

## The Society for PSP Awards Six More PSP Research Grants

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### mRNA Profiling in the Post-Mortem PSP Brain: Identifying Abnormal Signaling Pathways

**Sponsored by the Erwin and Pearl Poizzner  
Research Fund (\$47,500)**

Susan J. Augood, Ph.D.  
Department of Neurology  
Massachusetts General Hospital  
Boston, MA

The clinical course of PSP suggests that multiple brain regions are affected simultaneously. Indeed, studies of energy metabolism in the brains of PSP patients have consistently shown reduced glucose utilization in numerous brain areas which correlate with PSP symptoms. Impaired energy metabolism is broadly indicative of malfunctioning brain systems.

Recently, in studies funded by the Society for PSP, my colleague, Dr. David S. Albers, and I have found compelling biochemical evidence for such cellular dysfunction within the postmortem PSP brain. In this research grant, I now propose to investigate the molecular pathways involved in this underlying cellular dysfunction. I will use Affymetrix oligonucleotide GeneChip technology to examine the genetic profiles of different

### Mechanisms Regulating Neurofibrillary Tangle Formation in Progressive Supranuclear Palsy

**Sponsored by the Erwin and Pearl Poizzner  
Research Fund (\$42,406)**

Nancy A. Muma, Ph.D.  
Stritch School of Medicine  
Department of Pharmacology and  
Experimental Therapeutics  
Loyola University, Chicago, Illinois

Progressive supranuclear palsy (PSP) is one of the neurological diseases characterized by the presence of aggregates of abnormal proteins in the brain. In PSP, the tau protein accumulates in brain cells in abnormal aggregates called neurofibrillary tangles. The mechanisms causing tau protein to form neurofibrillary tangles are not known. Our long-term research goals are to determine the mechanisms causing tau protein to form neurofibrillary tangles instead of performing tau's normal function. By knowing the mechanisms underlying the formation of neurofibrillary tangles, we can target drugs to prevent neurofibrillary tangle formation and preserve normal brain cells in PSP.

Although the mechanisms causing the formation

#### INSIDE

**"Visions and  
Job Opportunities"**

**"Helping to  
Conquer a Rare  
Brain Disease"**

**"The Society  
for PSP  
Survey"**

# The Society for Progressive Supranuclear Palsy

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Reba and David Saks

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Core Director, Micronesian Health Studies

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

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

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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

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(757) 838-0777 • FAX (757) 838-6086  
(In memory of Henry and Jane Ogiba)  
Assistant to the Editor: Debra Thompson  
(In memory of Lois Croft Davis)

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# Director's Doings



I love the sound of music that motivates and inspires. What impact a song or an orchestral piece can have that is rooted in achieving meaningful action. I like to compare the sound of that music to the organizational "movement" of The Society for Progressive Supranuclear Palsy.

Just as emotional response emerges from the music, hope emerges from The Society for

Progressive Supranuclear Palsy. We are a vision-building organization and we have captured the trust of our audience. For those families isolated in rural communities throughout the United States, the Society offers the sounds of support through on-line services, peer communicators and solo contact with the PSP office. For those families living in larger communities, we offer working ensembles through support groups and regional symposia. To all PSP families, we offer hope of the grande finale that we have found a cure through the funding of cutting edge research.

As PSP families have "banded" together, our impact has become profound. We have grown in numbers as well as strength.

What is the next step for us?

We can't orchestrate our success-oriented plans without the addition of qualified professionals to broaden our impact. We need to boost our support and educational services with the addition of a Director of Outreach and Education. We need to capture and capitalize on new financial opportunities with the addition of a Director of Development.

Yes, the music from the Society makes for powerful listening. However, our Society orchestra needs skilled and qualified teachers and leaders to motivate, influence, and inspire its members and its audiences. We can only do this with talented and experienced additions to the Society's professional staff.

These times are filled with amazing possibilities and unforgettable sounds of hope. Just listen to us grow.

*Ellen Katz*

## Denny Neagle Celebrity Golf Tournament

The Society for PSP and Denny Neagle of the Colorado Rockies have teamed up to host SPSP's first golf tournament in 2001 to raise money that will support funds for the Society. We will be forming a committee to work on this event and would welcome interested readers to contact the Society's office for more details.

Please call 800-457-4777 as soon as possible since we will need to begin planning for this event as soon as possible. Don't delay on being part of this exciting event.

## "Visions and Job Opportunities"

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

### ASSISTANT DIRECTOR:

The Society seeks a highly skilled professional to manage all of the Society's administrative functions including human resources, office management, information systems, finance and payroll. Bachelor's degree and Master's degree preferred. Minimum of five years experience.

### DIRECTOR OF DEVELOPMENT:

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

### DIRECTOR OF OUTREACH & EDUCATION:

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

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



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

Continued from Page 1

## mRNA Profiling in the Post-Mortem PSP Brain

pathologically-confirmed PSP brain areas which are relatively vulnerable or resistant to the disease process.

A GeneChip is similar to a computer microchip and is divided into thousands of tiny compartments, each of which contains a different sample of DNA corresponding to a different gene. Exposing this GeneChip to DNA extracted from postmortem brain tissue from PSP and control cases generates a computerized list of which genes are expressed in which brain areas. More importantly, this approach of comparing samples from vulnerable brain areas with those from resistant brain areas from PSP patients and controls allows the rapid identification of genes which are either over- or under-expressed. This identification would take months or years using more traditional techniques.

This proposal extends considerably our previous biochemical and molecular studies of PSP and will allow us, for the first time, to examine simultaneously thousands of genes in order to determine what sorts of cellular activities render a particular brain region vulnerable or resistant to PSP. The identification of groups of functionally-related genes that are working incorrectly in the PSP brain will shed invaluable insight into the disease and may lead to new ideas for treatment or prevention.

## Mechanisms Regulating Neurofibrillary Tangle Formation

of neurofibrillary tangles from tau protein are not known, work in our laboratory and others is revealing some mechanisms that are likely to be involved. We found that in PSP, one form of tau protein, the form with 4 repeat regions, is over-produced in the brain. This same form of tau protein is also overproduced by mutations that cause another neurological disease characterized by neurofibrillary tangles. We also demonstrated that in PSP, tau protein is abnormally cross-linked by an enzyme, transglutaminase. Transglutaminase can cross-link proteins to form very stable protein polymers by linking together two or more proteins such as tau protein.

The goal of the proposed research is to determine the mechanisms involved in the abnormal transglutaminase-mediated cross-linking of tau protein in PSP. In the first set of experiments, we will examine different forms of transglutaminase in the PSP brain. In the second set of experiments, we will determine the factors that lead to increased cross-linking of tau protein. For example, we will determine if the form of tau protein which is over-produced in PSP (the 4 repeat form of tau) is more likely to be cross-linked by transglutaminase than other forms of tau protein.

### 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.*

## Comparison of Region Specific mRNA Expression Profiles of PSP Brains with Those of Alzheimer, FTDP-17, Pick Disease, and Non-Affected Brains Using DNA Microarray Technology

**Sponsored by the Eloise H. Troxel Memorial Research Fund (\$45,000)**

Peter Heutink, Ph.D.

Dept. of Clinical Genetics  
Erasmus University Rotterdam  
The Netherlands

Vincenzo Bonifati, M.D.

Dept. of Neurosciences  
La Sapeinza University Roma  
Italy

Progressive supranuclear palsy (PSP) is a neurodegenerative disorder characterized by parkinsonian signs and cognitive decline. The pathology of PSP consists of neuronal loss and the formation of aggregates consisting of hyperphosphorylated tau protein in neurons and glial cells similar to those found in other neurodegenerative disorders such as Alzheimer's disease (AD), Pick's disease (PiD), Cortico Basal Degeneration (CBD), and Frontal Temporal Dementia and Parkinsonism linked to chromosome 17 (FTDP-17). Genetic studies have shown that the microtubule associated protein tau gene is an important risk factor for PSP but how this risk is conferred is unknown.

Mutations in the tau gene have been found to cause FTDP-17 and this has opened the way to study the role of tau in neurodegeneration in more detail. Research on PSP can benefit from the work on FTDP-17 but the disorder is clearly a distinct entity and model systems specific for PSP need to be developed as well. Our research proposal is to compare the expression pattern of a large numbers of genes in affected areas of brains from patients with PSP and compare these with brains from other neurodegenerative disorders in which the tau gene is important. In this way, we will compile a catalogue of genes that have changes in expression pattern as a consequence of the disease. The found changes will then be verified and studied further in biological model systems such as cell lines and transgenic mouse models available in our laboratory. The result will help us to identify and characterize the similarities and differences in the disease processes underlying the different neurodegenerative disorders and this will help us to understand the pathogenesis of PSP and help us to develop better therapeutic strategies.

### 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@umdj.edu](mailto:golbe@umdj.edu) or Fax 732-235-7041.

## Doparesistant Parkinsonism in Guadeloupe: Evaluation of Isoquinolines Derivates and Acetogenines Toxicity in Rats

**Sponsored by the Eloise H. Troxel Memorial Research Fund (\$50,000)**

Dominique Capparros-Lefebvre, M.D.  
Neurology Department  
Centre Hospitalier Univeritaire de la Guadeloupe

(Information about this grant was previously presented in the PSP Advocate 2000, Fourth Quarter, Vol. 11, No. 4)

## Tau Auto-Antibody Production in Progressive Supranuclear Palsy

**Sponsored by the Eloise H. Troxel Memorial Research Fund (\$38,976)**

James W. Tetrud, M.D. and Laurel M. Bolin, Ph.D.  
The Parkinson's Institute Research and Treatment Center  
Sunnyvale, CA

The abnormal accumulation of the microtubule-associated protein, tau, results in PSP pathology. Since PSP is a disease of aging, and the aging immune system is prone to auto-immune abnormalities, it is possible that pathologic tau protein causes the PSP patient to make antibodies against tau. Preliminary data from a small group (14) of PSP patients and age and sex-matched controls suggests that this is the case.

We propose to (a) characterize tau antibodies in patient sera, (b) determine if these auto-antibodies react with particular types of tau, and (c) investigate the pattern of antibody reactions in PSP brain tissue.

These experiments may identify a "biomarker" for PSP in the form of a tau auto-antibody, which could result in more accurate diagnosis of PSP. Furthermore, data from these experiments may lead to new research strategies for investigating a possible auto-immune component in PSP pathology. The long-term goal of this research is to understand mechanisms that cause PSP neurodegeneration and design effective therapies to combat it.

## Regulation of Human Tau Gene Expression and Its Role in PSP

**Sponsored by the Dudley Moore PSP Research Fund and the Harold W. and Barbara Fox Living Trust (\$45,794)**

Jane Wu, Ph.D.  
Department of Pediatrics and Department of Molecular Biology and Pharmacology  
Washington University School of Medicine  
St. Louis, Missouri

The messenger relaying information for the hereditary material (genes or DNA) to the functional unit (protein) is called messenger RNA (mRNA). The production of mRNAs of the vast majority of mammalian genes, including the ones essential for the nervous system, involves a critical step of cutting off the intervening, generally non-coding sequences present in the mRNA precursors (pre-mRNAs). This process is known as pre-mRNA splicing.

An increasing number of studies suggest that abdominal

pre-mRNA splicing contributes to development of dementia and other neurodegenerative disorders. Recently, aberrant alternative splicing of tau genes has been associated with an inherited form of frontotemporal dementia and Parkinsonism linked to chromosome 17 (FTDP-17), a disease that shares certain common neuropathological features with PSP. In particular, both PSP and FTDP-17 are associated with certain tau alternative splicing isoforms.

We propose to investigate the role of aberrant tau splicing in the pathogenesis of PSP. We have begun to collect PSP brains and systematically screen these samples for potential defects in pre-mRNA defects. We will use combined molecular and biochemical approaches to study the regulatory mechanism underlying tau alternative splicing. With support from the National Institute of Aging, we have established both in vitro biochemical assays and a cell culture system to examine effects of newly identified and previously known splicing regulators on tau alternative splicing. Our study has identified certain regulatory factors important for this regulation. Furthermore, we have begun to use a tau mini-gene system to screen for potential drugs that may modulate tau splicing.

Molecular dissection of the regulatory factors controlling tau alternative splicing will not only help in understanding the basic mechanisms, but also reveal new players in the pathogenesis of PSP and other tauopathies. Such a study may also provide information useful for potential treatment of neurodegenerative diseases.

## Cleveland PSP Relative Study

Kenneth B. Baker, Ph.D.  
Department of Neurology, Cleveland Clinic Foundation

In a recent study conducted at the Movement Disorders Program of the Cleveland Clinic Foundation, researchers found that relatives of individuals with PSP, including brothers, sisters, sons and daughters, were more likely to perform abnormally on a Parkinson's disease test battery (PD Battery) than normal individuals having no history of PSP or other movement disorder in their family. In fact, of the 23 relatives tested, ranging in age from 27 to 83, nine scored in the abnormal range, whereas not one of the age-matched normal individuals scored abnormally. The test battery itself, developed originally as a tool to help physicians make the diagnosis of Parkinson's disease earlier and more accurately than is currently possible, derives its final score from a combination of three separate tests: 1) a video game-like wrist movement task, 2) a "scratch and sniff" test of the sense of smell, and 3) a questionnaire regarding a person's mood.

It is not clear at this point why the rate of abnormal performance among PSP relatives is so high, particularly considering that the chances of any of the participants actually going on to develop PSP is extremely small based upon our current understanding of the disease. Still, the difference may point to an as yet unknown factor that is shared among the individuals scoring abnormally. Whether this factor is genetic, related to some shared environmental exposure, or a combination of the two is yet to be discovered. However, it is possible that, by comparing the genetic makeup and environmental exposure history between those family members who score in the abnormal range and that of the relatives who score in the normal range, researchers may be able to identify the shared factor. Once identified, the role of that factor in the cause of PSP and the possibility of preventing the disease can be explored.

# A Man For All Seasons



## A Star-Studded Birthday Salute to Dudley Moore

Presented by Music For All Seasons

Monday, April 16, 2001, 7:00 PM

Carnegie Hall, New York

An evening of music, comedy, and film

featuring live appearances by Lauren Bacall, Chevy Chase, Christopher Cross, John Dankworth, Bo Derek, Jill Eikenberry, Eric Idle, Amy Irving, Cleo Laine, Robert Mann, Mary Tyler Moore, Tony Randall, Ann Reinking, Brooke Shields, Barbara Walters and many other co-stars, friends, and associates...

A post-concert Black-Tie Dinner with the Stars at the Essex House where his colleagues will pay informal tributes to Dudley

**Event Co-Chairs: Dame Julie Andrews & Sir Michael Caine**

Performance, Cocktail Party and Dinner with the Stars \$500 - \$1000

Performance and Pre-Performance Cocktail Party \$250

Performance tickets only \$35 - \$150

***SEND A PERSONAL MESSAGE TO DUDLEY***

Souvenir Tribute Book Pages from \$5,000 - \$25,000, Half Pages \$2,500, Quarter Pages \$1,300

**Don't miss the event of the year!**

**CALL FOR BENEFIT TICKETS NOW ☑ 908-322-6300**

**Call CarnegieCharge for Performance Tickets ☑ 212-247-7800**

Proceeds will benefit the work of Music For All Seasons and the Dudley Moore Research Fund for Progressive Supranuclear Palsy

*Save The Date!*

# THE PHILADELPHIA REGIONAL PSP SYMPOSIUM

***For Persons With PSP, Families and Caregivers***



Sponsored by  
The Society for Progressive Supranuclear Palsy

SATURDAY, MAY 12, 2001

9:30 am-1:30 pm

Embassy Suites at the Philadelphia Airport

An informational brochure and registration form will be mailed to PSP families and caregivers in the following states: Pennsylvania, Delaware, Maryland and New Jersey. If you do not receive a brochure by mid April, please call the Society office. The program will include:

- Continental Breakfast
- "Overview of PSP" by Howard Hurtig, MD
- "Update on Research" by Dennis Dickson, MD
- "Physical Therapy Techniques in PSP" by Heather Cianci, Licensed Physical Therapist
- "Maintaining and Promoting Nutrition in PSP" by Anne Golaszewski, MS, RD
- Panel discussion with neurologist, Stephen M. Gollomp, MD, a geriatric social worker, a dietician, a speech therapist, a nurse and a caregiver.
- "Our Visions and Opportunities" by Ellen Katz, Executive Director, The Society for PSP

Symposium will end at 1:30 p.m. Attendees are welcome to have lunch on their own in the hotel restaurant. Registration fee will be \$25 per person.

## *Announcing* COLORADO PSP MEETING

April 27, 2001

12:30-3:00 p.m.

Swedish Medical Center  
501 E. Hampden Avenue  
Englewood, CO 80110

Presented by the Colorado Neurological Institute and  
Parkinson's Association with sponsorship from  
The Society for PSP.

Colorado Residents: Watch for details in upcoming  
registration brochure.

For more information contact Debra Stef at her email  
address: [education@thecni.org](mailto:education@thecni.org)

*The Society for PSP  
will have an  
informational exhibit  
for medical professionals  
at the  
American Academy of Neurology  
53rd Annual Meeting  
May 5-11, 2001  
Pennsylvania Convention Center  
Philadelphia*

# SPSP - A Look Inside

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

### HONORARY CHAIRMAN

JOHN C. STEELE, M.D., F.R.C.P.

Dr. John Steele is the Honorary Chairman of the SPSP. In 1964 in Toronto, he and Professors J. Clifford Richardson and Jerry Olszewski first described the clinical and pathological features of a neurological disease which they called progressive supranuclear palsy because of its distinctive symptoms. Some also refer to it as the Steele-Richardson-Olszewski (SRO) syndrome.

During the past 20 years, Dr. Steele has lived on Guam, an American Territory and southernmost of the Mariana islands in the far Western Pacific Ocean. With assistance from international scientists, he has investigated another neurological disease called lytico-bodig which is common among local people living on those small islands. Because bodig is very similar to PSP, Dr. Steele and his colleagues hope that their studies in distant Guam can give understanding of its cause and maybe also of PSP.

Readers of the Advocate will be interested in a recent book by author Oliver Sacks which tells about the Pacific islands and Dr. Steele's life there. It is called the "Island of the Colorblind" and can be obtained at bookstores or ordered from [www.Amazon.com](http://www.Amazon.com).

### STEPHEN G. REICH, M.D.

#### CHAIRMAN EMERITUS

Stephen Reich, M.D. chaired the Board of Directors for the Society for PSP from 1990-1998. Dr. Reich completed college and medical school at Tulane University in New Orleans in 1983. He completed a neurology residency at University Hospitals of Cleveland before pursuing a fellowship in movement disorders at Johns Hopkins University School of Medicine. Since 1988, he has been on faculty at Johns Hopkins and is director of the Parkinson's Disease Center in addition to a large practice devoted to movement disorders. Dr. Reich has a strong interest in general neurology, particularly geriatrics, headache and degenerative diseases. He is involved in several clinical research projects investigating new drugs for the treatment of Parkinson's disease.

### JOANNE ARMSTRONG

#### HONORARY MEMBER

Joanne Armstrong has served as a librarian/media specialist in Delaware and Maryland public schools for 30 years. In 1990, Joanne met David Saks, Society founder, and began working with him to form an organization encouraging research into the cause and cure of PSP. Eleven persons joined the organization and the Society was launched in September 1990.

"How rewarding it has been to continue my involvement through the growth stages of the Society," Joanne says, "and to be the chair of a committee which defined the qualities the organization would be seeking in an executive director and formulated interview questions for the position in the fall of 1996.

As chair of the Bylaws Committee and the Board Nominating Committee, it was gratifying to witness the involvement of so many others as they joined an ever-expanding and truly dedicated working board with national representation. How exhilarating it was to serve as chair of the committee which would draft the Volunteer/Board Development section of the Strategic Plan for 2000-2003!"

In 1999, after serving nine years on the Board, Joanne was pleased to hand over her vote to a new board member and to take her place as an honorary board member, entering into discussions and offering historical perspective. She continues to serve as a member of the Development Committee and the Recruitment Committee.



*In 1991, David Saks, Society founder, meets Dr. John Steele.*

### GEORGE S. JANKIEWICZ, JR. CHAIRMAN

George S. Jankiewicz, Jr. was born in Baltimore, Maryland and still lives in the Maryland area. He has been a practicing CPA for 20 years and recently passed the Certified Financial Planner exam. For the past four years, he has been working as a manager in the health care and financial planning practices of the firm Clifton Gunderson L.L.C. George and his wife,

Laurie, have two sons, Phillip (15) and Matthew (11). George is a very active member of his church community and the Boy Scouts of America as a merit badge counselor and volunteer. George's father was diagnosed with PSP. George previously served as treasurer of the Society. "I accepted the chairmanship of the Society because the work of the Society is extremely important to many people, and indications of progress and growth were manifesting. My goal as chairman is to guide the organization in better meeting the needs of people with PSP by raising the awareness level among health care professionals, working to increase support for research in finding the cause and cure for PSP, and finding better ways to manage the disease at present."

### CAROL MARCHI VICE CHAIRMAN

Carol Marchi is a native of Massachusetts and received a B.A. in English from the University of Massachusetts (Amherst) and an M.A. in education from Stanford. Carol moved from New England and transplanted in California. She is a former high school English teacher and spent several years of work in adult education in both the public school system and the Catholic Church. For over ten years, Carol has worked in outreach for Parkinson's disease and other movement disorders (notably PSP). Carol has been married for 35 years to Joe Marchi, a retired college counselor. They have two adult sons. The Society congratulates Carol on her recent retirement from the Parkinson's Institute in Sunnyvale, California and the birth of her first grandchild, Ashley!

### JOHN FIEDLER, CPA. TREASURER

John Fiedler is a CPA for the Baltimore firm of Davis, Tankersley & Wolfe. He was born and raised in the Baltimore area, is a graduate of York College in PA, and loves golf. He has served as treasurer for the Society since November 1999.

## SPSP - A Look Inside

Although, John has no ties to the organization through a relative or family friend with PSP, he expressed his desire to become involved in community service and became interested in the Society for PSP. John "welcomes the challenge of dealing with the financial changes in this dynamic organization. I believe donating time is just as important as donating money. After all, many may not be able to contribute financially, but we are all able to donate our time and energy."

KELLEY ANN HARRISON PH.D.  
SECRETARY

Kelley Harrison, Ph.D. is a clinical psychologist who specializes in the treatment of behavior disorders in children and individuals with developmental disabilities. She received her bachelor's degree from Florida State University in 1985 and her doctorate from the State University of New York at Binghamton in 1991. She went on to become a faculty member at the Kennedy Krieger Institute and the Johns Hopkins University School of Medicine in Baltimore. She moved to Rhode Island in 1999 to be closer to her family and start a new position as a clinical director of the outpatient program at The Groden Center, Inc., a nonprofit agency in Providence.

Kelley started volunteering with the Society for PSP in the spring of 1997 after her father was diagnosed with PSP. She became a Board member in the fall of 1997. Currently, Kelley serves on the Executive Committee, is secretary of the Board, chairs the Recruitment Committee, and serves as a member of the Development Committee.



*The families of Society founders, David and Reba Saks, meet with the Society Board of Directors.*

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## Education

### Eye Movement Studies In Progressive Supranuclear Palsy

Jean A. Buttner-Ennever, Ph.D.  
Anatomy Institute, University of Munich  
Munich, Germany

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

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

In progressive supranuclear palsy (PSP), the rapid eye jumps (saccades) become slowed or impossible, particularly in the downward direction. The other types of eye movements remain normal at early onset. This is why persons with PSP often complain that they have difficulty walking downstairs or reading. Several studies on the saccade pathways in cases of PSP have been carried out and others are still in progress. One fact that seems clear from these eye movement studies is that the degeneration of nerve pathways in PSP spreads along the chains of nerve brain region called the superior colliculus – a structure essential for orienting the eyes, head and body towards any startling sight or sound – and that this could be the route through which the saccadic eye movement becomes affected in PSP.

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

# Helping to Conquer a Rare Brain Disease

By Theresa Argondezzi

## *Media exposure, research, nuclear medicine give HOPE TO PATIENTS of progressive supranuclear palsy*

Most people have never heard of it. Physicians don't know much about it. Late last year, actor and composer Dudley Moore surprised his fans and announced he suffers from it. And now, nuclear medicine technology might help unlock some of its secrets.

"It" is progressive supranuclear palsy (PSP), a rare degenerative brain disorder related to Parkinson's disease. While PSP affects only one in 100,000 people, there is no cure for the disease, and its cause is unknown. Further, diagnosis is often delayed due to the subtlety of early symptoms and the rarity of the disease. The Society for Progressive Supranuclear Palsy Inc. (SPSP), Baltimore, estimates there are 20,000 people in the United States with PSP, but only 3,000 to 4,000 people have been diagnosed.

By courageously publicizing his condition, Moore gave a face to the disease and made the public more aware of its existence. New technology like advances in single photon emission computed tomography (SPECT) help give professionals the tools they need to learn more. In recent years, the medical community has stepped up research to find better ways to diagnose and treat PSP.

### CLUES TO DIAGNOSING PSP

Early symptoms of the disease often occur in the patient's 60s and include falling, difficulty walking, imbalance and slow movement, similar to Parkinson's disease. In fact, physicians often misdiagnose PSP as Parkinson's or even Alzheimer's disease, and it was not recognized as a distinct illness until the 1960s.

Other symptoms include difficulty with speech and swallowing, changes in mood or behavior, and vision problems, such as blurred or double vision. According to experts, the most characteristic sign of PSP is limited up and down movements of the eyes, called vertical ophthalmoparesis. Stephen Reich, MD, of the Johns Hopkins school of Medicine, Baltimore, explained that the most important clue to Moore's diagnosis was this symptom.

"Using a technique known as infrared video oculography, [Drs. Martin Cizzi and Michael Rosenberg at the New Jersey Neuroscience Institute] were able to measure the speed of Mr. Moore's eye movements," Dr. Reich explained in a recent statement. "This demonstrated that his vertical eye movements were very slow, and this is one of the earliest features of PSP, but often difficult to appreciate clinically."

### EXPLORING EFFECTIVE TREATMENTS

In addition to researching easier ways to diagnose PSP, doctors are also investigating ways to treat the disease and its symptoms. Studies show that people with PSP suffer from a degeneration of dopamine nerve cells in the striatum of the brain, an area important to the control of motor function.

With an experimental type of SPECT imaging called beta-CIT SPECT; professionals can locate dopamine nerve cells and assess the degree to which PSP or another similar condition has affected them. Beta-CIT is a ligand, or tag, which bonds to specific cells in the brain that make dopamine, allowing them to measure the relative density of the cells in the striatum, a specific area of the brain. Doctors say this type of brain scanning is similar to other SPECT imaging, and uses widely available SPECT cameras.

The pharmaceutical industry has begun to test medications for the symptoms of PSP, and beta-CIT SPECT proved particularly useful in a recent clinical trial of a drug intended to slow the degeneration of dopamine nerve cells. Moore participated in the trial, in which the nuclear medicine technology helped quantify the drug's effectiveness.

The trial looked at 50 PSP patients at seven sites in the United States and Canada. Half the patients were administered pramipexole; a drug that doctors said has been on the market for a few years for Parkinson's disease. The other half of patients received placebo. Sixteen patients were scanned using beta-CIT SPECT. After six months, the 16 patients were scanned again to measure the rate of degeneration. Researchers are now analyzing the data.

### IMPACT OF THE beta-CIT SPECT

Currently, Yale Medical School, New Haven, Conn., is the only facility in the country where this imaging technique is performed. Kenneth Marek, MD, professor of neurology at Yale, explained the implications of the trial and the brain scan.

"The purpose of the study that Mr. Moore is participating in is really to evaluate whether we can use beta-CIT SPECT to assess the progression of the illness over time," he said, "and if some of the medications will affect that progression."

Lawrence Golbe, MD, professor of neurology at Robert Wood Johnson Medical School, New Brunswick, NJ, was involved with the trial and is the chair of the Medical Advisory Board for the SPSP.

"The test is very promising as a way of detecting Parkinsonian disorders at very early stages," Dr. Golbe said. He is hopeful that the medical community will soon find a way to stop the progression of these disorders, and then a test like the beta-CIT SPECT could be a crucial test.

Dr. Marek said nuclear medicine technologists should keep an eye out for the beta-CIT SPECT.

"One of the advantages of this technology is that the signal to noise ratio is very robust," he said. "From the perspective of nuclear medicine tests, this proves to be a very easy one, because you get such a striking signal. This may ultimately become a test that technologists would use routinely."

Experts say that much more research must be done to bring light to this mysterious disease. However, as radiology professionals become more involved in PSP research, and physicians learn more about the condition, patients and their families have hope that help is on the way.

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## Frequently Asked Questions About Hospice

### **1. When should a decision about entering a hospice program be made and who should make it?**

At any time during a life-limiting illness, it's appropriate to discuss all of a patient's care options, including hospice. By law the decision belongs to the patient. Understandably, most people are uncomfortable with the idea of stopping aggressive efforts to "beat" the disease. Hospice staff members are highly sensitive to these concerns and always available to discuss them with the patient and family.

### **2. Should I wait for our physician to raise the possibility of hospice, or should I raise it first?**

The patient and family should feel free to discuss hospice care at any time with their physician, other health care professionals, clergy or friends.

### **3. What if our physician doesn't know about hospice?**

Most physicians know about hospice. If your physician wants more information about hospice, it is available from the National Council of Hospice Professionals Physician Section, medical societies, state hospice organizations, or the National Hospice Helpline, 1-800-658-8898. In addition, physicians and all others can also obtain information on hospice from the American Cancer Society, the American Association of Retired Persons, and the Social Security Administration.

### **4. Can a hospice patient who shows signs of recovery be returned to regular medical treatment?**

Certainly. If the patient's condition improves and the disease seems to be in remission, patients can be discharged from hospice and return to aggressive therapy or go on about daily life. If the discharged patient should later need to return to hospice care, Medicare and most private insurance will allow additional coverage for this purpose.

### **5. What does the hospice admission process involve?**

One of the first things the hospice program will do is contact the patient's physician to make sure he or she agrees that hospice care is appropriate for this patient at this time. (Most hospices have medical staff available to help patients who have no physician.) The patient will be asked to sign consent and insurance forms. These are similar to the forms patients sign when they enter a hospital. The so-called "hospice election form" says that the patient understands that the care is palliative (that is, aimed at pain relief and symptom control) rather than curative. It also outlines the services available. The form Medicare patients sign also tells how electing the Medicare hospice benefit affects other Medicare coverage.

### **6. Is there any special equipment or changes I have to make in my home before hospice care begins?**

Your hospice provider will assess your needs, recommend any equipment, and help make arrangements to obtain any necessary equipment. Often the need for equipment is minimal at first and increases as the disease progresses. In general, hospice will assist in any way it can to make home care as convenient, clean and safe as possible.

### **7. How many family members or friends does it take to care for a patient at home?**

There's no set number. One of the first things a hospice team will do is to prepare an individualized care plan that will, among other things, address the amount of caregiving

needed by the patient. Hospice staff visit regularly and are always accessible to answer medical questions, provide support, and teach caregivers.

### **8. Must someone be with the patient at all times?**

In the early weeks of care, it's usually not necessary for someone to be with the patient all the time. Later, however, since one of the most common fears of patients is the fear of dying alone, hospice generally recommends someone be there continuously. While family and friends do deliver most of the care, hospices provide volunteers to assist with errands and to provide a break and time away for primary caregivers.

### **9. How difficult is caring for a dying loved one at home?**

It's never easy and sometimes can be quite hard. At the end of a long, progressive illness, nights especially can be very long, lonely and scary. So, hospices have staff available around the clock to consult by phone with the family and make night visits if appropriate. To repeat: Hospice can also provide trained volunteers to provide "respite care," to give family members a break and/or provide companionship to the patient.

### **10. What specific assistance does hospice provide home-based patients?**

Hospice patients are cared for by a team of physicians, nurses, social workers, counselors, hospice certified nursing assistants, clergy, therapists, and volunteers – and each provides assistance based on his or her own area of expertise. In addition, hospices provide medications, supplies, equipment, and hospital services related to the terminal illness, and additional helpers in the home, if and when needed.

### **11. Does hospice do anything to make death come sooner?**

Hospice neither hastens nor postpones dying. Just as doctors and midwives lend support and expertise during the time of childbirth, hospice provides its presence and specialized knowledge during the dying process.

### **12. Is caring for the patient at home the only place hospice care can be delivered?**

No. Although 90% of hospice patient time is spent in a personal residence, some patients live in nursing homes or hospice centers.

### **13. How does hospice "manage pain"?**

Hospice believes that emotional and spiritual pain are just as real and in need of attention as physical pain, so it can address each. Hospice nurses and doctors are up to date on the latest medications and devices for pain and symptom relief. In addition, physical and occupational therapists can assist patients to be as mobile and self-sufficient as they wish, and they are often joined by specialists schooled in music therapy, art therapy, massage and diet counseling. Finally, various counselors, including clergy, are available to assist family members as well as patients.

### **14. What is hospice's success rate in battling pain?**

Very high. Using some combination of medications, counseling and therapies, most patients can attain a level of comfort that is acceptable to them.

*Continued Page 12*

Continued from Page 11

## Hospice

### **15. Will medications prevent the patient from being able to talk or know what's happening?**

Usually not. It is the goal of hospice to have the patient as pain-free and alert as possible. By constantly consulting with the patient, hospices have been very successful in reaching this goal.

### **16. Is hospice affiliated with any religious organization?**

No. While some churches and religious groups have started hospices (sometimes in connection with their hospitals), these hospices serve a broad community and do not require patients to adhere to any particular set of beliefs.

### **17. Is hospice care covered by insurance?**

Hospice coverage is widely available. It is provided by Medicare nationwide, by Medicaid in 39 states, and by most private insurance providers. To be sure of coverage, families should, of course, check with their employer or health insurance provider.

### **18. If the patient is eligible for Medicare, will there be any additional expense to be paid?**

Medicare covers all services and supplies for the hospice patient related to the terminal illness. In some hospices, the patient may be required to pay a 5% or \$5 "co-payment" on medication and a 5% co-payment for respite care. You should find out about any co-payment when selecting a hospice.

### **19. If the patient is not covered by Medicare or any other health insurance, will hospice still provide care?**

The first thing hospice will do is assist families in finding out whether the patient is eligible for any coverage they may not be aware of. Barring this, most hospices will provide for anyone who cannot pay using money raised from the community or from memorial or foundation gifts.

### **20. Does hospice provide any help to the family after the patient dies?**

Hospice provides continuing contact and support for caregivers for at least a year following the death of a loved one. Most hospices also sponsor bereavement groups and support for anyone in the community who has experienced a death of a family member, a friend, or similar losses.

## Ask a Doctor

Lawrence I. Golbe, M.D.  
Stephen G. Reich, M.D.

*"My wife's biggest problem now is an enormous amount of saliva in her mouth after each meal. Is there anything you may recommend to help her with this problem?"*

**ANSWER:** Food itself or even thinking about food stimulates the production of saliva just as in healthy people. There is not an excessive production of saliva in PSP. However, people with PSP do not swallow their saliva as frequently or as efficiently as healthy people do. You may be able to reduce the production of saliva by giving more frequent, smaller meals spaced over the course of the day. Several medications are available to help reduce the amount of saliva, all of which have anticholinergic activity. That means that they block the action of the chemical acetylcholine which causes the salivary glands

to make saliva. The most potent anticholinergics include trihexiphenidyl (Artane) and benztropine (Cogentin). These medications should be started at low dosages and escalated gradually. Like all anticholinergic medications, they have the potential for side effects including constipation, blurred vision, difficulty urinating, and confusion but in general, when used at low doses are fairly well tolerated. The Transscop (scopolamine) patch is marketed as travel sickness prevention and is applied to the skin behind the ear. Scopolamine is also an anticholinergic, but when given through the skin, is released slowly, thereby reducing many of the side effects. However, patients who are demented or elderly have a high rate of exacerbation of confusion or even memory loss with scopolamine and one careful study found no difference in side effects between the scopolamine patch and oral anticholinergics. Although anticholinergics are generally helpful for reducing the amount of saliva, it is important not to overly dry out the mouth, as this tends to make swallowing even more difficult. The last option to help control saliva is the use of a portable suction machine, which patients can often learn to use themselves. We do not advise making any of these changes without first consulting with your wife's local physician.

### PSP EUROPE

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

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

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

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# News From Support Groups

## PSP Support Network of Houston

The PSP Support Network of Houston welcomed to a recent meeting Dr. David Mobley of Houston Health Hour radio fame. Dr. Mobley, a full-time practicing urologist, addressed the many aspects of incontinence.

Dr. Mobley left the group with what he called his take-home message: that all types of incontinence, including that which results from a neurological disease, can be helped. But to do so, he said, requires a urologist willing to try a number of treatments, trial and error, until something works; all patients do not respond to the same treatments in the same way.

Dr. Mobley did not promise complete cures for everyone, only that incontinence can be alleviated to a great degree once the specific and appropriate treatment for that patient has been determined. He also said that surgery may not be a good option for a person who is not ambulatory.

The Houston group has heard several informative speakers since its inception in May 2000. Texas State Senator, Tom Haywood (R-Wichita Falls) and his wife, Pat, traveled from Wichita Falls to join the group for the May inaugural meeting at which they both described their lives since the Senator was first diagnosed with PSP. Senator Haywood has participated in several print and TV interviews to help shine light on PSP and maintains a very active political life which included attendance at President George W. Bush's recent inauguration.

Sunita Kavrie, Ph.D., Director of Speech-Pathology at Houston's Methodist Hospital, described in detail (using video of swallow tests) the intricate mechanics of normal swallowing to help her audience better understand the implications of impaired swallowing. Dr. Kavrie also encouraged patients and caregivers to ask their doctors to order swallow evaluations as well as swallow and speech therapy for persons with PSP and other similar disorders to help them maintain function as long as possible.

Cynthia Tait, H.Ed., Ph.D. addressed eating habits and their relationship to illness and disease, and invoked the oft-heard phrase that "You really are what you eat!" Dr. Tait, who suffers from multiple sclerosis, reports being symptom-free for the past four years through the application of sound nutritional concepts to daily diet. She noted the tremendous increase in the incidence of diabetes nationally and mused on what the intake of fast foods and sugar-laden drinks would bode for our future national health. She stressed the importance of eliminating refined sugar, white potatoes, and white rice from the diet while increasing the intake of fresh fruits and vegetables.

Dr. Tait also focused on the importance of eating high quality protein from non-meat sources (nuts, beans, cottage cheese) in addition to the protein available from lean meat and fish. Dr. Tait serves on the nutritional board of Houston's American Cancer Society and maintains an office consultation practice with Whole Health Associates, Inc.

Charlene Fox, Coordinator of Alternative Therapy at Houston's Bradshaw Wellness Center, discussed the many physical and psychological benefits to be gained from massage therapy. We can all benefit from stress reduction, she said, and regular massage therapy reduces general muscle tension as well as pain and stiffness of the muscles and joints, helps to strengthen the immune system and promotes healing in general of both mind and body. Charlene led the group through a series of breathing exercises with humming-like vocalizations

designed to reduce stress and promote a sense of well-being.

William G. Ondo, M.D., Associate Professor of Neurology at Houston's Baylor Movement Disorders Clinic, used as a guide for his lecture the lengthy list of questions solicited from the members and submitted to Dr. Ondo a week before he spoke to the group. Dr. Ondo told the group that even though those with PSP may manifest some of the same symptoms observed in Parkinson's disease, causing diagnostic confusion in the early stages of PSP, Parkinson's and PSP are two separate and distinct diseases.

For more information on the PSP Network of Houston, please contact Karen Kennemer at 281-358-2282 or KMK1224@aol.com

## VERMONT SUPPORT GROUP

Vermont Support Group leader Janice Clements reports that there are now 11 members of this caregiver group. This group includes not only PSP caregivers but caregivers for related neurodegenerative disorders such as atypical Parkinson's, Parkinson's with dementia, and olivopontocerebellar atrophy. The group meets monthly at a conveniently located restaurant and members share concerns, frustrations, and successful strategies. At the December meeting, the group said farewell to two snowbird members of the group and exchanged holiday-baked goods, a great survival strategy for overwhelmed caregivers! Each member of the group brought a double batch of his/her favorite holiday goodie and ultimately each member of the group took home an assortment of goodies. At the recent January meeting, two new caregiver members were welcomed from across the border in Quebec. Members travel up to 90 miles to attend meetings. Meetings are the 2nd Monday of each month at 6PM. Contact Janice Clements for more info at janclem@together.net or 802-893-1263.

## LOS ANGELES/ORANGE COUNTY PSP SUPPORT GROUP

Carolyn Cheek and Bill Griffith report: Our group has been meeting for four years. As co-leaders, Bill and I plan and facilitate most of the meetings. We have at times passed the facilitating around to group members. We also plan special events such as the PSP Walkathon and Regional Seminars. Bill has set up a database with all of the people who attended our UCLA seminar.

Our members are mainly caregivers. We have about 20 people on our list. Average attendance is 12 and we meet monthly at a coffee shop with a private room. Our meetings are mostly sharing, and we have had four or five speakers. Bill and I plan to have more speakers – we have scheduled a family counselor for our meeting in March, and our June meeting will have a speaker to discuss long-term care insurance. Some of our members travel about 45 minutes to these meetings. For more information, please contact Carolyn Cheek (310) 534-8623 or Bill Griffith (714) 832-3731.

Please email or mail your support group news to the PSP Advocate Editor at NancyB.501@cs.com or 6 Bramston Drive, Hampton, VA 23666. Quarterly deadlines are as follows: January 20, April 20, July 20 and October 20.

## The Caregiving Years (PART I)

By Denise M. Brown

*Denise Brown is Executive Director and Founder of "The Center for Family Caregivers." The center is a non-profit organization dedicated to helping persons who care for chronically ill or disabled family members. She also maintains the caregiving.com website.*

When you expect a child, the community (your family, friends, co-workers) rally around you and your spouse. When you expect your first child, you receive gifts, well wishes and the encouragement that you are entering a wonderful, albeit challenging, chapter in your life. As you prepare to welcome your child, you feel pride at the thought of your role as parent: How you will shape the mind of a youngster, impacting him or her with your wisdom, insights and knowledge.

Now think about a similar life experience, just one on the other end of the spectrum. An aging relative, a spouse, a parent, a grandparent, needs your help. And, you want to help—you believe in making the most of the years you have left together. But, when you tell your friends, your colleagues, even other family members, the comments you may hear are a far cry from well-wishes. "I could never do that! Why do you?" Or, the more common response: "Why don't you just put your mother (or your wife, or your grandfather) in a nursing home? That way you won't be so stressed out."

With support like that, no wonder you might find yourself fighting self-doubts during your caregiving journey, asking yourself, "Why me? Why am I the one to do this?" These self-doubts can erode your ability to handle your caregiving responsibilities effectively and efficiently. Even worse, these self-doubts cloud your ability to understand how important this caregiving journey is—to your care recipient, your family, yourself.

The Caregiving Years is separated into six stages, each stage defined by the number of years spent as a caregiver. But these definitions were created to use only as a guide. Your care recipient's illness and diagnosis will determine how quickly or slowly you pass through the stages. While the length of time spent in each stage may differ for each caregiver, the emotions and experiences felt will remain constant.

*In the near future, I may help an aging relative.*

Who are you? You have a growing concern that within the next 12 to 18 months or so, your aging relative will need more and more of your assistance and time. You're concerned because of your relative's age, past and present medical condition, and current living condition.

Your keyword: Ask. Ask questions of your care recipient. Ask questions of health care professionals. Ask questions of lawyers and financial planners.

Your Purpose: You expect to become a caregiver; this is your time to prepare. You should research options, gather information, and provide the opportunity for your care recipient to share his or her feelings and values. This is also your time to concentrate on taking care of yourself—keeping up with family and friends, enjoying your hobbies and interests, pursuing your career goals, taking trips you've always dreamed of.

Although an immediate crisis may not face you, the threat of one seems to hang in the horizon. Rather than closing your

eyes to avoid seeing that horizon, you can take some proactive steps now that will make your future caregiving days easier.

As an "expectant caregiver," what can you do?

1. Consult with a good lawyer familiar with eldercare issues.

Find out about durable powers of attorney for health care and living wills; start the process to ensure that the necessary legal papers are in order.

2. Determine financial situations.

Knowing the financial status can help determine future health care choices. Determine monthly income from pensions and social security; learn about annuities, stock investments and bank accounts.

A TIP FROM DENISE:

*You may find yourself "taking away" from your aging relative—the keys to the car, the solo trip to the grocery store, her hosting the large family get-togethers. To balance the scales, try to replace what you take away. The exchange may not be equal (and in most situations, it won't be), but giving back some of what you take away will help your care recipient maintain her dignity and independence.*

*For instance, you feel that it's just too much for your mother to continue hosting Thanksgiving dinner every year. Your mother reluctantly relents to having the celebration at your house. As you plan for the day, try to incorporate some of your mother's traditions in the celebration: her favorite recipes, her special dishes, her most honored prayer. While your mother may miss hosting the tradition at her home, she'll feel that some of her house is at yours.*

3. Investigate community health care options.

What home health care agencies in your area offer quality, affordable home care? What housing options are available: retirement communities, assisted living centers? Contact community organizations to request brochures and pamphlets.

In addition, consider your aging relative's current living condition. Will your aging relative be able to reside safely in her home if she uses a wheelchair, becomes bedbound? What changes can you make today that will prevent future barriers to providing care in her home? Or, are the necessary changes almost an impossibility? If so, what other options do you have: your home, an assisted living facility, a retirement community?

4. Begin discussions with your aging relative about his or her wishes.

Asking questions now about your relative's care preferences will help you provide the care your relative wants. Where does your relative want to die? At home? At a care facility? What type of funeral would your relative want? Does your relative have a preference as to whom in the family provides care? How does your relative feel about end-of-life care decisions?

Although you may not be able to meet all your relative's wishes, you can begin to plan now to meet at least the most important.

5. Determine the current health care providers.

Who are the physicians, what is the diagnosis? In addition, learn about medications and why the medications have been prescribed.

6. Concentrate on the reality of the situations.

*Continued Page 18*

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Continued from Page 15

## Hospice

Keep a realistic view of their situations: What's the worst that could happen? What's the best possible outcome? Then, determine what options are available for each of these outcomes.

7. Start a journal; chronicle your feelings, your concerns and your actions.

You may be surprised at your feelings of loss. Your preparation of the future allows you to see what your care recipient—and you—might lose. You both will experience changes in your relationship, your schedules, your amount of freedom. Write down your thoughts about the potential losses—and how you might be able to hang on to them, through minor adjustments and changes, for a little longer.

*I am starting to help an aging relative.*

Who are you? You have been caring for an aging relative for six months to 18 months. Your duties range from errand-running and bill-paying to hands-on care.

Your keyword: Find. Find services that help; find support that comforts; find ways to enjoy your hobbies and interest.

Your Purpose: This is your entry into the caregiving role. This is your time to experiment, to get your feet wet and see what works. This is your opportunity to learn how the health care industry works with, or in some cases, against, you. Now is the time to shape your caregiving personality: What duties are you comfortable with? What duties make you uncomfortable? How well are you and your care recipient getting along? What situations would create overwhelming stresses for both of you? What situations should you try to avoid because you know they will lead to nasty fights and bitter arguments?

You'll get a feel for the present and future budgets needed to provide the care your care recipient requires.

In addition, keep up with your hobbies and interests (you may be able only to keep the ones that you enjoy most), ensuring you have made a habit of spending time on your own, enjoying yourself.

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

1. Learn as much as you can about your care recipient's illness, disease or condition. Consult the local branches or chapters of national organizations such as The Arthritis Foundation, the Alzheimer's Association, The Cancer Society. What does the future hold for you and your care recipient?

2. Learn how to provide proper care from health care professionals or from health care videos, manuals or books.

If your care recipient is hospitalized or receives short-term therapy at a nursing home, ask the staff to show you proper caregiving techniques: lifting, transfers, bathing. Or, search the Internet for hands-on care information.

It's very difficult to provide care when you are unsure of what you're doing. You'll feel much better when you're confident of your skills.

3. Join a support group—online or in your community.

It's so isolating to be a caregiver! Support groups will hook you up with others in similar situations; often, you'll learn of community resources and options from other caregivers that you were not aware of.

A TIP FROM DENISE:

*Making a decision on behalf of an aging relative can be intimidating, causing you anxiety, guilt and*

*confusion. You may be plagued by this thought: What is your responsibility?*

*Keep this in mind as you struggle to make the best decisions for an aging relative: You are responsible for providing a safe and healthy environment for your aging relative. That environment may be your care recipient's home. It may be your home. Or, it may be the nursing home.*

*If may be helpful to break down the decision and determine: Where will my care recipient be safest? Where will she enjoy the healthiest environment? Sometimes the answers become clearer when we have a goal to work toward.*

4. Count on regular breaks from caregiving.

You can't be a good caregiver to someone else if you don't take care of yourself. Plan for regular breaks—an hour daily, an afternoon weekly, or a day monthly—whatever you can manage. Enlist the help of relatives and community services (such as a volunteer group at your local church) so you can take time off regularly. Relatives can help in many ways—through financial support, social support (calling the care recipient regularly just "to talk"), as well as respite support.

5. Rely on help from community organizations. Meals on Wheels, home care agencies and day care centers, to name just a few, may offer services that your care recipient needs.

Contact your local Area Agency on Aging for a listing of services and organizations in your community. Visit your local medical equipment supply store to find devices and gadgets that enhance your care recipient's abilities—and independence from you.

In addition, ask about local, state or federal programs that might provide financial assistance for you and/or your care recipient. As your care recipient's care needs increase, so will the costs associated with his or her care. Understanding what programs can help, in addition to understanding what your care recipient can afford, will help you plan appropriately for the future.

6. Keep in mind what your care recipient's wishes are. If appropriate, ask for his or her input and ideas.

Does your care recipient still feel good about living at home? What does your care recipient fear or dread? (These are also good questions to ask yourself!)

7. Reflect changes in a journal.

How do you feel now? What are your concerns? Fears? What outcomes are you working toward? What losses have you noticed during this period? What changes in the relationship cause you to feel sad? What changes have given you comfort?

*I am helping a relative or friend.*

Who are you? You've been involved in your care recipient's care for two to five years. Your involvement is almost daily—if not constant. Your care recipient may live with you—or your involvement means that your day is structured to be available to your care recipient. You begin to wonder, how much longer can you live this way? Your mood is sometimes upbeat—you're proud you've been able to provide such wonderful care and make decisions that support your care recipient's best wishes—and sometimes melancholy—why you? You've been mourning the loss of your care recipient's abilities and functions and often long for the days before caregiving. And, you're tired.

Your Keyword: Receive. Receive help—from anyone who offers; receive breaks from caregiving; receive support.

Your Purpose: To develop a routine, create a familiar schedule for both yourself and your care recipient. A routine will help you deal with the overwhelming stresses and responsibilities that wear you out. A routine will provide comfort for you and your care recipient—this stage may be the most difficult for both of you. The changes you prepared for in Stage 1 and 2 are now a reality—you have become something of a lifeline to a family member or friend.

As an “entrenched caregiver”, what can you do?

1. Determine your limits. How long can your care recipient remain at home? What’s your comfort level in providing care in your home? For instance, some caregivers feel uncomfortable providing care when their care recipients become incontinent. Others determine they can provide care at home as long as Medicare or insurance benefits offset some of the home care expenses. Others feel that they can provide care as long as their other family members, like spouses and adult children, will put up with it. But, everyone has limits. What are yours?

2. Continue regular breaks. Consider annual weekly breaks—investigate short-term respite stays in your community’s nursing homes. Or, ask relatives to take over the caregiving role for a week or two every year or every two years. Continue to take daily, weekly and monthly breaks. Keep up with your own interests and hobbies as best you can.

#### A TIP FROM DENISE

*In order to survive a trying and emotionally-charged experience, we need to find the meaning. Your experience has a family caregiver is meaningful. You can find the meaning when:*

*—You receive help for yourself and your care recipient from community organizations, your church or synagogue, your family members, your care recipient’s friends and neighbors. Regular breaks mean you can gain a healthier perspective.*

*—You allow yourself, and your care recipient, to feel the emotions of the experience. Is your care recipient angry that she has had to leave her own home? Allow her to tell you about it. Do you miss your old life—its action, its freedom, its spontaneity? Allow yourself to vent your frustration in a healthy way, in your journal, to your support group, in your artwork.*

*When you receive and allow, you make room for meaningful moments between you and your care recipient. And, that’s when you find the meaning of your caregiving journey.*

3. Keep up with a support system—a caregiver’s support group or empathetic and understanding family members or friends.

4. Continue to learn about your care recipient’s illness or condition.

What’s next for your care recipient? Are you up to the next stages in his or her illness?

5. Start a second journal that you use to detail your care recipient’s needs and your caregiving responsibilities.

Note any changes in your care recipient’s health and condition so that you can confidently discuss your concerns during physician appointments. Continue to chronicle your caregiving journey in your first journal. What causes you to mourn?

**Editor’s Note:** *These are the first three stages of The Caregiving Years. Our next issue will contain stages four to six.*

## Starting A PSP Support Group

Step One: Establish the need for a PSP support group.

Any group of people with a common problem, experience, or situation, may contain candidates for a support group. The group can be as small as two or as large as there are members. Step Two: Contact the Society for PSP to express your interest in starting a support group.

Be sure there is not already one in your area. Get names of other support group leaders in your area or around the country who can help you get started. Request a list of PSP Communicators namely people who live in your area that are willing to share their experiences with PSP. Ask the Society to list your name as a support group leader and to contact others in your area to notify them of your support group. The Society will send you a packet of information on starting support groups.

Step Three: Be clear about the purpose of the group.

Usually the group purpose will be education and the relief and/or reduction of stress. Limit the purpose to the actual needs and realistic possibilities of the group.

Step Four: Plan the group structure.

Establish a meeting time and place. Often a church, library, or health center will allow you to use their facilities free of charge. Here are some places to start: hospitals, YM or YWCA’s, senior centers, public libraries, churches or synagogues, rehabilitation centers, senior housing communities and community room at local malls. You may meet as often as once a month for 1-1½ hours or less often, depending on the distances your members have to travel for meetings. Provide a contact list for members so that they may be in touch with each other between meetings by phone or e-mail and if able, personal visits. Publicize. Most newspapers accept public service announcements (PSAs) free of charge. They will require that you send it in writing, and at least two weeks in advance. Be sure to include the name and telephone number of a contact person. Radio stations also accept PSAs. Most supermarkets, libraries, senior centers and senior residential communities have bulletin boards where meeting notices can be posted.

Don’t forget your doctors’ offices—all of them! Doctors’ waiting rooms are great places for small posters and/or flyers. They will have greater “staying power” if you obtain permission (of course) and ensure that any printed items fit neatly into the literature rack. Provide refreshments (ask the group members to help with this.) Plan for issues of confidentiality and communication of information. Have information/resource pamphlets available to distribute.

Now that you’ve established the “where’s and when’s and how’s,” it is time to facilitate your first meeting.

Introduction Phase: Have each person give their name and expectation for the group. The verbal connection with people, early on, helps members feel more apart of the group.

Ground Rules: PSP Support Groups encourage and organize activities that foster communication, exchange, and interaction of comfort and mutual benefit to group members who are family, friends, caregivers and persons with PSP. Clarity of expectations is helpful for group members as well as the facilitators. While each member is encouraged to speak up with the concerns and suggestions to make the group more meaningful, they have the right to take part in the discussion or not. People should participate at their own comfort level. Members must actively listen when others are talking. Everything said in

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# Support - Our PSP Stories

Nancy,

*My mom was diagnosed with PSP in 1990 after struggling with the symptoms for four years. She passed away in June of 1996. She possessed an endless supply of courage and dignity as her illness progressed. She had always been a strong personality and lived a very active, vital life. I will forever be in awe of the courage she displayed in the face of her illness. Below is my love letter to her, Selma Levitt Brown.*

Helene Berger

## DEAR MOM,

Barely a day goes by when I don't wish you could see your beautiful grandchildren or tour our new home. I guess I will always miss the love, support and wisdom that guided me through my youth.

I can still recall the confusion and dismay that we all felt when you first began experiencing the symptoms of PSP. All those endless trips to different doctors that provided no answers to your many questions. How frustrating that must have been. Because you seemed so uninterested and uninspired compared to your former self, I was sure you were just experiencing depression. Although the diagnosis was very scary, it was a relief when it finally came.

I will always remember the grace you displayed when dad died and you were forced to greet all those mourners despite being unable to walk or speak clearly. In spite of advancing limitations, you continually seemed eager to enjoy the things that you could. I will always remember going to your favorite deli and watching the other diners stare at you. You didn't seem to notice or care, you were just happy to eat your lox, eggs and onion omelet. When the doctors first told you that you would need to be fed through a tube, you refused to allow such drastic measures. I will always admire you for changing your mind and allowing yourself another two years to watch your grandchildren grow. I will never forget the day that you told me you had been blessed with a wonderful life and felt no bitterness or anger about your illness.

I guess I am hoping writing this letter will help me deal with the fact that you were alone when you died. I will forever be sorry that we were not there with you. I will always feel that I could have done more for you. I know if you were here today, you would tell me that I did my best to support you and that I am a fine person. The grace, dignity and humor that you displayed as your illness progressed taught me many invaluable lessons.

I miss you and love you,  
Helene

Nancy:

*I have found much comfort in reading the stories that people have sent in about their loved ones and PSP. Here is my father's story.*

## JOHN'S STORY

My father, John Triunfo, was finally diagnosed with PSP in November, 1998. We (my brother and I) knew there was something going on with him for a few years but we attributed it to depression due to my mother's death a few years earlier. He was always a busy, helpful type of person – willing to lend a hand to do just about anything – and then he didn't seem to be interested at all. He didn't care to visit us or see

his grandchildren and this used to be very important to him. He would enjoy watching my older son play baseball or basketball and then he just stopped caring if he even saw them. He'd just sit in his chair, in the dark sometimes. There were also problems with his financial situation. Suddenly he couldn't balance his checkbook. My dad was never one to spend money without a good reason, so when he came to me for help with his bills and I saw the amount of debt he had incurred, I was shocked.

We were concerned about a few car accidents that he had been in. He had taken a few falls, which had us a little worried. In his healthier days, my father would think nothing of climbing up on the roof to clean the gutters or get up in a tree to trim branches. He was always very sure-footed, so when we heard that he fell down the steps or tripped in the street in front of his house, we were alarmed. Unfortunately, it took a trip to the hospital to get stitches for us to really get involved.

I started the rounds of doctors with him, and it was difficult for me since I had young children and lived about 45 minutes away. First, we got the diagnosis of Alzheimer's disease. His internist suggested a psychiatrist to treat the depression and he did some psychological testing and recommended my father join a research drug study for Aricept. We were still in denial that there was anything really wrong. I really didn't think he had Alzheimer's and suspected Parkinson's disease. He kept falling in the house and my aunt said he could not live alone anymore. I was trying really hard to coordinate his visits with the research center and all the other arrangements like Meals on Wheels and eye doctor's appointments. I was frantic and had no idea how I was going to get him to move from his home into an assisted living facility.

He was still trying to insist to everyone that he was all right. That became a joke. We used to call him "Johnny, I'm all right." He'd fall right in front of you and then say, "Oh, that's nothing, I'm all right." He even wanted us to get him a car. We had to take his car away when it became clear that his driving was a danger to himself and others. Then a specialist saw him and we first heard the term PSP. It was all downhill from there. The doctor suggested Eldepryll and we started dad on it right away. Unfortunately, he was still living alone and in charge of his own medications. We think he took too many pills because we had to rush him to the hospital. At first the doctors thought it was a stroke, but after many tests, they couldn't find anything except a possible drug overdose. But, it was a blessing in a way because the doctor would not release my father to live alone anymore. He spent a month in a nursing home to regain his strength. He was very difficult while there and took many falls because he would insist on trying to walk, and shower and do everything on his own. He had physical and occupational therapy. He was not a happy camper because he thought he was still "all right."

Finally, I was able to have him released into a beautiful assisted living facility. It took him awhile to adjust. Sometimes he'd try to leave and fall in the process. Once he had to get his head stapled when he fell in his room. Life got a little easier when he started staying in the wheelchair, because he stopped getting hurt. Thank God he never broke anything. He lived there for a year and half before he started having swallowing problems.

The end came so suddenly, and I was not prepared for it.

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# Support - Our PSP Stories

## A TEDDY BEAR'S DEN

By Margaret Byro,  
Granddaughter of Edwin Byro

In a crowded house, there's happy laughter, talking and a feast being prepared. The house is alive and moving with the sounds of a happy and boisterous family. But one room is quiet. In the center of the house, a small family room, very warm and cozy, resembles the den of some warm and fuzzy, lovable creature like Fozzy the Bear. He sits in the corner of his room, at ease in his recliner, arms poised on the arms of the chair like a tiger waiting patiently about to pounce on some unsuspecting prey. His chair appears as a manly forest green decorated with tiny flowers, which his wife must have thought necessary to keep with the feminine feeling of her gorgeously decorated house. I ask him, "How are you feeling today grandpa?"



He replies, "Tired!" and grasps the remote. "Grandpa, quit partying till dawn then!" I say, making the usual joke, "Uff Da! No, no I don't do any of that," he laughs, readjusting himself in his chair. When Grandpa laughs, I see him but not his old age. That familiar twinkle in his eyes returns, that sort of menacing smile appears, and I see a glimmer of his younger, healthier self.

Two of my cousins walk by and Grandpa starts a new conversation. "Say, what are you talking about over there?" Grandpa loves to be the life of the party and always has to know what everyone is talking about and hear the jokes that are told. But, the lifestyle he once knew has been coming to an end slowly over the past three years. Because of weakening strength, strong emphysema and progressive supranuclear palsy, he now lacks the stamina or balance to stay out of the house for more than a couple of hours, and only when necessary.

Someone yells, "Time for dinner!" This is evident from the wonderful aromas which have been floating from the kitchen for the past half-hour. "Grandpa, time for dinner." I say, implying that he should start getting up now. The simple act of getting out of his chair is an Olympian feat. First, he inches himself toward the edge of his chair. Next, he firmly grasps its arms and boosts himself, almost standing straight up, and then falls back again. Finally, on the third try he stands and I hold out my hand and grasp his in mine. We walk to the room next door and my grandma and dad help Grandpa sort of fall into his chair. His chair, formerly at the head of the dining room table until his stability began to decline, now rests on the side of the table next to me (one of his two adored granddaughters). He coughs through the meal and eats little, but this is still his favorite part of life—being waited on. Luckily, this is a family meal and he is not being fussy or annoying, but thankful and grateful. Small, everyday meals with Grandpa can seem like an eternity; he enjoys constantly pestering his wife and attempting to get up from the table when everyone is halfway through their food and into a conversation. Often to keep him sitting until I am finished with my dinner, I eat in slow motion, until he realizes that he has to wait for me to finish eating before leaving the table. When in a pestering

mood, he often yells "Mommy," referring to Grandma in a half condescending/half endearing tone, depending on the situation. He sometimes is very ornery in this respect and can make any simple task long and impossible.

Even though my grandpa is much different than he was during my childhood years, I can still see that familiar sparkle in his iris eyes, hear that funny giggle and then the occasional typical Norse expression, "Uff Da, Ya," or "then," (at the end of almost every sentence). On one of his good days, I can listen to a familiar memory or story about Buster (his beloved dog) or E.B. (his beloved cat). When he shares these memories, I know that I am still learning about my grandpa and I have to make the most of the time we have.

*Edwin Byro recently lost his battle against PSP.*

*Our thoughts and prayers to the Byro family and all PSP victims and their families.*

## LIVING AND DYING WITH PSP

I am both living and dying with PSP at the age of 69, but I consider myself very lucky: (a) I still have my strong faith and (b) I am surrounded by the love of my friends, including my ex-wife, who is typing this article for me. She believes the journey to Paradise is the roughest part, but that the final destination is wonderful. I agree with her. I do find the failure of my eyesight, my inability to look after myself, and of course, the palsy, to be very frustrating. For example, the Canadian Legion had loaned me a walker; unfortunately, when I used it I walked too quickly and wound up hitting a kerb. As fellow PSP patients know, with this disease, when you start to fall, you fall all the way. I wound up with a broken nose and covered in blood. Dr. Nancy Crossen, who has been my doctor for many years, sent me to a specialist, but he wouldn't operate as he felt that I was too weak to accept the operation.

I was then given "Breathrites" which helped my breathing through the flattened nostril. This next may sound like a digression, but please bear with me. In 1998 my granddaughter Tara, then aged 18, had been given one of my daughter's kidneys as both hers had suddenly failed. The operation was a great success, but sadly, Tara became over-confident and neglected to take her medication of 17 pills a day. By the time this was discovered on January 6th, 2001, she had slipped downhill so much that she was rushed into hospital. Here it was discovered that her donated kidney was only operating at 50% capacity. I had the bright idea of offering mine which I reckoned would kill me on the operating table; I also thought they could use other parts of my body as well. However, my offer was refused as doctors tell me the cut-off time for donation is 54 years. I am, however, still trying to give my other organs away. For example, I am donating my brain to medical research in the hope that it will help researchers solve the mystery of PSP. I urge other PSP patients to do the same; together, we can find the solution and help future generations conquer this disease.

I can truly say I am at peace and I wish that peace on fellow PSP patients. I have tried to serve my community, believing in the philosophy that it is not how much you make in this life that counts, but rather, how you have lived your life. I am ready to meet my Lord, knowing that I am leaving this world surrounded by the love of those who temporarily remain behind, and that the love of family and friends who have gone before awaits me at the end of my journey. Oh, glorious and happy reunion!

God bless you all.

Ian Andrews

# Support - Our PSP Stories

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## John's Story

One day he was sitting in the dining room eating a wonderful meal and going on trips to the casino and the beach, and then was in the hospital dying of aspiration pneumonia. His battle with PSP ended on August 30, 2000. I suppose one could say well, he is out of pain now, what kind of life is it to sit in a wheelchair and not longer be independent. But my dad made the best of it and I believe he was happy. I remember asking him one day how he was feeling and he said, "Oh, I can't complain." Can you believe that? A man who suffered the ravages of PSP and is now sentenced to live dependent on others for even the most basic of needs and he says he can't complain. My father really taught me something that day. I really miss him so much. He was the best father I could have ever asked for. It really makes me feel very sad that he had to suffer this way but I believe that we are here in this life for our soul to learn and to grow. I know that whatever my father's task was, it is fulfilled and he is happy and peaceful now. God bless all of you who are still struggling with this disease. Hopefully through all our efforts we can find a way to end the suffering.

Jeanette Triunfo Krokus

## REMEMBERING OUR MOTHER

Frances Muti

July 6, 1922-Sept. 25, 2000

Our mom, Frances Muti, who birthed and raised six children on her own, was diagnosed with PSP in 1993. On September 25, 2000, our Lord took her home to finally be whole again. This terrible disease prevented Mom from simple enjoyments like talking, laughing, crying, swallowing, walking, etc. and ultimately made her a totally dependent person from a very independent one! We are counting our blessings and we are thankful that she always lived at home, never had a feeding tube and was never hospitalized. Mom was taken to the hospital four days prior to her passing because aspiration pneumonia developed. Her breathing was stressed and labored.



Dreading that the end could be near but long and painful, we prayed for God's mercy and grace. With all of us at Mom's bedside, God answered our prayers. He not only enabled her to pass on with such peace and dignity, God restored Mom's beautiful face. Witnessing this horrific disease and needing to find a cure; we unanimously decided to donate Mom's brain for research to PSP. Although experiencing many obstacles, we persevered and succeeded. It was then that we learned about the Society's Brain Bank. Our heartfelt thanks to the PSP's newsletter and to all that generously donate so we may put an end to this long debilitating and fatal disease.

From the Muti Children

*"Please do not remember my grandmother with sadness. When I think of my grandmother, Mama Moon, what I remember most is laughter. She lived a fulfilled life. Don't measure her life by the struggles she endured, but by her strength, which got her through it."*

Your first-born grandchild, Ree-Ree

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## Starting A PSP Support Group

the group should remain confidential so that people feel free to express themselves.

The stage is now set for a safe, valuable experience. Some groups opt to have a "mixed" program that is half educational and half sharing of experiences or solely educational versus solely sharing. The group ultimately decides the program that will work while providing the members with the rewarding experience of helping others. Remember, somebody has to do it!

## PSP FAMILIES URGENTLY NEEDED!

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

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

None-the-less, we have a long way to go regarding public awareness of PSP. There are many reasons it is needed. Greater visibility of PSP does much in the search for its cause and cure. Patients still incorrectly diagnosed have a better chance of realizing they are dealing with PSP. This in turn increases involvement with The Society for PSP. Increased involvement brings more volunteers into the organization, leading to further ideas and activity. Greater numbers working together cultivate larger research dollars. The more of us giving voice to those struggling with PSP the more likely we will be heard and helped.

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

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

To help or to ask questions please contact:

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# Helpful Hints

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

What Advice or Helpful Hint Do You Have For:

***(These helpful hints are from one of our readers who was daughter and caregiver to her mother who was diagnosed with PSP for six years)***

## ANXIETY

My mother was given Ativan or Lorazepam for anxiety.

## ACTIVITIES (especially in the later stages of PSP)

We kept the TV on low to mid volume day and night.

Massages to relieve muscle spasms are appreciated.

## BATHING

At the beginning you notice difficulty getting into or out of the tub/shower and difficulty to bathe oneself.

Need for a shower chair arises, and then help with the physical soaping and rinsing.

Bed baths and hair washing in bed in later stages: have your supplies ready with plenty of soft absorbent cotton towels, protect the bedding with large plastic garbage bags with a bath towel placed under the head, and using a cup to pour clean water over the hair. A gentle hair dryer with a cooler setting so the scalp is not overheated is useful afterward. Either a short haircut or setting with rollers and pins can be done if the person with PSP desires. My mom soon lost interest in curls, and was fortunate that her hair had a lovely silvery salt and pepper color and natural waves.

## BLADDER CONTROL

For incontinence, adult disposable diapers can be used. If your person with PSP (PWSP) is sensitive to plastics you might want to try washable waterproofed cotton pads, which are easy to change by rolling the PWSP from side to side.

## CHOKING

Early, your PWSP may choke on food, or stuff their mouths full and not swallow. It is good to consult a speech therapist for exercises that may help with the problem. The choking will continue and worsen and one of the main causes of death for a PWSP is from aspiration pneumonia - bits of food and drink lodging in the lungs and causing infections to set in. At some point, you may make a decision whether the choking is such a problem to consider getting a feeding tube (PEG or Percutaneous EndoGastric feeding tube) to help alleviate the choking incidents. Even with the tube, the PWSP can take bits of food orally to enjoy the taste, and needs more frequent mouth care to clean and moisten the mouth and lips.

## DEPRESSION

This may set in early as persons with PSP find that they are becoming ill and unable to function in their normal ways. It also may be a chemical imbalance which can be alleviated with antidepressant drugs.

## DRY MOUTH

This is a frequent problem. We used sponge-tipped swabs impregnated with a mouth cleaner provided by the hospital or hospice; they are called toothettes, and are used to clean the

teeth and/or gums, tongue, and inside the lips as well as the lips. I also gave Mom a swipe every few hours with a flavored lip balm, which can be purchased in the dollar stores either one large one or three smaller different flavors in a package. Even with the feeding tube, we gave her sips of water, or later small amounts of water poured in and immediately suctioned out so that she did not have to swallow and choke from it.

## EATING

Manners will steadily decline, and the PWSP will spill more and more. One of the listserv members recommended making bibs or "aprons" from hand towels with velcro to attach easily to keep the clothing clean during mealtimes. When the eye problems advance to the stage where the PWSP cannot look downward, it may help to elevate the plate, or to help feed your PWSP. I tried to keep Mom involved in her own care for as long as she was able, and would constantly remind her to take a bite, chew and swallow. Sometimes, she would fill her cheeks like a chipmunk, or at others she would cry out in frustration asking me to help her.

At first you will be able to prepare regular meals. Later you may want to make things softer even to the point of pureeing everything in a blender. When I could no longer get Mom to eat anything solid, I mixed up a daily pitcher full of "milkshake" comprising canned Boost liquid drink, milk, honey and eggs, which she would readily drink. Later, she could not even swallow the liquids and we were forced by her steady weight loss to make the feeding tube decision. Mom and her doctor and I all discussed it and Mom decided that she wanted it. She lived with the tube another 15 months. I think it is best to be open and allow persons with PSP to make as many decisions about their own care as they are able.

## EXCESSIVE SALIVA

When this became a problem, we first made sure Mom was on her side so that it could flow out of her mouth, and kept small soft cotton hand towels on the pillow beside her face. Later we were prescribed a suction machine to help relieve the gurgling, choking sounds by suctioning the excess out of the mouth and throat. Medicare will pay for these machines rentals. If you have hospice, they will help you obtain the correct equipment.

## EYE MOISTURE

My mom's eyes either dried out or had excess tears, due to dryness. This is best alleviated with either a lubricating eye drop, or gel such as GenTeal that will keep the eyelids lubricated. Talk to your physician about the best drops for your PWSP. There are many brands, but I understand preservative free is the best type.

## GAIT/BALANCE/FALLING

Different people use different methods, but we tried Mom with a heavy duty walker, and she could negotiate that for awhile, but would skin the backs of her hands going through the door frames. Later, I would stand in front of her, holding hands and walking backward to lead her around. Later yet, as her feet would glue themselves to the floor, I would actually put a foot under the arch of her foot and walk her around like a life-sized rag-doll. Some people install poles near often-used furniture to aid in transfers from chairs or beds, or hoist lifts, etc. We used up a lot of Bag Balm on her cuts and scrapes.

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# Helpful Hints

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## HEAD POSTURE

Mom was one whose head went rigidly upwards, so that she was looking up most of the time. We tried her on muscle relaxants, but she never seemed to get relief from this neck spasm. Some people have reported good results with botox injections, others had too much relief and forward head drop associated with its use. We were never able to find a doctor locally who gave them.

## IMPULSIVITY

I consider this the "different" behavior that may have been my mom's early symptoms. Constant cleaning of the table, and leaning over and falling, even when told repeatedly not to do that, etc. My mom would wad up her napkins and poke them into her half eaten plate full of food. She would rush to get away from the dinner table, etc. She also repeatedly wanted to go home or lie down whenever we were away from the house.

## VISION

Mother's muscle tone changed – the calf muscles of her legs wasted away, and she had lots of pain from this. We tried adding supplements to her diet, tried having her drink quinine water (tonic), and rubs of every type. Nothing seemed to help alleviate this pain and wasting. During the last phases, her legs did try to bend, and we placed pillows under the knees to elevate them and relieve the spasms somewhat. Her left arm also became stiff and rigid with reduced range of motion. We placed soft stuffed animals under this arm to keep it from overheating her body and causing skin breakdown.

## VISION

I was taking Mom to eye doctors every other month in 1995 and the eyeglasses with added prisms are very

expensive. Upon getting a new change and leaving the doctor's office, she would immediately complain again about not being able to see! This was one of her most frequent and frustrating complaints, as she could not describe what was the problem so that we could get it corrected. We had laser retinal reattachment done, cataract surgeries in both eyes, and multiple changes of eyeglass prescriptions, with no improvement.

## WHEELCHAIR ADAPTATIONS

When you get your prescription for a wheelchair, plan ahead and get the best one you can get. Medicare will pay for only one. The cheaper, lightweight ones you can purchase for about \$150.

## OTHER

Watch out for bedsores, which can occur from remaining in one position too long and also from dragging transfers. My Mom got three bad ones after coming home from the hospital when her feeding tube was installed. Because of the transfers in and out of several beds, etc., when she came home, she had what appeared to be a huge blood blister there. Our health plan would give no preventive care for this until it became an open oozing bedsore. Then, they sent out a wound care specialist nurse to show me how to care for the bedsore. It took us over 6 weeks to heal them, applying special gel into the wound after cleansing it daily, and then placing special adhesive films over the wounds, and then applying electrical stimulation around the area. It is MUCH better to prevent them opening than having to heal them!

I hope these hints may prove helpful for some of you.  
*Linda Ives, daughter and caregiver to Mary S. (76 years old, diagnosed with PSP for 6 years, died September 3, 2000)*

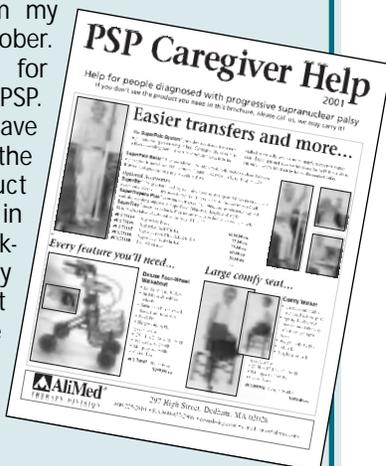
Dear Nancy,

I had to write to tell you how helpful the Alimed PSP Caregivers Help catalog is -- the one included in the Infopak at the St. Louis Symposium my sister and I attended last October. It includes so many ideas for taking care of someone with PSP. Even our two brothers have been looking through all the other wonderful product information we were given in the folder, and are now checking out some of the mobility and safety aids to see what we can buy to help make Mother's life (and mine, too) a little easier. Thank you and the Society for all that you do for our PSP families.

Mary from Illinois

### EDITOR'S NOTE:

Alimed Inc. is located at 297 High St., Dedham, MA 02026; 800-225-2610; Fax 800-437-2966; e-mail info@alimed.com



## HELP WITH "HELPFUL HINTS" NEEDED

Dear Friends,

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

What advice or helpful hint do you have for:

- Anxiety
- Bathing
- Bladder Control
- Choking
- Doctor's Questions After Visits
- Excessive Saliva
- Gait/Balance/Falling
- Impulsivity
- Toileting
- Vision
- Other
- Activities (especially in the later stages of PSP)
- Coughing
- Depression
- Dry Mouth
- Eating
- Eye Moisture
- Head Posture
- Spilling Food
- Tone/lack of
- Wheelchair adaptations

# The Society for PSP Survey

## How Are We Doing?

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

Date \_\_\_\_\_

Name \_\_\_\_\_

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

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

Address \_\_\_\_\_

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

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

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

Benefits and Services	Know About	Use	1	2	3	4
Toll Free Communication with Society office	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Quarterly Newsletter	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reporting and Funding of Research	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Communicators List, Physician Referral List	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support Groups	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Biennial and Regional Symposiums	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Brochures/Educational Material	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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Suggestion to improve current programs and services listed above.

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Suggestions for new programs and services.

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

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OPTIONAL:

Please tell us about the person with PSP

Name \_\_\_\_\_

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

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

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

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

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

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FUNDRAISING:

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

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

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

# Report Of Gifts - November 1 thru January 31, 2001

*The Society for PSP extends its thanks to our donors who have given so generously to help find the cure for PSP while helping families meet its difficult challenges.*

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Doanld & Glenda Klingsick in memory of Ethel Bade  
Ken & Paula Knarr in memory of Ethel Knarr  
Dennis Knutson in memory of Vernon Rutz  
Frederick & Elaine Koenig in honor of Elaine Koenig  
Henry & Shirley Koenig in memory of Reed Koenig  
Donna Kolin in memory of Mary Agnew  
Daniel & Anne Kondziela in honor of William Todd  
Daniel & Mildred Koster  
James & Pat Kozeny  
David & Deanna Kress in memory of Jennie Zagorski

# Report Of Gifts

## DONATIONS - PATRONS \$100 AND OVER continued

Delores Krpoun in memory of Roy Krpoun  
Roger Krug in memory of Lenore Schmidt  
Charles & Cynthia Krumbein in memory of Joe Nerden  
Debra Kurdelski in memory of Jacob Smith  
LaCiede, Inc.  
Larry & Pat LaDassor in memory of Ethel Knarr  
Antoine Langlois in memory of Florence Langlois  
Susan Lawler in memory of Wilma Billie Moll  
Charlene Lee in memory of Fred Overstreet  
Doris Lee  
Leeka & Rice in memory of Meredith Curry Teel  
Orlando J. Leon in memory of Margaret Hollestelle  
John Levender in memory of Helen Levender  
Robert Levie in memory of Martin Simon  
Jane Levin in memory of Marvin Levin  
Joel Levinson  
Mary Lewandowski  
Maddy Licata in honor of Jack Anderson  
Linell Custom Cabinets in honor of Paul Linell  
Bruce Lipstein in memory of Leonard Lipstein  
Ellen Lockwood in honor of Elaine Faulkner  
Catherine Loveland  
Luminaud, Inc.  
Mark & Gail Lynch in memory of Roy Shaver  
George & Gladys Lynn in memory of Juanita Lynn Mullen  
Victor Lynn in memory of Juanita Lynn Mullen  
Victor Lyon  
Carol Majewski in honor of Laura Cerveny  
Shirley Malchow in memory of Joseph Craven  
Lester Marks in memory of Valeria Marks  
Joette Marra in memory of Carmella Tuminno  
Kenneth Marshall in memory of Kathryn B. Marshall  
Billy Gene Mason in memory of Mabel Mason  
Ronald & Mabel Mazine in memory of Lester E. Henderson  
Helen Macalister in memory of Mary Smithers  
Thomas & Arlene MacDonald in memory of Edward Pousont  
Josephine Maguire in memory of Frank Maguire  
Robert & Margaret Maier in memory of Don Hinchee  
James & Barbara Mann in memory of Don Fosdick  
Robert Marks in honor of Dr. Steven Reich  
Barbara Masden in memory of Frank Masden, Jr.  
James Maxwell  
Nancy McCaffray in memory of Lovell Proby  
Regan McClellan in honor of James McCellan  
Don McConnell in memory of Jett Riley  
Doris McCray in memory of Harry McCray  
George & Pamela McKellar in memory of Judy McKellar  
Mary McLanahan in honor of Wanda White  
Frances E. McMahon  
Medical West HealthCare Center, Inc.  
Robert & Geraldine Melascaglia in honor of James Tahaney  
Mellon Bank in memory of George Gould  
Charlotte Meloche in memory of Lucille Turkins  
Greg Mendel in memory of Robert Mendel  
Michael & Karen Mercaldo in honor of Dottie Barnett  
Thomas Mercaldo in honor of Dottie Barnett  
George Merrick  
Patricia Mitchell in memory of Dr. Walter Smyth  
Michael Morgan in memory of Melvin J. Harris  
Shirley Mosholder in memory of John Veltre  
Moye's Auto Sales Inc. in memory of Jett Riley  
Jeannette Muirhead in memory of Charles Muirhead  
Sheridon Murphy in honor of Roylene Murphy  
R&F Murtrie  
Richard & Laurie Navin in memory of Larry Gold  
Elizabeth Neiswender in memory of Anne Constable  
Marcella Nelson  
Marjorie Neuwirth in memory of Beatrice Goreff  
James & Mabel Nevins Margaret Vaccaro  
Tommy & Shirley Nickels in memory of Tommy Nichels  
Henry Nields in memory of Olivia Nields  
Nielsen David & Shelly  
North Texas Chapter in memory of Meredith Curry Teel  
Robert & Geraldine Novak  
Julie Nunnari in honor of William Todd  
William O'Donnell in memory of Lenoa Liebl  
Catherine O'Toole my father John O'Toole  
Gerald R. Offsay in honor of Kenn Todd's Maratho  
Austin Okie  
Olson & Olson in memory of Meredith Curry Teel  
Stephen & Susan Olson  
William & JoAnn Olson in memory of Don Hinchee  
Mitchell Opalski in memory of Mary Cembalski  
Mark & Kathryn Parenti in memory of Kenneth Anderson  
Val Jean Parks in memory of Lois Parks  
John Pavis in honor of Fadetta L. Pavis  
Paul & Nancy Pederson in memory of Kathryn Turner  
Thomas Peirce in memory of Thomas E. Peirce  
Lucille Peloquin in memory of Stephen Chop  
Janice Penn in honor of John Slavik  
John & Theresa Peterson in memory of Jett Riley  
Lodelle Pettyjohn in honor of Gretchen L. Watson  
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Frederick & Shirley Plapp, Jr. in memory of Donald Mengle  
Plymarts, Inc. in memory of Myrtle Cole  
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Georgia Pontious in memory of Stanley Pontius  
Ann Poole  
Mary Potter in memory of Jerome Kirchner  
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Wayne & Gina Powers in memory of Kerry Branson  
Eugene & Irene Prather  
Hugh & Gayle Prather in memory of Frances Dupree Plant  
Hans & Audrey Protschka in honor of Audrey Protschka  
Edward Pucylowski in memory of Alice Pucylowski  
Michael Radner in memory of Esther Barbara Taxman  
Adam Ramotowski in honor of Edna Ramotowski  
Harvey Raschke in memory of Doris Raschke  
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Dale Rathje in memory of Mary Lou Rathje  
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Martha Reaver in memory of John Corbin  
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Regional Realty Consultants, Inc. in memory of Meredith Curry Teel  
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Sidney & Wilma Rosen  
Alison Ross in memory of Leo Grant  
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John Sablatura in memory of Meredith Curry Teel  
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Horace Sarter in memory of Sondra Sarter  
Margery Sayger in memory of Richard E. Sayger

# Report Of Gifts

## DONATIONS - PATRONS \$100 AND OVER continued

Jeanette Schall in memory of Frank Masden, Jr.  
Richard & Karla Schindler in memory of Loren Vettel  
Pauline Schlosser in memory of William Murphy  
Robert & Barbara Schmoll in honor of Dr. Robert Schmoll  
Phillip & Rose Schnell in memory of Dr. Walter Smyth  
Eugene Schreengost in memory of Donna Schreecgost  
John & Phyllis Schreck in memory of Albert Schreck  
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Ray & Connie Seegmiller in memory of Meredith Curry Teel  
Perry & Terry Sennewald in memory of Chester Valesky  
Shirley Serby in memory of Kenneth Serby  
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Shamrock Veterinarians in memory of Jett Riley  
Shannon Martin Finkelstein Sayre  
    in memory of Meredith Curry Teel  
Helen Shaver in memory of Roy Shaver  
David Sheahan  
Annette Shears in honor of Judith E. Shears  
Barbara Sheng  
Shield Healthcare Centers  
Dean & Kristen Shollack  
Louis & Deborah Shpritz in memory of Dr. Walter Smyth  
Richard & Barbara Sielaff  
Sierra Builders in memory of Jett Riley  
Teresa Silva in memory of Michael Chiechi  
Ray & Marianne Simmons  
Skarie, Inc. in memory of Jerome Kirchner  
Esther Sloan in honor of William Foster  
Simon Steemke Co. in memory of Martin Simon  
Camille Slayton in memory of Jett Riley  
William Small  
Berl Smith in memory of Earl Brannun  
Charles Smith in memory of Meredith Curry Teel  
Crystal Smith in memory of Fred Overstreet  
Danalu Smith in memory of Mary Newman  
Robert & Helen Smith  
Truett & Glenna Smith in memory of K.W. Dunwody, Jr.  
Wayne Smith in honor of William Todd  
William & Addie Smith in honor of William Todd  
Ben & Margaret Smolenski  
John Solon in memory of Louise Havill  
Gerald Souder in memory of Catherine E. Souder  
Eric Spar in memory of Ralph Peyser  
Paul Specia in honor of William Todd  
Alden & Shirley Stephens in memory of Shirley Stephens  
Samuel & Marilyn Stewart in memory of William Stearns, Jr.  
Sheila Stewart in memory of Meredith Curry Teel  
Rodney Stieff in memory of Susan Owen  
Lena Stockstill in memory of Prentiss Stockstill  
John & Linda Stokely in memory of Don Hinchee  
John & Charlene Storms in memory of Meredith Curry Teel  
Strauss-Goodman Family  
Gina Benivegna Straub in honor of Alberta Benivegna  
Richard Strub  
Glenn & Christine Stutzman in memory of Ethel Knarr  
Sunrise Housing Ltd. in memory of Meredith Curry Teel  
Gloria Swarhout in memory of Jett Riley  
Lawrence Swanson in memory of Reed Koenig  
Anne Tabb in memory of Jett Riley  
Harriet Tabb in memory of Jett Riley  
Sylvia Tansey in memory of Martin Simon  
Cleo Teel in memory of Meredith Curry Teel  
David & Ann Teel in memory of Meredith Curry Teel  
Henry Thompson  
Linda Thompson in memory of Billie Jean McCarty

Marion Thompson in memory of Malcolm Thompson  
Ned & Maryon Titus  
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Jennifer Todd in honor of William Todd  
Kenneth Todd in honor of William Todd  
William & Margo Todd in honor of William Todd  
Michael & Nancy Tooke in memory of William Stearns, Jr.  
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Robert Turner in memory of Kathryn Turner  
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Patricia Urani in memory of Angelo Urani  
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Donald Van Brunt in memory of Grace Van Brunt  
Dick & Fran Van Duzer in memory of Michael Chiechi  
Keith & Mary Van Meter in memory of Prentiss Stockstill  
Joellen Vangalder  
Bill Vaughan in memory of William Vaughan  
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Gwyn Vernon  
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Edwin Watts  
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Fred & Marjean Worle in memory of Loren Vettel  
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- #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)
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- #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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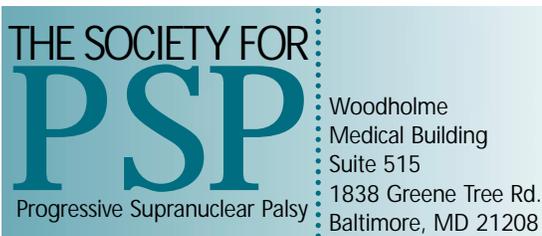
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