. There were no important side effects.

DIAGNOSIS

Oztenkin et al, Ankara, Turkey:

The value of three-dimensional magnetic resonance imaging-based volumetry in the differential diagnosis of idiopathic Parkinson's syndrome from multisystem atrophy and PSP.

This study used a unusual technique to calculate the volume of certain brain areas using MRI scanning. It found that PSP and multiple system atrophy could be distinguished from normal but not from each other. This technique, if refined, could assist in routine differentiation of PSP from other parkinsonian disorders.

Berg et al, Würzburg, Germany:

Differences of echogenicity and T2 relaxation time of the nucleus lentiformis in MSA and PSP as compared to Parkinson's disease.

In PSP, there is excessive deposition of iron in the lentiform nucleus, an important brain center for control of movement. This study used ultrasound to detect the iron. It was able to do so, but not with enough accuracy for this test to be used alone or to replace MRI, which can also detect iron. However, it may be useful in patients who cannot have an MRI.

Birdi et al, Saskatoon and Halifax, Canada:

PSP clinical diagnosis: problems and confounding factors.

The authors reviewed the clinical histories of 13 cases of autopsy-verified PSP. The most interesting findings were that 2 had pre-existing essential tremor, one had a strong family history of Parkinson's disease, 2 had a tremor typical of Parkinson's as their first symptom, it took an average of 4.2 years after symptom onset for the diagnosis of PSP to be reached, and 6 patients never developed eye movement problems.

NEUROCHEMISTRY

Fitzmaurice et al, Toronto, Canada:

Evidence of oxidative stress in the substantia nigra in PSP and multiple system atrophy.

Oxidation is a damaging type of chemical reaction produced as a byproduct of normal chemical reactions in cells. A certain amount of oxidation is normal and can be neutralized by the healthy brain. It is well known that excessive oxidation occurs in the brain of Parkinson's disease and contributes to the damage there, but this has not been well-established for PSP. This study finds evidence for this for PSP and MSA, thereby pointing to a possible avenue of treatment or prevention.

Lannuzel, et al, Pointe-à-Pitre, Guadeloupe and Paris, France:

Neurotoxic effects of alkaloids from *Annona muricata* (sour-sop) on dopaminergic neurons: potential role in etiology of atypical parkinsonism in the French West Indies.

Readers of the PSP Advocate are familiar with the observation of high prevalence of a PSP-like illness on Guadeloupe and that people with PSP there are disproportionately likely to have consumed certain native fruits. This study demonstrates that chemicals derived from one of those fruits, sour-sop, damage dopamine-producing brain cells in the laboratory. This work may help point to a dietary influence on the development of PSP not only on Guadeloupe, but elsewhere, via consumption of plant products that may harbor chemicals similar to those in sour-sop.

NEUROPATHOLOGY

Mori et al, Tokyo:

Cortical pathology in PSP.

Tufted astrocytes, a autopsy microscopical feature of the cerebral cortex, is relatively specific for PSP but not present in all cases. In this series, it occurred in 9 of 14 brains that were otherwise diagnostic of PSP. The cases with the most intense occurrence of tufted astrocytes had the most dementia and dystonia (fixed, twisted posture of a body part) during life. This finding may help identify sub-types of PSP that could aid in identifying specific causation or treatment in certain patients.

Scaravilli et al, Bolzano, Italy and London, UK:

Involvement of the Onuf nucleus in PSP.

Continued Page 6

Three patients with PSP and important difficulties in urinary bladder function had, at autopsy, loss of cells in a tiny area at the end of the spinal cord called Onuf's nucleus. This is the origin of the nerve cells that supply the bladder. It had been thought that this nucleus was rarely affected in PSP, but this study shows that at least in some patients it can be severely affected. This may help understanding of why the bladder malfunctions in many cases of PSP.

Boeve et al, Rochester, Minnesota & Jacksonville, Florida:

Progressive aphasic dementia in a case with combined corticobasal degeneration/PSP pathology.

This case report from the Mayo Clinic again demonstrates the close relationship between PSP and corticobasal degeneration - some findings of both occurred in the same brain at autopsy. (The patient had an unusual clinical picture dominated by language disturbance that is not ordinarily characteristic of PSP or CBD alone.) This case supports the hypothesis that if we find the cause of either PSP or CBD, we will have the cause of the other.

NEUROPHYSIOLOGY

Kühn et al, Berlin, Germany:

Abnormal activation of inhibitory neurons within the motor cortex of patients with PSP: a TMS study.

This study used transcranial magnetic stimulation to study PSP. This technique, a well-accepted technique for studying the brain circuitry, applies a strong electromagnet to the scalp over the area that controls movement and records the resulting hand movement. The result was that the brain in PSP can conduct messages normally but is impaired in its ability to inhibit an ongoing impulse. This could help devise new drug treatment or rehabilitation in PSP.

GENETICS

Morris H, et al, London, UK:

The alpha-synuclein, tau and apolipoprotein E genes in multiple system atrophy and PSP.

An association between the tau gene and PSP has been known since 1997. This study confirmed that association and found that two other genes that have been associated with Parkinson's and Alzheimer's diseases, respectively, were not associated with PSP. This data will assist in eventual genetic diagnosis of PSP.

de Silva et al, London UK:

Study of a polymorphism of the endothelial nitric oxide synthase gene in parkinsonism.

This study found no relationship of PSP with a gene that codes for an enzyme, NOS, which is associated with Alzheimer's disease.

Bandopadhyay et al, London UK:

Identification and analysis of novel polymorphisms in synphilin-1 gene in parkinsonism.

The same group of researchers that reported the study immediately above found no relation of the synphilin-1 gene with PSP or Parkinson's disease. They investigated this gene because the synphilin-1 protein interacts with alpha-synuclein, a protein recently found to be important in PD. Negative studies such as the last two are the price to pay for breakthrough discoveries, any one of which is always at the end of a long line of experiments with negative results. These "failures" actually provide valuable information in telling us where not to look for the cause and cure of PSP.

The Society Awards Two More PSP Research Grants

Are matrix metalloproteinases involved in the pathogenesis of PSP?

David S. Albers, Ph.D.

Stefan P. Lorenzl, M.D.

The New York Hospital-Cornell Medical Center, NY, NY

ABSTRACT:

A growing body of evidence implicates oxidative damage in a number of neurodegenerative diseases, including Parkinson's disease, Alzheimer's disease and Huntington's disease. Progressive supranuclear palsy (PSP) is a rare movement disorder that is associated with impairments of gait and balance. The etiological basis for PSP remains unknown; however, recent data from our laboratory suggests an "oxidative stress" contributes in the pathogenesis of PSP. One consequence of an oxidative stress is the activation of matrix metalloproteinases (MMPs) which are a family of Zn²⁺-endopeptidases capable of digesting components of the extracellular matrix. Accumulating evidence indicates that MMPs are involved in the pathogenesis of Alzheimer's disease, amyotrophic lateral sclerosis, stroke and multiple sclerosis suggesting an underlying imbalance in the MMP regulatory system. Cell survival appears to depend on the constant supply of survival signals provided by neighboring cells and the extracellular matrix. A change in the MMP expression may contribute to selective damage of neurons in PSP.

Thus, we propose to examine comprehensively the activities of a number of MMPs in post-mortem PSP tissue as well as in PSP cell hybrids. The significance of these studies can only be inferred at present. Nevertheless, 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.

"Effect of Lipoperoxidation on cdk5 Activity and Tau Protein Aggregation: A Model for PSP Pathogenesis"

Massimo Tabaton, M.D.

University of Genoa

ABSTRACT:

A crucial step in understanding the the cause of brain cell loss in PSP is to clarify why accumulations of tau protein (neurofibrillary tangles) occur in some brain cells but not in others. Important fat-like chemicals (lipids) in the brain are degraded in Parkinson's disease. We would like to determine whether this is true in PSP as well and whether this can help explain the differences among brain cells in their vulnerability to PSP. We have recently found a 1.6-4 fold increase of products of lipid peroxidation, a common type of lipid damage, in affected brain areas from PSP cases. The products of this damage are themselves toxic to brain cells. One such product, 4-hydroxynonenal (HNE), is known to disrupt microtubules, part of the internal skeleton of brain cells, in cells growing in the laboratory. The damaged cells even develop accumulations of tau protein. The aim of our project is to investigate the precise steps underlying this phenomenon.

One chemical used by brain cells to help them grow is called p35/cdk5. A modified form of this protein, p25/cdk5, has an opposite effect on brain cells growing in the laboratory,

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Research

Genetic Susceptibility Research

Dr. Huw Morris and Dr. Rohan de Silva

This article is reprinted with permission from the PSP Bulletin, (The Official Newsletter of the Progressive Supranuclear Palsy Association PSP Europe). Winter Issue, 1999.

"A vastly important milestone was reached in the progress of research into human genetics – the first "complete" chromosome sequence was published. For the first time scientists can access all of the contiguous genes and control sequences in a substantial fraction of the human genome. This publication of the chromosome 22 sequence, completed by a team based at the Sanger Centre in Cambridge, is the culmination of many years of effort by geneticists throughout the world and also reflects the advances in gene sequencing technology and the impetus brought to the project by competing commercial interest in the genome sequence.

Within the first three years of the new millennium it is anticipated that all of the gene-containing areas in the human genome will be sequenced and that this data will be freely available to scientists working throughout the world. When the human genome project was started, completion of the genome sequence seemed to be an immense and almost insurmountable task in its own right, but as the project nears completion, the problems of making sense of all of the information available starts to become apparent. A major part of understanding the function of genes will be in identifying how groups of genes can be switched off and on to determine the immensely complex growth and development of human beings. But, as with the earliest gene discoveries, a great deal of effort will be expended in understanding how all of these genes (probably in excess of 100,000) contribute to human disease. Our understanding will move on from simple familial disorders, which are usually caused by a single faulty gene, and towards sporadic disorders in which many more minor and subtle gene variations acting together lead to the disease state. This will involve both a bald description of which genes and which variations are involved and an understanding in test tube and possibly animal models of how these genes and proteins work and how their function changes with gene variation. The first gene variation involved in PSP has been described, but we anticipate that many other genes will be identified which contribute in some way to the development of PSP.

The expansion in the funding of PSP-directed research on both sides of the Atlantic, and the growth of research in related conditions, means that research bodies and scientists are developing a strong position to exploit the exciting possibilities for PSP thrown up by the "post-genome" era. This position relies on the availability of DNA samples from PSP patients and control individuals together with funding of specific research projects. Both the PSP (Europe) Association and the American Society for PSP, representing both patients and carers, have been very successful in facilitating and encouraging this process. New treatments from this research are not yet "around the corner" but the pace of progress and the increasing involvement of pharmaceutical companies suggests that we can be optimistic about what the new millennium holds for PSP patients and families.

Patients with Progressive Supranuclear Palsy Sought

Scientists at the National Institute of Neurological Disorders and Stroke (NINDS) studying neurobehavior are seeking patients with progressive supranuclear palsy for cognitive neuroscience studies.

Eligible patients should be mild to moderately affected, between the ages of 18 and 70, and have no other significant disease. Those enrolled in the study will undergo neuropsychological testing and brain imaging studies. The studies will be conducted at the National Institutes of Health (NIH) Clinical Center in Bethesda, MD. All study related expenses will be paid by the NIH.

For more information, physicians should contact Dr. Jordan Grafman, Chief, Cognitive Neuroscience Section, NINDS, Building 10, Room 5C205, 10 Center Drive MSC 1440; Bethesda, MD 20892-1440; telephone (301) 496-0220; fax (301) 480-2909; email grafmanj@ninds.nih.gov

Research Grants

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leading to alterations of tau protein and death of the cell. We will study the effect of HNE on both of these proteins. We will also examine the specific changes caused in tau protein, either in a model in brain cells growing the laboratory or in samples of autopsied brain tissue from people with PSP. This will shed light on whether in fact alterations in these "signal" proteins are important in PSP. If this turns out to be the case, then mutations in the genes that code for p35/cdk5 proteins would be strong candidates for either causing the rare familial forms of PSP or for being contributing factors in the vast majority of PSP in which there is no apparent family history.

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@erols.com
SPSP, Inc. Woodholme Medical Building, Suite 515
1838 Greene Tree Road, Baltimore, MD 21208

Challenges In The Management Of PSP: Difficult Decisions

By James Tetrud

Clinical Director

The Parkinson's Institute, Sunnyvale, CA

Department of Neurology

Stanford University School of Medicine

Progressive supranuclear palsy (PSP) is considered a rare disorder, yet it is the second most common neurodegenerative cause of parkinsonism seen in movement disorder clinics. Like other neurodegenerative disorders, such as Alzheimer's disease and Parkinson's disease, the risk of developing PSP increases with age. Thus, the prevalence (number of individuals having a disease at a given time) of PSP will steadily increase over the coming years as the Baby Boom generation ages. These facts underscore the need for an increased research effort directed at finding the cause and cure of the disease as well as a focused approach to medical management and caregiver support. There should also be an effort to increase awareness among physicians and the public at large to the special needs of patients with PSP.

Patients with PSP and their caregivers often face a confusing period before the diagnosis is eventually made. When first seen by the family physician, the patient might be told that the symptoms are due to a stroke or to Parkinson's disease. Quite likely, an MRI or CT brain scan will be performed and interpreted as being "unremarkable" or showing "nonspecific" changes. Following a referral to the neurologist, the patient will, in all probability, be diagnosed as having Parkinson's disease and be placed on an antiparkinsonian drug such as carbidopa/levodopa (Sinemet™). Since many individuals with PSP will derive some benefit from this drug, the diagnosis of Parkinson's disease may well persist for some time. There may also be a referral to a local Parkinson's disease support group, but it will soon become evident that many of the problems faced by the patient with PSP are quite different from those faced by patients with Parkinson's disease.

This sequence of events is not the result of incompetence or lack of compassion; rather, it stems from the fact that the clinical features specific to PSP may not clearly emerge until several years following the initial visit to the neurologist. Furthermore, even when the diagnosis is suspected, there may be reticence on the part of the neurologist to communicate suspected PSP to the patient or the patient's family, since the diagnosis is generally less optimistic than that of Parkinson's disease. Nonetheless, in the majority of cases, the clinical "features" of PSP can be quite distinct and the problems faced by patients and caregivers are quite different from those of Parkinson's disease. Thus, it is important for the patient's doctors and caregivers to recognize and deal with these specific problems as early as possible.

Although the clinical spectrum of PSP is variable, some of the major problems faced by patients and caregivers include: visual symptoms, impaired balance leading to falls, speech and swallowing difficulties, personality and mood changes and sleep disturbances. Some of these symptoms will emerge late in the course of the disease, but others develop early. Each of these problems presents a separate management challenge.

The hallmark clinical feature of PSP is a disturbance of eye

movement from which the term progressive supranuclear palsy is derived. In particular, this refers to the inability for patients to look down on command, yet when the head is tilted by the examiner, the eyes can be induced to deviate down. Thus, there is no paralysis of the eye muscle or the neurons in the nuclei directly responsible for down gaze. Rather, the problem is "supranuclear," or above these nuclei. Some patients with PSP will not manifest definitive down-gaze palsy until later in the course of the disease. Other eye movement problems can occur in this disease as well, including impairment of quick eye movements, slowing of visual pursuit (i.e., following a moving object), instability of fixation, and a disturbance of convergence (needed for binocular focusing on close objects). These eye movement problems result in a number of visual symptoms including blurred vision, occasional double vision, and reading difficulty, all of which may further compound problems with gait and balance. Some patients will also develop a problem with eye opening due to either blepharospasm (a form of dystonia resulting in forced eye closure) or eyelid apraxia (difficulty with voluntary eye opening). Both of these conditions have been treated with botulinum toxin (Botox™) injections in the eyelid and muscles surrounding the eye, although it appears that blepharospasm responds best to this procedure. These visual symptoms are best evaluated by an ophthalmologist familiar with neurological disease. The neuro-ophthalmologist can provide visual aids such as prism lenses and tinted lenses, botulinum toxin (Botox™) injection and even lid crutches to help patients with these visual problems.

Impairment of gait and balance is one of the earliest symptoms experienced by patients with PSP. In fact, unexpected falls, a symptom that rarely if ever occurs in the early stages of Parkinson's disease, often prompt the first referral to a neurologist. This symptom requires immediate attention because, all too frequently, these falls result in serious injuries such as a fracture or concussion. A physical therapist familiar with neurological diseases can be of great assistance in providing gait training, preventative measures aimed at avoiding or buffering falls, in-home safety measures such as grab bars for the hallways and bathrooms, and assessing the need for an appropriate walking aid or wheelchair. Because of the tendency for some patients with PSP to fall backward, a walker may not provide adequate protection, although there are now a wide variety of walkers available including some that provide some protection against backward falls. The decision to use a wheelchair is often one of the most difficult faced by patient and family, because it may be perceived as giving in to the disease or losing independence. Yet, a walking aid or wheelchair may actually reduce dependence on the caregiver and even allow the patient a wider range of activity. Importantly, these devices will reduce the risk of a serious injury stemming from a fall with the possibility of hospitalization and surgery. Although it is never easy to accept the need for a walker or a wheelchair, the patient and caregivers must keep in mind the progressive nature of this disease and the fact that these aids will likely improve the patient's quality of life.

Patients with PSP can develop a severe impairment of speech and swallowing. These problems are linked to neuronal damage within the brainstem and their connection to higher brain centers, especially the basal ganglia. Impaired function of the muscles involved in speech and swallowing appear to be a complicated mixture of slowed reflexes and dystonia (involuntary muscle contraction). Swallowing problems are

Continued Page 9

Education

Difficult Decisions

Continued from Page 7

known as "dysphagia" and speech problems as "dysarthria." The most serious complication of dysphagia is aspiration of food into the lungs resulting in pneumonia. Thus, it is vitally important for the patient with PSP to undergo a speech and swallowing evaluation periodically. A comprehensive examination of swallowing involves using fluoroscopy and video recording to image a bolus of food as it travels from mouth to stomach. By using different consistencies of food, this examination can detect which foods are best tolerated and whether or not there is any aspiration. This examination is also an important factor in determining whether or not the patient should have a gastrostomy tube placed. A gastrostomy procedure involves inserting a plastic tube directly into the stomach through an opening in the abdomen and stomach wall. Its purpose is to provide a route for food and liquids that bypasses the mouth and esophagus, thus providing adequate nutrition and minimizing the risk of aspiration pneumonia. Unquestionably, the placement of a gastrostomy tube is a major decision by the patient and caregiver as it is often perceived as an ominous sign of disease progression. However, in most cases, a gastrostomy tube will improve the patient's quality of life because it allows for adequate nutrition, minimizes the chance of aspiration pneumonia and reduces caregiver anxiety.

It is not uncommon for patients with PSP to exhibit personality and mood changes. As reported by Dr. Litvan (PSP ADVOCATE, second quarter, 1997), patients often become uninterested in their surroundings and tend to avoid interacting socially (i.e., they become apathetic). Occasionally, they will exhibit inappropriate behavior quite different than their personality prior to developing PSP. In addition, the patient may exhibit sudden bouts of crying or laughing, often referred to as "emotional incontinence." Personality and mood changes can be very disturbing to the family and can be so striking as to undermine the relationship between patient and caregiver; these changes are further complicated by certain cognitive deficits such as mental slowing and impaired memory. Thus, it is important for the family and caregivers to realize that these changes are part of the underlying disease process and to communicate such issues to the family physician and neurologists. Psychiatric counseling can be very helpful in these situations and, although depression may not be a major feature of PSP, certain antidepressants can be of some benefit.

A variety of sleep disturbances can be associated with PSP, including insomnia, frequent awakenings (often related to bladder urgency), sleep apnea (periodic cessation of breathing), periodic limb movement during sleep and "REM sleep behavioral syndrome" (disinhibited movements related to dream activity, which can sometimes be violent) and hypersomnia (excessive sleep). This unusual sleep activity can be confusing, not to mention disturbing for family and particularly for the spouse. Again, it must be recognized that these symptoms are related to the underlying disease process and that there are treatments available. It is most helpful for the patient to undergo a comprehensive sleep study to characterize the sleep disturbance. Sleep centers operated by experts in sleep disorders can be found near most major medical centers throughout the country and are often overseen by neurologists. For those with REM sleep behavior

syndrome, small amounts of a drug called clonazepam can be helpful. For sleep apnea, a variety of drugs may be of some benefit and in more severe cases the use of an apparatus that opens up the airway by means of nasal continuous positive airway pressure (CPAP) can result in improved sleep.

There is no question that PSP can present a formidable challenge for patients, treating physicians, and caregivers alike, but it is wrong to assume that nothing can be done. Sometimes the decisions are quite difficult, such as deciding on a wheelchair or a gastrostomy tube, but as yet there is no cure for the disease and attention should therefore be centered on maximizing the patient's quality of life until the time when a better treatment and, hopefully, a cure are discovered.

Over the past few years there has been a steady increase in PSP awareness as well as an increasing understanding of the factors associated with nerve cell damage in this disorder. One of the factors involves an important nerve cell protein called "tau," which plays a major role in supporting "microtubules" responsible for transporting chemicals throughout the cell. Tau is produced in several different forms (isoforms) and in PSP there are specific isoforms that accumulate in neurons and glial cells (cells that support neurons). Determining the mechanisms by which tau accumulates and the reason why only certain cells are affected will likely bring us closer to finding the cause of this disease. Thus, research efforts in PSP have now finally begun to see a definite glimmer of light in that which has been a long dark tunnel for so many years.

The PSP ADVOCATE has provided patients and caregivers with up-to-date information on PSP, and support groups are now emerging throughout the country. The disclosure by Dudley Moore of his battle with PSP has also helped increase public awareness of this disease. Financial support for PSP research, like the generous gift by Jay Troxel, is now yielding results, but clearly, more funding is needed. Now, for the first time, we can look forward with optimism to finding the cause of PSP and, in the near future, developing a cure.

Dear Ellen,

As you might-know, I just accomplished a great milestone in my life-my Bat-Mitzvah. Although I really wished my grandma was there to watch me, I knew she was in spirit. Ever since my grandma was diagnosed with PSP, I have always known that was the fund I would give my gift money to. I hope that this money will help the researchers



find medications and hopefully some day a cure. I know that finding a cure might not happen for some time, but I believe if people work at it, they will succeed. My grandma always said that if you work at something, you will achieve it. I hope that someday PSP will achieve its goal by finding a cure. I hope you do know that if there is anything I can do to help, you may call me. It would really mean a lot if I could be included in achieving our goal. Thanks so much.

Sincerely,
Amy Todd

Education

Ask a Doctor

By Stephen G. Reich, M.D.
Honorary Member Society Board of Directors
Professor of Neurology
Johns Hopkins University School of Medicine

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

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

“My father is always exhausted. Is it better to encourage physical activity or will it exacerbate the fatigue?”

Fatigue is generally synonymous with poor endurance and therefore, is best treated by increasing physical activity to enhance stamina. All patients with PSP should be encouraged to remain as active as possible and ideally, participate in regular exercise. It is important to make sure that there is not a medical cause of fatigue such as anemia, heart failure or depression but, in the absence of that, I encourage your father and others with PSP to remain as active as possible since being sedentary tends to have a deleterious effect on the disease.

“As PSP progresses, is a hacking cough a usual manifestation?”

The “hacking cough” which you refer to is probably related to impaired swallowing and choking on saliva. Coughing and choking during and after eating and drinking is another important sign of impaired swallowing. Unexplained episodes of bronchitis or pneumonia are other clues about underlying trouble swallowing. The medical term for impaired swallowing is dysphagia. The investigation of dysphagia should include an evaluation by a speech and swallowing therapist and may also include a swallowing study in which an x-ray movie is taken while one swallows barium. There are a number of interventions available to help reduce the risk of choking or developing pneumonia. Dysphagia is one of the most serious problems in PSP and needs careful and early attention.

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” from those suffering through the hardships of progressive supranuclear palsy.



The publications of the PSP Advocate for the Year 2000 have been generously funded by Jay Troxel in memory of his beloved wife, Eloise H. Troxel

GRANT ANNOUNCEMENT:

The Society for PSP announces The Annual Eloise H. Troxel Memorial Fellowship, 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@umdnj.edu or Fax 732-235-7041.

Special Events

Houston PSP Support Network

By Jo Ann Coen

The first meeting of the Houston PSP Support Network was held on Saturday, May 20, 2000. Forty-five people attended, including relatives, caregivers, persons with PSP and friends. The meeting was opened by Karen Kennemer. Many thanks to this untiring person who spent several months organizing this event.

Bill Buchanan, caregiver to his wife, Mary Bell, moderated the program. He discussed how PSP affects family and friends and the importance of a meeting such as this one to offer support to all impacted by this devastating disease.

The featured speaker was Senator Tom Haywood of Wichita Falls, Texas who is diagnosed with progressive supranuclear palsy. Senator Haywood was very informative as well as humorous as he discussed managing life with PSP for the past 8 years. The Senator was articulate and spoke in an unexpectedly strong voice. "Life is not over yet," he said, "it just took an unexpected turn." He asked the audience to listen to what he was saying rather than how he was saying it. When he showed that his shirt was fastened by velcro, the audience applauded!

The Senator then opened the floor for questions and discussion. Medications were the dominant topic: Botox, Sinemet, Requip, etc. One person asked Senator Haywood if he often fell. Mrs. Haywood responded that one time he fell and it required 28 stitches to his head. Another falling incident required stitches to his hand. She said that he still falls often and always seems to fall on his left knee causing a repeated open injury. Lifts, walkers, wheelchairs, feeding tubes, helmets, sleeping habits and the quality of life were other topics discussed. All in the audience introduced themselves or were introduced and shared their affiliation with PSP.

The meeting was adjourned at 3:55 pm and refreshments were served. There was a great deal of friendly visiting and one-to-one exchanging, which was extremely helpful. Each of us, I believe, derived great benefits from being at this meeting as we shared our situations and realized we were not alone.



Senator Tom Haywood from Wichita Falls, Texas



Senator Haywood and Libby Lipp

Louisiana PSP Support Group Inaugural Meeting

Kenner Picayune

THURSDAY, JULY 6, 2000

Father's strength inspiration for palsy awareness chapter

By Christine Lacoste Bordelon
Kenner Times

When Brenda Gremillion's father, Malcolm Olivier, was diagnosed with progressive supranuclear palsy, she and her family had never heard of it. Neither had many local doctors.

A rare disease that affects fewer than two in 100,000 people, it is often mistaken for Parkinson's disease due to a few shared symptoms: stiffness, slowness and clumsiness. In fact, Olivier

was first told he had Parkinson's after he began to stumble and fall frequently. He was improperly treated for eight years and took medication that Gremillion said sometimes made him hallucinate.

Her family went through years of caring for him with little outside support. When Olivier died in 1997, they still knew nothing more about the disease.

This lack of information prompted her to start the Louisiana chapter of the Society for Progressive Supranuclear Palsy.

The organization's first meeting was held Friday at East Jefferson General Hospital in Metairie.

"I didn't want to see other families suffer like we did," Gremillion, 38, said. "I wanted them to know there was someone out there to help."

About the time of Olivier's death, the national society was making strides in getting information out and creating awareness about the disease.

See DISEASE, Page 2

When Brenda Gremillion's father, Malcom Olivier, was diagnosed with PSP, Malcolm, Brenda, family and even local physicians had never heard of it. Olivier was initially informed that he had Parkinson's disease and was treated as such for eight years prior to the diagnosis of PSP.

The Olivier family went through years of caring with little information and support. Brenda learned about the Society for PSP near the time of her father's death. Lack of awareness and education prompted Brenda to organize the first meeting of the Louisiana Support Group. "I did not want to see other families suffer like we did," Brenda, 38, stated. "I wanted them to know there was someone out there to help."

On June 30, 2000, twenty-five people met at the East Jefferson Hospital in Metairie, LA. Dr. Jay Rao of the LSU Medical Center was guest speaker. After Dr. Rao's presentation, he conducted a question and answer period. For more information about future meetings, please contact Brenda Gremillion at (504) 467-6658 or home (504) 538-6528. Her email address is bgrem737@aol.com.



Dr. Jay Rao of the LSU Medical Center speaks to members of the Louisiana Support Group

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, phoning and visiting PSP families. Please contact:

ARIZONA:

Gale Kittle & Christina Watts
Muhammad Ali Parkinson Res Cent
500 W. Thomas Road, Suite 720
Phoenix, AZ 85013
(602) 406-4931
Maxine Faubion
9302 S. Citrus Lane
Sun Lakes, AZ 85248
(480) 895-7646
Rena Valdes-Birch
20 South Buena Vista #1
Gilbert, AZ 85296
(480) 632-1797

ARKANSAS:

Patsy Cunningham
P.O. Box 180615
Fort Smith, AR 72918
501648-1814
patphillip@prodigy.net

CALIFORNIA:

Carolyn Cheek
23009 Nadine Circle, Unit A
Torrance, CA 90505
(310) 534-8623
Nancy Frederick
1131 Eden Avenue
San Jose, CA 95117
(408) 243-9987
Lila Kirkpatrick
310 La Herran Drive
Santa Clara, CA 95051
(408) 244-5958
Carol Platt
2821 Gibson View Way
Antelope, CA 95843
(916) 332-6041
Mary Miano
2298 Via Puerta, Apt. N
Laguna Woods, CA 92653
(949) 855-3972

CANADA:

Sandie Jones/Janice Stober
Parkinson Foundation of Canada
4211 Yonge Street, Suite 316
Toronto, ON M2P 2A9
CANADA/(416) 227-9700;
stoberj@hotmail.com
Marie-Josée Fortin
The McGill Centre for Studies in Aging
Douglas Hospital
6825 LaSalle Blvd.
Verdun, Quebec H4H 1 R3
Carolyn Connors
The Parkinson Foundation of Canada
150 Newbold Court
London, Ontario N6E 1 Z7
CANADA
619-630-0430
parkinso@hotmail.com

COLORADO:

Dr. Lauren Seeburger/Kim Mantin
Movement Disorder Center
Colorado Neurology Institute
701 E. Hampden, #530
Englewood, CO 80110
(303) 788-4600

CONNECTICUT:

Frank Cadwell
203 Cowhill Road
Clinton, CT 06413
(860) 664-9524

FLORIDA:

Paula John
5383 Lake Arrowhead Trail
Sarasota, FL 34231-7374
(941) 927-3955
Shirley Vlahakis
1067 Island Manor Drive
West Palm Beach, FL 33413
(561) 969-9553
Virgie Saltzman
23 Lafitte Drive
Nokomis, FL 34275
(941) 484-7259
John Arnold
523 Adams Avenue
Cape Canaveral, FL 32920
(407) 784-5660

FLORIDA (Miami)

Beatriz Chirino
(305) 270-8401
Yolanda Medina
(305) 553-4911

GEORGIA:

Kathy Thomas
3305 Francine Drive
Decatur, GA 30033
(770) 939-2612
Bud Branson
449 Gould Road
Quincy, FL 32351
(850) 627-6216

ILLINOIS:

Bea Irminger
One W. Onwentsia Road
Lake Forest, IL 60045
(847) 234-1928

INDIANA:

Elizabeth Risk
239 S 12th Avenue
Indianapolis, IN 46107
(317) 786-8613

IOWA:

Esther Cooling
1917 "B" Avenue, NE
Cedar Rapids, IA 52402
(319) 363-4752

LOUISIANA:

Mary Schumann
1021 Wilson Drive
New Orleans, LA 70119
(504) 484-7840
Brenda Gremillion
10 Bistineau Court
Kenner, LA 70065
(504) 467-6658

MAINE:

Faye Ryan
HCR 74, Box 88A
Whiting, ME 04691
(207) 259-2152

MARYLAND:

Ruth Goldstein
PSP (Office)
1838 Greene Tree Road, Suite 515
Baltimore, MD 21208
(410) 486-3330; (800) 457-4777

MASSACHUSETTS:

Patti Ryan
1000 Paradise Rd.
Swampscott, MA 01907
(781) 595-4431 (H); 599-1000 (W)

MICHIGAN:

Carol Ann Kiank
4100 Longleaf
Commerce Township, MI 48382
(248) 363-9064

Janet Maguire
22933 Garfield Street
Saint Claire Shores, MI 48082
810-294-0071

MINNESOTA:

Charlotte Tripet
2440 Carvell Avenue, North
Golden Valley, MN 55427
(612) 546-1694

MISSISSIPPI:

Denver Flanagan
2108 Monaco Street
Jackson, MS 39204
(601) 372-1784
denfian@aol.com

MISSOURI:

Pay Lynn
1427 Tanglewood Road
Jackson, MO 63755
(573) 243-3964
Amy Mandiman
#8 Bavarian Court
St. Louis, MO 63146-5301
(314) 432-5461

NEVADA:

Carol Upton
3131 LaCanada, Suite 107
Las Vegas, NV 89109
702-731-8329;
parkinsonslv@cs.com

NEW JERSEY:

Mary Gualandi
131 Ticonderoga Drive
Toms River, NJ 08755
(732) 505-1739

NEW YORK:

Mary Connolly
5077 Foster Road
Canandaigua, NY 14424
(716) 394-5306
Marcy Todd
2 South Court
Port Washington, NY 11050
(516) 883-7455

OHIO:

Debbie Mills/Parkinson's Center
P.O. Box 670525,
Univ. of Cincinnati
Cincinnati, OH 45267
(513) 558-7312
Bernice Bowers
7617 Ashler Court
Canal Winchester, OH 43110
(614) 833-2588
Jennifer P. Smith
302 N. Broadway Street
Barnesville, OH 43713
740-425-3253

OREGON/NORTH CALIFORNIA:

Betty Scoggins
2272 London Avenue
Redding, CA 96001-2115
(530) 241-6663

OREGON:

Sandi Hansen
11733 South East Koala Drive
Clackamas, OR 97015
503-698-8129

PENNSYLVANIA:

George Weaver
RD #1, 245 C
Mill Hall, PA 17751
(570) 726-6164

PENNSYLVANIA (South Central):

Daniel K. Lake
220 Broadmoor Drive
Willow Street, PA 17584
H: 717-464-4057
W: 717-397-9037
e-mail: dansr@desupernet.net
Ruth Nulph, R.N.
511 S McCandless Road
Butler, PA 16001
(724) 287-8600
Jane Wright
PA Hospital, Neurology Department
330 S. 9th Street
Philadelphia, PA 19107
(215) 829-7273
Tina Moyer
216 S. Market Street
Selingsgrove, PA 17870
(570) 374-7496

SOUTH CAROLINA:

Doris McCray
613 5th Avenue, South
Myrtle Beach, SC 29577
(843) 445-1647

TEXAS:

Karen Kennemer
2235 Cedar Falls Drive
Kingwood, TX 77339
(281) 358-2282

Judy Brannen
312 Meadowhill Drive
Benbrook, TX 76162
(817) 249-0824

RHODE ISLAND:

Kelley Harrison, Ph.D.
72 Dana Street, Apt. 3
Providence, RI 02906
(401) 621-8566

VERMONT:

Janice Clements
649 Everest Road
Milton, VT 05468
(802) 893-1263;
janclem@together.net

VIRGINIA:

Allen Rohifing
332 Whiting Lane
Virginia Beach, VA 23456
(757) 426-5281
Kathy M. Sands
9603 Symphony Meadow Lane
Vienna, VA 22182-4421
(703) 242-9322; (703) 676-5319
e-mail: Kathy. rn. sands@saic.com

WASHINGTON:

Roberta Hunt
Rt. #1, Box 60A
Walla Walla, WA 99362
(509) 529-1364
Fran MeHahon
7148 191st Avenue, SW
Rochester, WA 98579
(360) 273-9496
franmcdoll@aol.com
WISCONSIN:
Barbara Sharkey
5066 Evergreen Court
Rhineland, WI 54501
(715) 362-1777

If you would like to help start a support group in your area, please call the SPSP office at 1-800-457-4777.

News From Support Groups

CHICAGO PSP SUPPORT GROUP



The Chicago Support Group met May 20 at the Abington Rehab Center of Glenview. They were pleased to welcome Dr. Teepu Siddique, Director of Neuromuscular Disorders at the Northwestern University Medical School. Dr. Siddique summarized the research goals for PSP. The Chicago Support Group normally meets the first Saturday of every month at the Abington of Glenview, 3901 Glenview Road, Glenview, IL 60025.

BALTIMORE SUPPORT GROUP



Back row: Ronald Simmont, Sr. Ginger Wick, Ruth Goldstein, Bruce Barnett
Front row: George and Shirley Curry, Doris McCray (support group leader)



Ellen Katz and Valerie Levitan, Educational Director of the Dystonia Medical Research Foundation, attend the NORD Tribute Banquet in Washington, D.C. in May.

DALLAS-FT. WORTH AND SURROUNDING AREA ORGANIZATIONAL "Caring and Sharing Meeting" SATURDAY, OCT. 21, 2000

... A Word from your Editor

Dear Friends,

During the week of Oct. 22, 2000, the American Academy of Ophthalmology will be holding their annual meeting in Dallas. I will be representing the Society for PSP with several other PSP volunteers at an informational exhibit during that week. As most of us know, the majority of our PSP searches begin at the ophthalmologist and then continue as we trek to other specialists. The Society is striving to promote PSP awareness and provide information critically needed in the field of ophthalmology.

On Saturday, Oct. 21, 2000, the Society for PSP will be hosting an organizational meeting of "Caring and Sharing" for PSP families and caregivers in the Dallas/Ft. Worth and surrounding areas. A registration/ invitation with more information will be sent to all addresses in the area in Sept. I will be representing the Society at this meeting. I want to meet and talk with all of you! It is the Society's hope to bring you together so that you will learn that you are not alone and that future forums of support and networking will emerge from this meeting.

If you have any questions, please contact me at (757) 838-0777, email 103301.640@compuserve.com. I look forward to seeing you at the Dallas/Ft. Worth "Caring and Sharing Meeting."

Sincerely,
Nancy Brittingham

THE SECOND ANNUAL CANADIAN PSP SYMPOSIUM

The Second Annual Canadian PSP Symposium is planned for November 4 in Toronto, Canada.

The Toronto Inaugural PSP Symposium was such a success that a second one is being planned. The second meeting will include some of the information of the first, but a much different program is being planned. This year the focus will be on a therapeutic perspective for both PSP and MSA. The speakers are all trained therapists (physical, occupational, speech) who have worked with individuals with these diseases and will address various strategies of ways to improve one's quality of life with these chronic diseases. Dr. Mark Guttman, neurologist and movement disorder specialist, will discuss PSP/MSA from a medical and research perspective. For further details about this symposium, please contact social worker Janice Stober by email stoberj@hotmail.com or by telephone at (905) 472-7082 #3.

MISSISSIPPI SUPPORT GROUP

Group by Denver Flangan

We had our third support group meeting at the Inglewood Manor Nursing Home where my wife, Catherine, is a resident. David Hill, Executive Director of the Home, was kind enough to furnish us with a private room and refreshments compliments of the Inglewood Manor. As far as I know, we are the only support group in Mississippi.

We are a small group and two of us have PSP. We try to meet every quarter, if possible. If anyone would like more information about our meetings and group, please contact me at (601) 372-1784 or email Denflan@aol.com.

ATLANTA SUPPORT GROUP

Kathy Thomas of Atlanta writes that their group tries to meet once a month at The Wellness Center at the DeKalb Medical Center. The group continues to grow. Information about PSP is discussed and there are sharing discussions among caregivers and persons with PSP. For more information about dates and times, please contact Kathy Thomas at (770) 939-2612.

Support - Helpful Hints

Nancy,

A very useful device for us is a "gait belt" provided by the physical therapist. This is a washable webbed cotton belt about 2 inches wide with a saw-toothed metal buckle. My husband is 6 feet tall and I, like most of his caregivers, was considerably shorter and lighter. By holding the belt from the back or side, we could help him keep his balance while walking or standing or at the toilet. Holding the belt from the front was very helpful in getting him up from his bed, his chair or from the floor.

Paula

PSP LOOKING FOR ACTIVITIES

LISTSERVE SHARING

requests@hydra.welch.jhu.edu

Subscribe psp your name

We take Mom out on the porch and put potting supplies on an over-the-lap table, for her to plant things. We have those plastic hanging bags with holes down the sides that you have to put your finger in the hole to dig a space, and then put the bulb or plant in. Mom needs lots of help doing this, but she likes getting her fingers in the dirt, and she loves the resulting hanging blooms.

We also have a variety of plush animals for her to hold on to that make sounds. This is good exercise for her hands and seems to amuse her. We also have the pop-eye rubber "doll" that you squeeze to make the eyes, ears and tongue pop out. That's good exercise too. Those bubble wrap plastic packaging make good exercise to pop the bubbles. Sometimes we just give her the bed control and she "adjusts" the head, foot and height. She generally ends up with her head down, and feet up, but that position is healthy for her.

We also have a dog and a cat, and she enjoys them on her bed, though we have to be in close attendance so she doesn't get scratched or licked on the mouth. She is so disabled now that we have to help her pet them appropriately at first, then they generally just lie down beside her, with her hand on them. If you don't have a pet, you could call your humane society to see if they have someone who takes animals to visit nursing homes, etc. That way you could see how she reacts to a pet.

Mom also enjoys the "Win a Million" quiz show. We have to read the choices for her, but often she knows some of the answers. On the night they had movie questions, she knew Bob Hope MC'd the most Oscar shows, when the rest of us thought it was Billy Crystal.

We have a trapeze on Mom's bed that we use to help us pull her up to the head of the bed. She likes to keep hold of it afterwards for awhile. We have a cordless phone with the speaker in the phone — and she insists on holding it when people call her. She frequently hangs up on them - or hits the intercom button, etc., but that just gives us more to talk and laugh about.

I am lucky enough to have a nice view and Mom's bed is in the window, where she can see out. We keep a hummingbird feeder in her view, a platform for corn for the squirrels, and a bird feeder. I don't know how much of this she can focus on, but it adds socializing for us to point the activity out to her . . . and it makes us feel better.

Patsy caregiver to Fran



While Ed still had the interest I used to sit and play games with him after lunch, telling him it was therapy time. One of his favorites was "Dominoes." I bought a set with large blocks and colored dots which were easy to handle and the color made it easy for him to match up. We also played with a set of design blocks of different colors. We would try making a pattern or he could just turn all the blocks to the same color so it showed a solid color. We played with games that had belonged to our children when they were young. He liked dropping a marble into a slot and watching how all the marbles moved. (Avalanche) and stacking "Blockhead" blocks till they tumbled over. We used Lego's Lincoln Logs and wooden Tinker Toy set pieces. When we used games with many small parts, I'd put them in an extra-large sheet cake pan to make pick-up easy. He screwed nuts and bolts together and took them apart again. He used crayons and tried to color pictures.

The grandchildren would toss a ball with him or play "Old Maid" card games. I think what was most important was the one-on-one interaction he got as we played. Think of your PWSP's (person with PSP) interest and try anything that might be fun for the both of you. When he no longer had enough co-ordination to do these activities, I would put his old favorites on the stereo and he would listen to music, classical, marches, Mitch Miller, Mario Lanza, operettas, folk songs. I am thankful we had a large record collection to choose from. I also put videos on with comedies like The Three Stooges and Charlie Chaplin or travelogues of places he would have liked to have seen.

He also enjoyed TV—train journeys and programs on PBS, Discovery, History Channel and the like. He was able to enjoy them even when it was hard for him to see. He would lie and listen to anything that caught his interest. He spent his days on the sofa or his recliner so he was in the middle of any activity. He loved to get company. He would listen as we talked and if something struck him as funny he would give a loud laughing sound. He was good company even when he couldn't talk and he knew what was going on right up to the end. I miss his presence in my life!

Hugs, Pat

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. Please check with your physician.

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

Fax: 757-838-6086

email: 103301.640@compuserve.com

October-Our First National PSP Awareness Month and Our 10th Year Anniversary Commemoration

Dear Friends,

In October of this year, we will be commemorating the Society's 10th year anniversary - "A Decade of Caring." It is also planned that October will be designated as National PSP Awareness Month. The society is asking your help as we strive to make our first National PSP Month and our 10th year anniversary commemoration a success.

We are asking each Support Group as well as any families affected by PSP to plan an event during the month of October to raise awareness of progressive supranuclear palsy. We know that so many of you are overburdened with caregiving responsibilities, however, perhaps you may have friends or family members who want to help in the fight against PSP. We envision a nationwide campaign of grassroots efforts planning special events. Perhaps you know someone who could organize a walk-a-thon or simply a pot luck supper. We are also asking each group to contact the local media and tell them about their event.

We would like each group to take a group photograph, if possible videotape, and write up a short account of their event. This will be made into a special publication, "The Faces of PSP." Most importantly it will bring all us together as we pay tribute to all persons with PSP, loved ones that have lost their lives because of PSP, families, caregivers and the Society.

So often a person or group asks - what can we do to make a difference? Here is one possible opportunity. We look forward to your participation in this special Society tribute. Thank you very much.

Sincerely,

George Jankiewicz, Jr.

George S. Jankiewicz, Jr.

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.

Meet Us In St. Louis!!

The St. Louis PSP Support Group will be hosting a "PSP SYMPOSIUM-FOCUS ON FUNCTION" on Sunday, October 15, 2000. Speakers will include a licensed physical therapist, a registered occupational therapist, a speech-language pathologist, a licensed counselor, an attorney knowledgeable in Durable Power of Attorney status, a caregiver and our own Society Director, Ellen Pam Katz. Watch for the REGIONAL flyer and registration form to arrive at your address in September. Mark the date!! For more information contact the Society office. We'll Meet You In St. Louis!!

Reading
Period 7

Jeremy Pohlman
Nov. 1, 1999

ANYTHING IS POSSIBLE IF MY GRANDPA WAS O.K.

If my Grandpa was O.K. I could talk to him and he could talk back to me.

If my Grandpa was O.K. I could go on bike trails with him like we used to.

If my Grandpa was O.K. he could watch me ride my dirt bike.

If my Grandpa was O.K. he could watch me play sports like he used to.

If my Grandpa was O.K. he could take me places with him and we could have lunch together.

If my Grandpa was O.K. he would be able to feed himself and dress himself.

If my Grandpa was O.K. he would be able to get out of that dumb wheelchair he has to be in.

If my Grandpa was O.K. he would be able to walk and run.

If my Grandpa was O.K. he would be able to laugh at the funny things I say and do.

If my Grandpa was O.K. he would not cough and struggle to breathe.

If my Grandpa was O.K. I wouldn't always be worried about him.

If my Grandpa was O.K. I wouldn't have to always think this is the last day I will ever see him again.

If my Grandpa was O.K. I wouldn't have to feel sad when I see him.

If my Grandpa was O.K. we would do all kinds of things together.

If my Grandpa was O.K. my Mom wouldn't cry and feel so sad.

If my Grandpa was O.K. the doctors wouldn't say that he will pass away any day now.

If my Grandpa was O.K. he would be able to do anything he wanted to do just like he used to.

God's Champion

God chose a champion in our Dad
Dad has never let him down
His heart is filled with pride
His strength knows no bounds
He is the greatest champion
Yet he is only a man
He has come through life's tests
with his dignity in hand
He is our Dad
We have all been through a lot
He loves us all completely
We cherish all that he has taught
He always met life with courage
Our respect and admiration grew
And during all of the bad times
His love has carried us through
How much adversity can a man take?
He had more than his share
Still never did he falter or
Say that life was unfair
His strength was amazing
Pick yourself up no matter how tough the test
He expected no less from his girls
Always give life your absolute best
Keep moving forward, don't look back
And don't let life get your down
Always determined, driven and strong
We felt safe when he was around
He felt illness and death far too often
And it greatly rocked his world
He just kept pulling himself up
He had to be strong for his girls

It is said we are not given more than we can bear
He did not ever let us down, not Dad
He took care of his three girls
In good times and in bad
Who would have thought
That such a horrible disease
Could slowly take down our Dad
Not him, no not him please!
He has given a valiant fight
For many years on end
A tougher battle he had not fought
But, this one he can not win
The Dad we have know and loved
Is quickly fading away
His eyes are blank and distant
Soon he will no longer be able to stay
In his mind he knows what was happening
Though he cannot tell us much
His disease makes speech so difficult
Still we know what he feels through his touch
The suffering will soon be over
God will call his champion home
Our memories and thoughts of Dad
Will keep us from ever being alone
If heaven is a place filled with souls like you
Then we will not be afraid or sad
When our time is up and we must go
Because we will all be together again DAD
With love to our Dad, Carl Hale
Your Girls,
Melanie, Carla and Cherry

Broken Strings

A little over a century ago, the violin of Nicolo Paganini was enchanting many an audience in Europe. Paganini was a gaunt and an awkward-looking individual, and many times his clumsy movements provoked unrestrained laughter.

During one of his concerts, it seemed that all the evil fates had conspired against him. He came limping on the platform because of a nail that had run into his heel.

After he had played only a few notes, one of the strings on his violin broke and the audience snickered. When the second string broke, the laughter became more audible. When the third string snapped and Paganini continued to draw divine music from the single remaining string, the audience forgot the mishaps that might have wrecked a less determined musician. They realized that genius was unfolding itself before them; Paganini's beautiful music continued despite his broken strings.

Who has not been called upon to make his contribution to the symphony of life without broken strings, without having suffered grief and adversity? Inspiring, indeed, are those individuals who continue to make beautiful music on the stage of life, despite the gnawing pain of disappointment, grief and sorrow.

We lovingly recall those who gave us life, recommitting ourselves to being fully present in the symphony of life despite our inevitable broken strings.

*Shana tovah,
RABBI JAY R. GOLDSTEIN*

Support - Our PSP Stories

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

The Road Trip

By Sandy Riley, wife and caregiver to Jett

Jett is 44 years old and diagnosed with PSP 3 years ago

It is so painful to watch someone you love go through PSP and feel so helpless. I think we're on the right track with trying to be cheerful and loving. I have to work on this myself. I keep telling myself that this is the way it is, I cannot change the course of this disease, and I have to make the best of it. The trick is finding out what that is according to what stage the PWPSP (person with PSP) is in. The PWPSP and their families should live their lives to the fullest while they can. My husband's progression has been very rapid at times, then plateaus for periods of time. I am so grateful we were able to travel some early in his illness. I wish we could do more now. Last week we took a short trip (5 hr. drive) to Georgia to a hunt camp where we have an old trailer and pickup truck. It took half a day to load all needed equipment, food, cooler, etc., into the car. Then I got my husband/PWPSP loaded and ready to go, and "click"!! The car wouldn't start. I got the jumper cables out of our daughters' car, and jumped the dead battery to life. (Not a good sign on the beginning of an adventure!) My husband was able to use the bathroom before we started, I was glad for that. He really doesn't like me taking him into the women's or men's restroom. Too bad there aren't more "family restrooms." I told him I would put a bag on him for the ride, but he didn't want that. He lasted the whole ride without going again until we got there.

We ended up going to the wrong piece of property in the wrong small town (hunting property in small towns in GA all look alike to me), but after an hour delay, found the right place. I got him inside, opened up all the windows, and started unloading. The electricity worked, hence the A/C worked — thank goodness for small miracles. This was one of those 100 degree days. The water lines had more air than water and kept "blasting" at me. I brought soup, potatoes, creamed veggies so I lit the gas burners and started heating up supper. That lasted about two minutes, then out went the flame! Both gas bottles were empty. I found a key to a friend's trailer that had a microwave (even better, huh!) so was able to have a hot supper after all. I got the blender going and whipped up a delicious shake also. I found an old friend - Jack Daniel - to help unwind a bit. The highlight of the trip was a mama fox and her kit playing outside the window where we were sitting. We finally finished the evening meal about 10:30; no hot water without gas, so no showers. I made up his bed and I got the sofa. The A/C worked so good -all or nothing- I had



The Rileys, December 1998: "A favorite picture"
Left to right: Casey, 18; Nickie, 20; Holly, 17; Sandy & Jett

to find blankets in the middle of the night. Long night.

The next day was busy with cleaning out food from cabinets and fridge left from last fall (guess neatness is not a priority in a hunt camp). The morning started with breakfast, then load the car back up, lunch, etc., then back on the road. We have always enjoyed the small towns in Georgia; the rolling hills, farm fields, neat little towns with beautiful turn of the century homes and churches. It's relaxing just thinking about it! There's a beautiful old historic hotel that has been restored in Americus, GA that is a "must see" for any of you close enough. We have

stayed there before and enjoyed wonderful meals in their dining room.

Why is it the trip back home always seems longer? He wanted some good Southern-fried chicken you could smell cooking at a country store where we stopped for gas before leaving town. He wanted it soooo bad, but he just can't eat this kind of food anymore. He insisted, so I got a few nuggets and a drumstick. It was so frustrating, but he just couldn't chew it up. I had cold tomato soup in a sipping bottle, water and juice in other bottles. He was having a hard time holding on to the bottles, finding his mouth and sucking. Traveling Interstate 75 at 75-80mph and driving with my left hand while trying to help him drink is a bad situation, and dangerous. I finally got off, pulled over under a big oak tree and got a Coke and yogurt out of the cooler and made him drink and eat all before we went any further. We made it back home in one piece but I don't think I'll attempt another road trip without at least someone else along to help. It was an exhausting two days for me, but I think he enjoyed the change, and just getting out of the house.

Do what you can with your loved ones, while you still can. Make the effort; you won't regret it. We can look back and have something to laugh about. Laughter is good. I guess after this long-winded story, the point I was trying to make is I think we really have to make the effort to bring about those special moments, to share what we can through communication, humor, silly jokes, etc. Even though our PWPSP may not be able to talk to us, for the most part, they can hear and understand everything. Don't shut them out. Include them in as much as possible. I don't think they want to be babied, pitied, or talked about like they are not there. I pray that we will all have the strength, understanding, patience and compassion to show respect and care for our PWPSP.

Sandy wife/caregiver Jett

Living and Coping with Progressive Supranuclear Palsy

By James A. Stephens

.....progressive supranuclear palsy.....

Had you ever heard of it? Well we didn't either until my wife of 54 years was diagnosed with it. That has been six years ago. I remember I started to notice she had a slight stutter in her speech. This worried me but I talked to our druggist and he asked me if I knew what medications she was taking. When I told him of a pill that she took to help her sleep he said it was possible that the sleeping pill could cause a slur in a person's speech. I asked our daughters if they noticed it. They said that they didn't. Not at that time. But they started to pay attention and listen when my wife talked and they too did start noticing it. It seemed her speech kept getting worse. One day while she was out shopping, she walked out of the shopping mall and without any warning she fell on the sidewalk. She didn't even realize she had fallen. She was helped up by a Good Samaritan and escorted to her car. She had fallen on her face and broke her glasses. Her face was black and blue. When she got home and told me what happened I was really worried.

She and I knew something terrible was wrong. She went to the doctor and had X-rays, which showed nothing. After that incident, we started to notice she was having more problems. After counseling with her physician, he decided that she might have Parkinson's disease. He referred her to a specialist. It took a long time and numerous tests. Finally, she was diagnosed with this "progressive supranuclear palsy."

We were so thankful because I was afraid it was brain cancer and I had asked God, "Please don't let it be cancer." I was very relieved that it wasn't. When her doctor explained more about PSP to us, it was hard to believe that all those things were going to happen to this woman I married when she was just 16 years old. Our daughters and I did not want to accept the bad news we had received, so we asked the doctor if she minded if we got a second opinion. Our doctor provided us with all the test results and we made an appointment at the University of Washington Medical Center in Seattle. It was sad but we had some hope that they would find something different. But it did not happen. They said that her doctor's diagnosis was correct. I asked God, why my Mickie? She is about as perfect a person as anyone could find. I know my Mother would have picked her for me if she'd had the chance.

Six years have gone by now. I have seen this proud woman dwindle away a little at a time since we began our downward journey. At first, I resented her having to buy a cane and then I resented the walker and then, the terrible wheelchair. Mickie was a craftsman, a bowler and a maker of beautiful afghans and even bedspreads. I have seen those beautiful hands spend a whole evening ripping an afghan completely apart if she made a little mistake; it had to be perfect. I would roll the yarn back in a ball for her as she took it apart. (If it had been my fishing line, I would have thrown it away). She made her mother and each of our three daughters one of those afghans for their homes.

It grieves me deeply that such a very neat and proud woman would come to this point in life. She has lost the use of those pretty little petite hands that I always adored. Hands that used to make such wonderful dishes and special pies. I

don't think I will ever like pies or cinnamon rolls again. No one in our family was as special as my little petite, brown-eyed wife. I am in my seventies now and so is she. I have taken over the kitchen that she enjoyed so much. I know it hurts her to see other people working in her kitchen. My wife was an in-charge person when she was able to do so. I don't know how she stands it now. At this point, she has to be fed and she has so much trouble speaking. I am thankful that we know and trust in the Lord. I know "He" has a purpose for everything. Maybe this thing that's happened in our lives has some purpose. I, and so far no one else, knows what causes this disease, but it's a terrible thing and there is no known treatment for it.

Mickie worked hard to get her job at Washington State University. She started as a house cleaner and did so well at her work. She was there for 15 years and they promoted her to a supervisor position. We retired early. We got in some enjoyable things before the disease started manifesting itself.

We had been getting wonderful home health care but due to the changes in the Medicare program, they are unable to help us anymore. This is an example of how wrong our Medicare program is. We are a couple who worked hard all our lives. We each get small retirement checks each month from the places we worked. Along with Social Security we get by, but we have to hire home help, which cuts us to the edge on our finances. I am taking care of Mickie on a full-time basis. I am her care provider. She is unable to even feed herself or move without help. Recently I fell and broke my left wrist. When this happened, home health came in and helped until I was healed enough to be able to give her shots. Once I could do this, they pulled out. At this time we are getting no help from them.

Our closest daughter lives 300 miles away. Dianna is able to come once a month, which is a lot of help to me. Without her help, I'm not sure if I could make it. Our good friend, Lee S. is Mickie's hairdresser. She comes to our house every Friday to do Mickie's hair. Mickie has been going to her for years but when she could not go to Lee any more, Lee started coming to her. Our daughters set this up for their Mom. No doctors here are able to treat Mickie. All they do is give her medication for depression. She is so dearly loved by our children and grandchildren. Our people from church come to our home for communion also. They tape sermons so that we can listen at home. I am thankful and I can feel blessed that I still have Mickie and that she is so content to be confined to her home day in and day out. She can see and hear and does enjoy TV programs and we have lots of roses and a pretty yard. I feed the birds and squirrels each day and we both enjoy that. I don't mind giving up the things I used to do, like fishing and the outdoors and traveling. Our minister asked Mickie what, if she could choose, would she ask the Lord for and she replied, "I would ask the Lord to let me walk again." I guess if I was asked, I would ask that I stay able to care for her.

We had our church congregations and friends writing to our Congressmen and Senators and I wrote to the President as well. He wrote back and said he would sign the appropriate bills as soon as they come to his desk. But no one is aware of this PSP - progressive supranuclear palsy. The only research being done is supported through private donations. We desperately need more research to find out the cause, treatment and cure for it. I hope that the government will allocate more money for PSP research. It may be too late for my Mickie, but there are many others out there and I would be happy if something is done that may help them.

Support - Our PSP Stories

Diagnosed With PSP

Continued From Page 3

at night during the early evening, I take a nap. I have also stopped reading when I eat so that I can concentrate on swallowing. Then I have less opportunity to forget about what I am doing and choke. I consider these management techniques. I may have become worse because I know what is wrong. However, I would not want to fall without knowing why. This disease is very frightening anyway.

Do not go to a completely new game plan. I did not. I have always liked to write things down. In fact, I was accused of having my dogs go through time management seminars. (I don't make them do that.) I have used my existing tendency to use time management techniques. They have helped me develop a way to make my diet, medication and life consistent. This is not the only way to keep on track, it is just one way and it is what I do.

WHAT WILL HAPPEN

I know what will happen, I just don't know when. I was given a time window of 0-10 years. I have decided that I am only going to manage today. One day at a time means that I will only deal with the feelings and concerns that I have right now.

One of these concerns is what will happen in the future. I have always had this concern. So I am currently seeing a counselor to deal with this disease and my feelings towards it. I also want to deal with a fear of people that I have always had. I simply don't have time for it any longer. These feelings, I think come from the disease itself. I do not want to dwell on it. So I have developed a written plan. I do want to have a plan to base my management of this disease on. This also fits my usual character.

FEEL THE WAY YOU FEEL

Feel the way you feel. Do not let others tell you how to feel because only you know. What I mean is that you may be embarrassed by the noise your choking makes. So may others that are with you. Their embarrassment usually occurs because others do not know about what you have. Or you may be upset by the attention that you draw to yourself when you fall. This too, can be embarrassing.

Of course, you still need to behave according to the social norms that you accept, but your feelings of frustration are still yours. Because you have your water and are in your place others think that you are fine simply because your physical needs are provided for.

Go with that and remember that others are only doing what they can to help. The only advice that I can offer in this vane is to "let" others help. I want emphasize the word "let". In my family it does not work to expect or even demand that they help. You simply must "let" them.

Also it is a good idea to join support groups or make sure that your caregivers do. I have limited my thinking to positive things only. I let my caregiver read the negative things and tell me if I need to know. Trust is most important here. This is a good way to keep abreast of what is going on and to stay in touch with those who care about those with this disease.

Society Upcoming Events

OCTOBER-PSP AWARENESS MONTH

OCT. 14

The St. Louis Regional PSP Symposium, "Focus on Function"

OCT. 21

The Dallas/Ft. Worth Texas Family Meeting of "CARING AND SHARING"

OCT. 22-26

The Society presents an exhibit at the American Academy of Ophthalmology, Dallas, Texas.

OCT. 28

The Society for PSP's 10th year Commemoration, Baltimore, MD

NOVEMBER 2000

NOV. 4

The Second Annual Toronto PSP Symposium for Families, Caregivers and Persons with PSP

Upcoming Events For PSP Europe

OCTOBER 5, 2000

PSP Europe Symposium for Carers and Therapists, New Castle upon Tyne, (North England)

NOVEMBER 5, 2000

PSP Europe brings forty participants to New York to run New York Marathon to raise funds

NOVEMBER 6, 2000

Michael Koe, Chief Executive of PSP Europe to visit SPSP offices in Baltimore

OCTOBER, 2001

International Medical Workshop

DO YOU WISH TO BE A PSP COMMUNICATOR?

PSP Communicators allow their names to be part of a communicators list by state so that others in their state may contact them. If you would like to be a communicator please notify the Society office. A list of communicators in your state is also available at your request.

CORRECTION:

The Comfort of Home: An Illustrated Step by Step Guide for Caregivers
Care Trust Publications, Inc. (800) 565-1533

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.

Regular Report of Gifts

May 1 thru July 31, 2000

PSP PARTNERS - \$10,000 AND OVER

William Budge
Eugene and Renee Waldron in memory of Judy Waldron
Lois Zoller

GOLD BENEFACTOR - \$1,000 AND OVER

Allen Bezner in honor of Toby Bezner
Mary Ann Patton Casey in memory of Richard B. Patton
Richard Clift in memory of Miriam Clift
Alexander A. Courtney in memory of Mary E. Courtney
Dorothy Eubank
James C & Elaine D Hendershot
Charles Hinckley
Peter Holland in memory of Bob Holland
Jefferson Pilot Financial in honor of Barbara McKee
Jenkins Brick Company in memory of K.W. Dunwody, Jr.
Karen Keen in memory of Audrey L. Brooks
Michael McClellan
Mitsubishi Polyester Film
Modern Woodmen of America
Paramesh Nalval in honor of S.P. Srinivasaiah
New England Financial in memory of Margaret Parker
Edith Parker in memory of Edward Parker
Marlys Peters in honor of F. James Sauer
Philip & Sally Reynolds in honor of Sally Reynolds
David Richardson
Carolyn Scotton in memory of John Scotton
United Way of Southeastern Pennsylvania
Alan B. Willis in memory of Patricia Willis
Stewart Greenebaum
Janice Young in memory of Robert McKinley

GOLD PATRON - \$500 - \$999

Alta Med Health Services
Dorcas Atkinson in memory of James Atkinson
Milo Badger in honor of Joy Badger
Richard S. Colvin, M.D. - John Clements, M.D.
Memorial Education Fund
Cottingham Paper Co. in memory of Patricia Willis
C. Rae & Matt J. Franey in memory of Shirley Stephens
B. D. & Elsie Garland in honor of Elsie Garland
Freda Hale
Kitty & Echol Hayes in memory of Mary Newman
Henry B. Shovers Company Inc. in memory of Virginia Shovers
Mark L'Heureux in memory of Loretta Gilsdorf
P.H. & Kathleen Moore
Palm Desert Ace Hardware in memory of Chester Dorn
Joan Reifler in memory of Norman Reifler
Mark & Elizabeth Robinson in memory of Sue Robinson
Lucia Rosebrock in memory of Mary Ann Botjer
United Way of Tri-State
Kristin Vaughters in memory of Msgr. Lawrence Costello

SILVER SPONSOR - \$250 - \$499

Ian Andrews
George Apregan in honor of George Apregan
Stephen & Beth Carveth in memory of Tom Harrington
Taryn Leigh Chase in memory of Lee Liebl
Cissell Manufacturing Company in memory of Donald Giancola
Club Car, Inc. in memory of Eugene Irminger
Computer Associates International, Inc.
W. Carroll Coyne in memory of Donald Giancola
D.C. Daniels
Chester Dorn in honor of Chester Dorn
Keith & Jean Downard in memory of Josephine Vukovich
Robert & Prudence Drummond in memory of
Carol Becker Hutchinson
Joseph Dunn in honor of Beyond the Fringe/Dudley Moore
Friends & Relatives of Edna James in memory of Edna James
General Motors Corporation in memory of Irene Hanzak
Marian Golic in memory of Mervin Golic

Gothic Production Corporation in memory of Margaret Carole Tucker
Thomas Harkleroad in memory of Douglas Harkleroad
Ethel Haugen in memory of Oswald Haugen
Robert Henning
Lori Hensley in memory of William Lappin
Howard & Mary Heun
William Joyce in honor of Marie Joyce
Audrey Kancler in memory of Margaret F. Percy
Robert Karam in honor of Dale Ferris
Reuven & Cate Katz in memory of Halbert E. Payne
Karen Kennemer in memory of Mary McNicoll Cheslak
Edward & Helen Kezele in memory of Chester Dorn
Alma Klinetsky
Patricia Lappin in memory of William Lappin
Lions Club Of Racine in memory of Virginia Shovers
Miriam Malone in memory of Paul Malone
McDowall Company
Eugene Morris in memory of Phyllis Franck
Northern Trust Company in memory of Eugene Irminger
Pepsi-Cola Company
Eunice Phillips in memory of Delbert Phillips
Reflexite North America in memory of Charles Edmunson
John & Judith Remondi in memory of Joan Cullen
Jerri Shaw & Ray Johnson in memory of Mary F. Gist Shaw
William & Virginia Shelton in memory of Jane S. Mullen
Corine Skolnick
William & Martha Stearns, Jr.
Edward & Carol Stika
United Way of The National Capital Area
United Way of Tri-State
Van Hollebeke Family in memory of Donald Giancola
Edwin Watts
William Yetter in memory of Jeanne B. Yetter

DONATIONS - PATRONS \$100 AND OVER

Aaxon Laundry Equipment in memory of Donald Giancola
Donald Agnew in memory of Mary Agnew
Ronald & June Ahrens in memory of Halbert E. Payne
David Albertini in memory of Virginia Shovers
Jane Alexander in memory of John Clements
American International Group
Owen & Kay Anderson in memory of Virgie Ryon
Walter & Dale Angers
Joanne Armstrong
Darlene & John Atkinson
Katherine Avery in memory of Edward Pousont
Stephen & Mary Bailor in memory of Eugene Irminger
Donald & Sara Ball on occasion of their 45th Wedding Anniversary
Mary Ann Barber in honor of Charles Barber
Lester & Ina Barnes
Donald & Vicki Barrigar in honor of Vivian Barrigar
Vivian Barrigar in honor of Vivian Barrigar
Donald & Janet Barter in memory of Donald Giancola
Norman Bartz, Jr.
Lawrence Bates in memory of Carol Becker Hutchinson
Richard Bazemore in memory of Howard Bazemore
Connie & Maurice Beam in memory of Ellie Garcia
Robert & Susan Beeby in memory of Halbert E. Payne
Maxine Benson in memory of Leslie T. Benson
Berkeley Heights Traveling Baseball in memory of Albert Miller
V.D. Betts in memory of Mary Newman
Buster Bickerstaff in memory of K.W. Dunwody, Jr.
R. H. Bickerstaff in memory of K.W. Dunwody, Jr.
Walker Bickerstaff in memory of K.W. Dunwody, Jr.
David Blough in memory of Bessie Blough
Amy Ruth Boerger in honor of Marguerite Boerger
James Boerger
Darlene Bolton in memory of Donald Giancola
Boral Bricks in memory of K.W. Dunwody, Jr.

Report Of Gifts

DONATIONS - PATRONS \$100 AND OVER continued

Walter & Roberta Bregman in memory of Halbert E. Payne
udy A. Bryson in memory of Reynolds Bryson
Junior Maitin Bryson in memory of Reynolds Bryson
Frank Burman
Gwen Bush in memory of Alden Smith
Charles & Gilda Caines in memory of Mervin Golic
Mrs. Hugh Campbell in memory of Hugh Campbell
Michael Carlascio
Ida Carrier in memory of Paul Carrier
Chase Manhattan Foundation
Timothy Cheslak in memory of Mary McNicoll Cheslak
Chin & Hensolt, Inc. in memory of John Lo Pinto
Anne Clark in memory of Carol Becker Hutchinson
Barbara & Michael Clarke in memory of Frank Walsh
Class of 48 U.S. Naval Academy in memory of K.W. Dunwoody, Jr.
David Clements - John Clements M.D. Memorial Education Fund
Janice Clements in memory of Kenneth Bowers
Anne Collins
Peter M. Collins - John Clements, M.D. Memorial Education Fund
Patrick Condon in memory of Eugene Irminger
Michael & Barbara Connor in memory of Donald Giancola
Continental Girbau Inc. in memory of Donald Giancola
Mary Ann Cooper in memory of Eugene Irminger
Angela Coso
Travis Craig
Thomas & Jan Crews in memory of Annabelle Geller
Dorothy Dent
Thompson Dietz
Susan Dillman in memory of Jack Dillman
Juliette Dively in memory of Donald Giancola
Marcella Dolgin in memory of Morris Dolgin
William & Betty Drake in honor of William Drake
Paul & Becky Dutil - John Clements, M.D. Memorial Education Fund
Robert & Faye Edgar in memory of Kenneth Bowers
Janet Edmunson in memory of Charles Edmunson
Steve & Cindy Egger in memory of Charles Cooling
Empire Pathology Medical Group in memory of Josephine Vukovich
Employees of Palm Desert in memory of Chester Dorn
Teri English in memory of Patricia Willis
Fairfield Laundry Machine in memory of Donald Giancola
Paula & Richard Falender
Charles & Elizabeth Farrington in memory of Donald Giancola
Warren & Elizabeth Farrington in honor of Elizabeth Farrington
John & Dorothy Fenner in memory of Helen Harstad Strickler
Lisa Ferris in memory of Nancy M. Ferris
Film X Inc. in memory of Charles Edmunson
FIMCO Inc. in memory of William Tuomi
Karla & Gary Finley in memory of Eugene Irminger
Vicki Fiorella
Marian & Robert Fish in memory of Esther S. Cohen
Forenta in memory of Donald Giancola
Marcia Foss in memory of Sue Robinson
Lois Franklin in memory of Eugene Irminger
Sam Freitag in memory of Delbert Boyce
Friends of Verle Little in memory of Verle Little
Friends of William Tuomi in memory of William Tuomi
Fust Charles Chambers LLP in memory of Donald Giancola
Mary Gdovin in memory of Edward Gdovin
John Gehlert in memory of Ann Gehlert
Twila Gensel in memory of Donald "Red" Gensel
Jacqueline George in memory of Charles Edmunson
Alek Gilbert
Linda Gilliss in memory of Hugh Campbell
Margot Glick
Dorothy Golubin in memory of Irene Elizabeth Flick
John & Arlene Graham
William & Jean Griswold in memory of Charles L. Sooy
Kenneth Grundy in memory of Mildred Grundy
Eugene Hamilton in memory of Phyllis B. Hamilton
Sis Hammack
Jack & Jane Handy - John Clements, M.D.
Memorial Education Fund
John & Diane Harris in memory of Charles Edmunson

Robert Hayles
Patricia Hearn in memory of Claude Hearn
Jack & Doris Hedrick
Henry Brick Company in memory of K.W. Dunwoody, Jr.
Sharon & Richard Herzberg in memory of Chester Dorn
Winifred Hinze in honor of R. Hinze's birthday
Morris & Ruth Hirsch
Kenneth Hodge On the Occasion of 2 Strikeouts by Danny Neagle
Willa Hoerner in memory of Edward Hoerner
Jacqueline Hohler in memory of John Hohler
James Holloway in memory of Patricia Willis
Charlsie Holmes in memory of Henry D. Holmes, Jr.
Irwin & Emily Honigberg
Monique Houde
Larry & Chloe Huber in memory of Eugene Irminger
James & Betty Huffer in memory of Donald Giancola
Thomas Hug in memory of John Hohler
In Step Mobility Products
Phyllis Irish
Ann & Ned Irwin in memory of Florence Kauffman
Jack Pittman & Associates in memory of John Hohler
Eugene James in memory of Edna James
Catherine Jarvis in memory of Kathryn B. Marshall
J.C. Steele & Sons, Inc. in memory of K.W. Dunwoody, Jr.
Jerry Jonas - John Clements M.D. Memorial Education Fund
Doloris Jones in memory of Jesse Jones
Gary Jones in memory of Lisby Lucius Wade
Frank S. Joseph in memory of Marjorie Perrine
Vernice Kaphingst in memory of Robert Kaphingst
Virginia Kay in memory of Eldred Kay
David Keller in memory of Carol Becker Hutchinson
Brenda Kinsey in memory of Donald Giancola
Miriam & William Kinsey in memory of Charles Edmunson
Robert P. Kirkley in memory of Robert E. Kirkley
Beau & Gwen Kitchens in memory of K.W. Dunwoody, Jr.
Philip M. Klauber
James & Pat Kozeny
Robert Kress in memory of George Smith
Susan Kumar in memory of Marcella Gewirth
Lake Forest Library Board & Staff in memory of Eugene Irminger
Suzanne & Howard Landis in memory of Steve O'Connor
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Cheri Lawson in memory of Imogene Shively
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Muriel Leslie in memory of Thomas F. Leslie
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Walter & Sandra Lew in memory of Jesse Jones
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Osvaldo & Susan Lopez in memory of Charles Cooling
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Luminaud Inc.
Merle Lundstrom in honor of Violet Livingstone
Rich & Denise Lunoe in memory of Catherine E. Souder
Lutherhaus, Inc. in memory of Odis Dula
Lorna & John Mack in memory of Halbert E. Payne
Timothy & Patricia Malloy
Erica Marks in memory of Valeria Marks
Maury Marmor
Kerri Marshall in memory of Kathryn B. Marshall
Lois Martin in memory of Robert Cheek
Viola McCary in memory of Alvah D. McCary
Scott McCurtain in honor of Vernona S. Willey
Courtney McGowin in memory of Junius Graves
Rosanne & Arthur McGrath in memory of Halbert E. Payne
Richard McKee in memory of Jack Litten
Scott & Jane Medling in honor of Jean Pashalides
George & Judith Mellicker in memory of Bill Venard
William Mertens in memory of William Tuomi
John P. Meyer in memory of Eugene Irminger
V. E. & Mary Mikkelsen in memory of Edward Mikkelsen
Jacqueline Milgrim in memory of Sidney Milgrim

Report Of Gifts

DONATIONS - PATRONS \$100 AND OVER continued

James & Saranna Miller in memory of John Harold Brown
Joseph & Jean Mitchell in memory of Donald Giancola
Monsanto Fund
Jeannette Muirhead in memory of Charles Muirhead
Lorenz & Mary Muller in memory of William Lappin
Ena Murphy in memory of Martin J. Murphy
Sheridon & Roylene Murphy in honor of Roylene Murphy
Harriet Nall in memory of K.W. Dunwody, Jr.
National Institute of Mental Health in memory of Joselia & Ralph Muehrer
Randal & Kathryn Near
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Marta Nichols in memory of Martha DeClue Nichols
Florence Nicholson in memory of Donald Giancola
Richard & Melissa Nicol in memory of Vera Nicol
North American Bear Co., Inc. in memory of Annie Meyer
Northern Trust Company in memory of Eugene Irminger
Norwest Venture Capital Management
Donna & Steve O'Connor in honor of Stephen J. O'Connor
Marcia Olson in memory of William Tuomi
Cheryl Opalski in memory Mary Cembalski
Mary Anne & William Opalski in memory of Mary Cembalski
Pacific Air Reps in memory of Maria Maggiore White
Catherine Paddock in memory of Cyril Goss
Kathleen Palmer in memory of Mary M. Cavanaugh
William & Diana Parker
Richard Pepin in memory of William Tuomi
Julius Pericola in memory of Donald Giancola
Elizabeth Petricone in memory of Boris Schwartz
David Poulin in memory of Carol A. Rayworth
Charles & Elsin Powell
Pratt Audio Visual & Video Corporation in memory of Charles Cooling
Hans & Audrey Protschka in honor of Audrey Protschka
Provident Bank of Maryland - Pikesville Office
R W Martin & Sons, Inc. in memory of Donald Giancola
Doris & Daniel Raasch in memory of Donald Giancola
Fred & Verna Raiche in memory of Kenneth Bowers
Bill & Bonnie Ramsbottom in memory of K.W. Dunwody, Jr.
Stephens & Jackie Rand in memory of Bill Venard
Harvey Raschke in memory of Doris Raschke
Richard Ray in honor of Barbara R. Ray
Virginia Ray in memory of Eugene Irminger
Betty Reyher
Barbara Reynolds in memory of Delbert Phillips
Jacqueline Riley
William Riley
Rio Pinar Country Club in memory of Kathy Lorenzen
W. Harold Roberts in honor of Olza L. Roberts
Allan & Margaret Roder
Jan Como Rodriguez in memory of Ilio Como
Clarence & Zoda Rogers in memory of Kenneth Bowers

Joseph B. Rose in memory of Margaret Rose
Bruno Rosenberger in memory of Anne-Lisa Rosenberger
Charles W. Roska
Mary Sabra
Preston Sammons
Mary Adelaide Sanders in memory of Carol Becker Hutchinson
Peter & Anna Scholz in honor of Peter Scholz
Victoria Schreck in memory of Albert Schreck
James & Ann Schwarzkopf in memory of K.W. Dunwody, Jr.
Douglas Sheeley, Jr. in memory of Douglas V. Sheeley, Sr.
Thomas Sherman in honor of Phyllis Sherman
Shigeyuki Shimada in memory of Eugene Irminger
Ronald Simmont in honor of Claudia Simmont
Simpson Brick Sales in memory of K.W. Dunwody, Jr.
Esther Sloan
Virginia Small in memory of Donald Giancola
Ginny Smith in memory of Alden Smith
Patricia Smyth
Southern Brick Institute in memory of K.W. Dunwody, Jr.
James & Marie Sparks
Sheila Stathakis in memory of Grady E. Jack Maddox
Martha Stearns in honor of William Stearns, Jr.
Ian Stokes - John Clements M.D. Memorial Education Fund
Roger Storey in memory of Margaret Parker
Mark Strickland
Lorraine Strobel in honor of Philip Strobel
Robert & Mary Sublewski in memory of Mary Bridge
Ernest & Patricia Sulouff in memory of William Turner, Jr.
Sussman - Automatic Corporation in memory of Donald Giancola
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United Way Crusade of Mercy
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Andra Burke Varin
Tara Veith & Friends in memory of Steve O'Connor
Craig Wm. Venard in memory of Bill Venard
Joanna Venard in memory of Bill Venard
Warner Construction Consultants, Inc. in memory of Sam A. McTyre
Jerome Weiner
James Werner in memory of Donald Giancola
Westover Controls Corporation in memory of Mildred Bogetich
Donald White in honor of Wanda White
White Conveyors, Inc. in memory of Donald Giancola
White Electrical Construction Co. in memory of Mildred Hammond
Glenn Wilson in memory of Frieda B. Wilson
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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 86029
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- #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
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- #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.
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THE SOCIETY FOR
PSP
Progressive Supranuclear Palsy

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