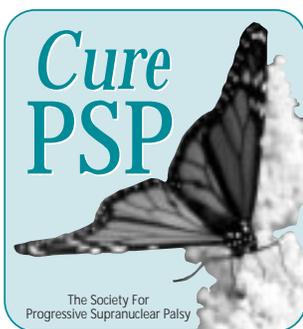


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**INSIDE:**

**LATEST PSP  
RESEARCH  
GRANTS**

**SWALLOWING  
DIFFICULTIES  
AND PSP**



## Flying Foxes, Lytico-bodig, and PSP

### *A novel hypothesis*

John Steele, MD, FRCP(C)  
Honorary Chairman, Society For PSP  
Neurologist, Guam Memorial Hospital

Recently, there have been many reports in the media about fruit bats called "flying foxes" as the cause of the neurodegenerative disease of Chamorro natives on Guam. Their disease is a tauopathy called lytico-bodig, which has many similarities to PSP, but also to Alzheimer's disease and amyotrophic lateral sclerosis (Lou Gehrig disease or ALS). This novel idea proposes that this illness was caused by eating these bats (*Pteropus mariannus*).

The hypothesis was first proposed last year by neurologist and author Oliver Sacks and Paul Cox, a respected PhD botanist, who is the director of the National Tropical Botanical Garden in Kalaheo on the Hawaiian island of Kauai. They noted that for many centuries these small mammals were abundant on Guam, they were easily hunted, and they were a favorite and frequent food for Chamorros who ate them, including their brains and internal organs, in coconut soup. But after the Second World War, the Chamorros acquired guns and over-hunted the bats. The bats were also preyed upon by the brown tree snake, a predator that inadvertently reached Guam in military transports during the War. Their numbers sharply declined and Chamorros could no

longer eat them. In 2002, Sacks and Cox observed that cases of lytico-bodig were also declining, and at the same rate as the steady extinction of the bats. They suspected the two events were connected and suggested that the fatal neurological disease of Chamorros might relate to a poison in the bat.



They speculated that this poison came from the seeds of the local cycad tree (*Cycas micronesica* Hill) which the bats were known to feed upon. Researchers first suggested in 1963 that one or more of the neurotoxins in the cycad might be the cause of lytico-bodig. In 1964, a report was published of damage similar to that of ALS (which is very different from that of PSP) produced in a single monkey given cycad, but

clear evidence of an ability to cause neurodegeneration has since failed to accumulate. An amino acid called beta-N-methyl amino-L-alanine (BMAA) was discovered in the cycad plant in 1967. An attempt in 1972 to produce neurological damage in mice via feeding BMAA failed, but a 1986 publication reported that monkeys fed BMAA did develop damage in their brains and spinal cords similar to ALS. Thus, the idea of BMAA toxicity is not new and attempts to evaluate this idea have been few and inconsistent.

Then, last year Dr. Sandra Banack, an ethnobotanist who is a colleague of Cox and also on the faculty at California State University, Fullerton, tested the idea of a connection to fruit bats. She measured cycad toxins in museum specimens of bats shot 50 years before. She confirmed that they did indeed contain extremely high levels of BMAA. Apparently, the bats suffered no ill effects of this poison, which is highly toxic to the human nervous system. It is a situation similar to ciguaterous fish. Ciguatera toxin is made by plankton and is concentrated in the bodies of fish that feed on it. The fish are unaffected, but their flesh is poisonous to humans.

Last March, another of Cox's colleagues, protein chemist Susan Murch, tested brain specimens of six deceased Guamanian patients



*John Steele, MD, FRCP(C)*

*Continued Page 5*

# The Society for Progressive Supranuclear Palsy

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

## VISION

A world free of PSP

## MISSION

The Society for PSP is dedicated to increasing awareness of this under-recognized disorder, advancing research toward a cure, and providing support and education for persons with PSP, their families and healthcare professionals.

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(In memory of Henry and Jane Ogiba)

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## Director's Doings

Dear Friends,

After seven and a half years of service, I am leaving the Society for PSP. During my tenure, I have met many wonderful people, forged enduring friendships, and learned a great deal about an illness most of the world has never heard of.

There have been many great rewards. The organization has grown from two part-time people to what it is today. There have been so many positive accomplishments to help the families in the area of outreach and education and the research program. I feel proud to have been part of such a meaningful and important endeavor.

The greatest rewards, though, have been listening to families affected by PSP and helping them through their difficult times. I feel I have made a difference that no PSP family has to travel this difficult journey alone.

I thank the dedicated staff and volunteers whom I have had the great pleasure to work with, the donors who have so generously supported our mission, and the health professionals and researchers who endeavor every day to help find a cure as well as treat the patients.

I feel blessed that I have the opportunity to serve and look forward to other endeavors—taking along the sweet memories of working for the Society for PSP.

If you wish to contact me, please direct your messages to the PSP Office.

*Ellen Pam Katz*

Warm regards,  
Ellen Pam Katz



### *A Special Thanks*

*For the fifth year, Mr. Jay Troxel continues to support the publication of The PSP Advocate in memory of his beloved wife, Eloise H. Troxel.*

## President's Corner

*"Don't be dismayed by good-byes. A farewell is necessary before you can meet again. And meeting again, after moments or lifetimes, is certain for those who are friends."*

Author: Richard Bach



As you can see from the Director's Doings, our good friend, Ellen Katz, has resigned from her position as executive director of the Society for PSP.

Much of what the Society is today can be attributed to Ellen. When Ellen came to the organization over 7 years ago, it was literally a two person operation.

Today, the Society employs 11 staff members.

- The number of names in the database has grown from 3,000 to 35,000.
- The annual budget of the Society has increased from \$60,000 to \$1,300,000.
- The number of support groups has grown nationally from 3 to 56.
- The amount of research supported by the Society has amounted to \$2,000,000 representing 55 grant awards.

These are significant accomplishments that have positioned the organization for growth as we move ahead with the implementation of the new three year Strategic Plan this summer. More importantly, she has given hope to a great many families affected by PSP. She has earned our friendship and respect and we wish her much success as she continues on her journey both personally and professionally.

Until we meet again,  
Elizabeth Brisson, President

## Summaries of Latest Research Grants Awarded

### DISCOVERY OF TAU PHOSPHORYLATION INHIBITORS FOR TREATMENT OF PSP

Kenneth S. Kosik  
Professor of Neurology  
Center for Neurologic Diseases  
Brigham and Women's Hospital, Boston, MA

This proposal begins with a collection of small molecules that we have identified over the past two years. These small molecules represent potential drugs that may be useful in the treatment of PSP and other diseases that fall under the broader heading of tauopathies. Discovery of Tau Phosphorylation Inhibitors falls under the broader head of tauopathies. We discovered these compounds that make tau more toxic. We discovered these compounds by assembling in a core facility about 60,000 compounds and screening them robotically for those that inhibit a protein called Cdk5, which can modify tau in a way that makes it more toxic. These compounds are highly novel in the way they work because they bind to Cdk5 with high specificity and are therefore unlikely to become drugs of the future. Presently, we have six compounds that fall into four different chemical categories. Advancing all of these compounds along to testing in rodents is very costly and therefore we propose to select the ones that are most likely to be effective. One approach to this problem is to screen the compounds in a fly model and the other tauopathies. When a certain tau mutation or Cdk5 is expressed in flies, the neuron dies. We will determine whether feeding the flies our compounds can prevent the toxicity to neurons.

### PARKIN MUTATIONS IN A MOUSE MODEL OF PSP

Parvoneh Navas, PhD  
University of Washington, VAPSHCS  
Seattle, WA

PSP is a rare neurological disorder characterized by parkinsonism and vertical gaze palsy. Behavioral and physical changes in PSP are caused by the loss of substantial numbers of brain cells called neurons. In PSP, these dying neurons have inclusions called "tangles." These neuronal tangles are made of the protein tau. The human gene encoding tau (MAPT) has been identified as being involved in the onset and progression of PSP. A specific series of sequence changes in the DNA, encoding the tau protein, called the H1 haplotype, is over-represented in subjects with PSP when compared with unaffected subjects. Some disease-associated changes (mutations) in tau have been identified in subjects that have PSP or PSP-like disease; however, MAPT mutations in PSP are rare. We identified a single MAPT mutation (change in the fifth



amino acid of the protein R5L) in an individual with autopsy-confirmed PSP. Recently, we identified a heterozygous P437L mutation in the parkin gene (mutations in both copies of the human parkin gene are known to cause early onset Parkinson's disease) in the same R5L subject. Subsequent evaluation of a single nucleotide polymorphism (DNA fingerprint) within parkin in a panel of 179 PSP subjects has revealed an over-representation of a specific pair of "fingerprints" (genotype) in the PSP population versus unaffected subjects. Thus, mutations or polymorphisms within the parkin gene may also contribute to the onset or progression of disease in PSP. Funding from the Society for PSP for the proposed project will allow us to generate a mouse model of PSP with the human gene encoding tau (MAPT) and parkin mutations that are equivalent to those found in the identified PSP subject. The long-term goal of this study is to assess the genetic contributions and interactions of parkin and tau proteins in PSP.

### CYSTAMINE: A TRANSGLUTAMINASE INHIBITOR FOR THE TREATMENT OF TAUOPATHIES

Nancy A. Muma, PhD  
Professor of Pharmacology  
Loyola University, Chicago, Illinois



Alzheimer's disease (AD) is one of the neurological diseases characterized by the presence of aggregates of abnormal proteins in the brain. In AD and other diseases such as progressive supranuclear palsy (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 AD.

Although the mechanisms causing the 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 and others have identified mutant forms of tau protein in individuals with PSP. We also demonstrated, that in AD and PSP, tau protein is abnormally cross-linked by an enzyme, transglutaminase. We found that the activity of transglutaminase is higher in PSP than in controls. This is important because transglutaminase can cross-link proteins to form very stable protein polymers by linking together two or more proteins such as tau protein. For the proposed experiments, we will use a cell culture system and a transgenic mouse model that develop neurofibrillary tangles due to a mutation in tau protein. Our data demonstrate that transglutaminase cross-links tau protein in the neurofibrillary tangles in the transgenic mice. The goal of the proposed research is to determine if inhibiting transglutaminase will reduce the abnormal transglutaminase-mediated cross-linking of tau protein, neurofibrillary tangle formation and loss of function in these models of AD and PSP.

# Research

## CORRELATION OF CLINICAL SEVERITY, BRAIN INFLAMMATORY CHANGES AND APPARENT WATER DIFFUSION IN PROGRESSIVE SUPRANUCLEAR PALSY AND IDIOPATHIC PARKINSON'S DISEASE.

David J. Brooks, MD  
Hartnett Professor of Neurology  
Imperial College London  
London, UK

Recent research has shown PSP and PD are associated with inflammation of affected brain areas which may in turn exacerbate disease progression. In our study, we plan to measure the extent of this inflammation in life using a novel brain-imaging technique called position emission tomography (PET) and a radiotracer called C-<sup>11</sup>PK11195 in 10 patients with PSP and 10 patients with PD. We want to correlate the extent of inflammation with clinical findings and also with a special MRI (magnetic resonance imaging) scan measuring water diffusion in the brain that recently has been found to sensitively differentiate between PSP and PD. With this research, we hope to better define the role "neuroinflammation" plays in these disorders using non-invasive imaging tools and how it relates to water diffusion changes and clinical symptoms. Based on that knowledge, we will proceed to test drugs such as monoclonal antibodies that are aimed to suppress the inflammatory component in these disorders and, we hope, slow the disease process.

### Research Grants Program

The Society for PSP provides grant support for basic and clinical research <[http://www.psp.org/research\\_center/research\\_grant\\_recipients.asp](http://www.psp.org/research_center/research_grant_recipients.asp)> in progressive supranuclear palsy. Application deadlines are April 1 and October 1 of each year.

Proposals designed to collect pilot data in preparation for a Federal or other large grant application are encouraged. In 2002-2003, 15 of 36 submissions were funded.

PIs will be expected to present their results at the Society for PSP's annual research symposium held as a satellite to the meeting of the Society for Neuroscience. Travel and lodging expenses for this one-day meeting should be included in the budget. The presentation would be made at the first symposium occurring after the expiration of the term of the grant.

To learn more about the details of past PSP research grants <[http://www.psp.org/research\\_center/research\\_grant\\_recipients.asp](http://www.psp.org/research_center/research_grant_recipients.asp)> please refer to back issues of our newsletter, *The PSP Advocate* <[http://www.psp.org/press\\_room/newsletter.asp](http://www.psp.org/press_room/newsletter.asp)>

## Flying Foxes, Lytico-bodig, and PSP

*Continued from Page 1*

with lytico-bodig and of two Canadians who had died with Alzheimer's disease, another tauopathy. She found similar levels of BMAA in both groups but no BMAA at all in any of a group of 13 individuals who had died with no neurological illness. Her finding leads Cox to propose that BMAA may be the cause of both lytico-bodig and Alzheimer's disease, and that it might also be the cause of related tauopathies, including progressive supranuclear palsy.

My Chamorro patients on Guam are currently participating in studies to confirm these important observations and this unusual hypothesis. In recent months and with Alzheimer disease authority Patrick McGeer of Vancouver, we have collected human and animal tissues and biological samples for analysis by Murch. She is now rigorously investigating these diverse samples at the Institute for Ethnobotany on Kauai, and we should know of her results within six months.

BMAA is produced by a common type of bacteria called cyanobacteria. On Guam these bacteria are associated with the root system of the cycad trees and the BMAA they produce is absorbed into the tree and concentrates 100-fold in the seeds. The toxin then becomes concentrated another 100-fold in the flesh of the bats that feed on the cycad. But cyanobacteria occur also in water and soils in all parts of the world. This leads Cox to propose that these cyanobacteria and their toxin BMAA may be the primary agent of many tauopathies. But the toxin causes no immediate symptoms and its effects do not show themselves for many years.

McGeer and I hope Cox and his associates are correct in their hypothesis of delayed neurotoxicity. If they are, it is a major breakthrough and will begin a journey towards the cure of common neurological diseases that affect millions of the world's aging population. We are assisting them, we wish them success, and we are pleased to be a part of their investigations and discovery.

*In 1963, Dr. Steele, together with Dr. J.C. Richardson and Dr. J. Olszewski, identified PSP as a distinct neurological disorder. Dr. Steele has spent the last 25 years on the Pacific island of Guam researching lytico-bodig which reached epidemic levels in the late 1950's, devastating the native Chammos people on the island. Lytico-bodig has died down and its cause has not been established, even though there has been extensive research. It has been thought that by studying Lytico-bodig in depth, a clue may be found as to what triggers PSP and other related neuro-degenerative diseases.*

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[www.psp.org](http://www.psp.org)



## Outreach and Education

# The 107th Annual Meeting of the American Academy of Ophthalmology

November 15-18, 2003, Anaheim, California

This past November, Society's Outreach & Education Director, Jessica Quintilian, and Development Director, Kathleen Speca, staffed an informational exhibit at the American Academy of Ophthalmology's annual meeting in Anaheim. Over 14,000 physicians and allied health professionals attended the meeting, which was held at the newly remodeled Anaheim Convention Center. Jessica and Kathy also had the opportunity to meet several PSP friends while on the West Coast. On November 16, 2003, a thank you dinner was held at the Coast Anaheim Hotel to recognize special donors Peter and Henrietta Bodourian and Charles and Aileen Mason. Jessica and Kathy also enjoyed meeting with Joyce Munsell, a registered nurse with CalOptima who provided wonderful ideas on how to expand the educational literature offered by the Society.



*Information about PSP and the Society.*

Academy of Ophthalmology seeks to advance the lifelong learning and professional interests of ophthalmologists to ensure that the public can obtain the best possible eye care.

The Society was glad to have the opportunity to provide an informational exhibit at the Annual Meeting because so many people with PSP begin their journey by visiting an eye doctor. An ophthalmologist is often the first medical professional seen when a person with PSP begins having visual difficulties. Because the visual problems are such an important part of PSP, it is important that eye doctors are educated about the disease so that they are able to recognize the symptoms when they occur. For example, the impaired ability to move

the eyes downward is often the first clue to the physician that a person has PSP. Encouragingly, more and more ophthalmologists are becoming aware of progressive supranuclear palsy. Many of the professionals who stopped by our booth were familiar with the disease. However, not all of them were aware that they can refer patients and families to the Society to gain education and support! The Society looks forward to continuing to exhibit at the American Academy of Ophthalmology meetings, where we can have personal contact with these eye doctors and better increase their awareness of PSP and the services that the Society provide for families.

### Why the AAO?

The American Academy of Ophthalmology is the largest national membership association of eye doctors. Eye doctors, known as ophthalmologists, are medical doctors who provide comprehensive eye care, including medical, surgical and optical care. More than 90 percent of practicing eye doctors in the United States are Academy members, and the Academy has more than 7,000 international members. The American

## The Society is On the Road Again!

*It's a new year, and the Outreach & Education program is gearing up for a new season. Below is a listing of recent and upcoming Outreach & Education events.*

### **The San Francisco PSP Family Conference**

San Francisco, California  
April 24, 2004

### **American Academy of Neurology Annual Meeting**

San Francisco, California  
April 26-29, 2004

### **Michigan Symposium on Parkinson's Disease, PSP and Related Diseases**

East Lansing, Michigan  
October 8, 2004

### **Society for Neuroscience Annual Meeting**

San Diego, California  
October 23-27, 2004

### **American Academy of Ophthalmology**

New Orleans, Louisiana  
October 23-26, 2004

### **The 2004 International PSP Research Symposium**

San Diego, California  
October 28, 2004

### **The San Diego PSP Family Conference**

San Diego, California  
October 30, 2004

### **The New Jersey/New York PSP Family Conference**

Robert Wood Johnson University Hospital  
New Brunswick, New Jersey  
November 6, 2004

*Plans are also underway for a summer/early fall conference to be held in the Seattle, Washington area! (Date to be determined) For information about any of the above events, contact the Society at 1-800-457-4777. Be sure to visit our website ([www.psp.org](http://www.psp.org)) monthly for specific event details.*

## Special Events

### Help to Raise Money to Find the Cure!

The Society for Progressive Supranuclear Palsy is gearing up for fundraising events during our new year. Anyone interested in helping to raise money to find a cure, please contact me – Kathy.

You can fundraise in a variety of ways. If you like to entertain, you can invite friends and family over for dinner and tell them it's to support The Society for PSP. Your guests will make a donation to come to your house for a fabulous dinner. Some event planners charge a specific amount such as \$50-\$100 per plate. I will leave the cost up to you! You can also have a jean day at your office where employees donate \$5 to wear jeans for a day. Or perhaps it's dancing and dining that you enjoy – you can organize a shrimp feast and dance. Great food, combined with dancing, then throw a couple of gaming tables like a plant wheel where people can place money on a number to win a plant, the wheel spins and they may just become a winner. A Big Six wheel is fun, too. If you haven't seen one before, it is another wheel with playing cards on it. The same playing cards are on a plastic sheet on the gaming table. You place your bets and if your cards come up – you're a winner. With today's awareness of fitness everyone likes to walk - how about a walkathon? 5K races are popular and you can add many venues.

If you happen to like the fun and extreme, there's always a "Kiss a Pig" contest. You get a dignitary, local celebrity like a newscaster, weather man or political figure. (In Baltimore, while I was a director with another charity, we had a few celebrities and even the mayor.) You find a person to kiss the pig, preferably someone who is marketable so that people will pay money to see him/her kiss that pig. You help the celebrity/person get sponsors. Your celebrity will provide an invitation list for you to solicit sponsors. In addition, you will advertise and send flyers, etc. to everyone you know. Or, you can charge a specific amount with a ticketed event. The Four H Clubs will donate a pig for that special day. You can get sponsors to cover food and music and make a full day out of this fun and crazy event.

How about a disco dance or a luau? The disco dance could feature a contest for the best looking 70's outfit. You can incorporate a hula hoop contest with the luau. There are so many events that can raise money that don't involve a lot of planning. Call me, let's chat. I can help you plan your event. Together we can find a cure. The possibilities are endless.

Kathy Matarazzo Specca  
Director of Development  
1-800-457-4777



### The McAlpine & Peitz Golf Tournament for PSP

Saturday, June 5, 2004  
Hartland Glen Golf Course  
Hartland, Michigan  
12:00 Shotgun start

The McAlpine & Peitz Golf Tournament for PSP. \$125 per golfer—all proceeds benefit The Society for PSP. Lunch at The Turn and Steak Diner with a prize/50-50 raffle and silent auction. All are welcome! Currently seeking gifts and sponsorship donations. Signage for sponsorship is available for \$250. For more information, please contact:

Andrew McAlpine  
Phone: 248-545-3993  
E-mail: chief48238@yahoo.com or  
Donald McAlpine  
Phone: 734-367-8056  
E-mail: drscotmac@yahoo.com or  
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**P S P**  
Progressive Supranuclear Palsy

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800-320-0476

Don't get hassled selling a used car – if you itemize, you may be ahead with a tax deduction and also help the Society.

# Special Events

## Plunge for PSP

Dear Society for PSP,

I am pleased to inform you that our "Plunge for PSP" fundraising event was a big success. My fiance and I came up with the idea for the "Plunge for PSP" when we heard that the year 2004 would mark the 100th anniversary of the L Street Brownie's New Year's Day Swim in Boston Harbor. The Brownies is the oldest Polar Bear club in the US and to mark this event we, along with 35 co-workers decided to "take the plunge" to raise money for our own individual charities.

I have enclosed an excerpt from a letter I sent to family and friends to inform them of my plans and inviting them to sponsor me in the "Plunge for PSP."

*After battling PSP for almost a decade, my mother, Carol Rayworth, succumbed to the devastating effects of this rare disease three years ago. During that time she lost her ability to eat, to move, to read and even to talk, but she persevered courageously and never lost hope. My mission is to promote awareness of PSP, to fund research to find the cause and a cure, and to support the non-profit Society for PSP so they can continue to provide vital information and support to those with PSP, their families and caregivers. Please consider supporting my "Plunge for PSP" in the Mercury 100 Charity Plunge.*

*Thanks to all of you who provided support and comfort to my family and me throughout my mother's illness. Your caring made a difference. And together we can make a difference in the search for a cure for PSP.*

So, what was the final result of our plunge into the icy Atlantic on January 1? I have to admit we were somewhat lucky that day. Both the air and water temperature were in the 30's, which is not exactly "a day at the beach," but in the days following the "Plunge" the temperature dropped to zero, so we were spared the worst! More importantly, with contributions from family, friends and co-workers, Dave and I raised \$3,700 for the Society for PSP, survived to tell the tale, and felt a tremendous sense of accomplishment and gratitude toward all who supported us. We hope this story will encourage others to venture into the rewarding "waters" of fund-raising for PSP!

Warm regards,  
Rhonda Grady and Dave Poulin



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## Attention Shoppers

*Kroger & Randall's Shoppers in Texas (& parts of Louisiana)*

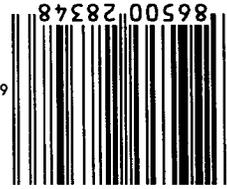
Shop at Kroger and Randall's and earn money for the Society. Cut out this card and put it to use at Kroger.

Here's how these programs work. At Kroger, present your Share Card to the checker along with your Kroger club discount card. The checker will scan both cards before scanning your groceries. Hint: Copy the Share Card bar code so that it is clear and distinct onto sticky-backed paper. Then cut out the bar code only and stick or tape it to front side of your Kroger club card. Do not cover the bar code on the back side of the card or you won't get sale prices! The bar code can be trimmed to fit the key chain card, but cut at least a quarter inch above the 4 and 6 numbers on either side of the code. The checker will scan both sides of your club discount card—no need to carry an extra Share Card in your wallet.

To participate in the Randall's similar Good Neighbor Program, stop by any Randall's courtesy booth and fill out a short Good Neighbor Program application form that will link the Society for PSP to your club discount card number. The Society's account number is 10806. Courtesy booth personnel can look up this number for you.

With both of these programs, that help non-profits raise money, one percent of each grocery order (less taxes, tobacco and alcohol) will automatically be placed in the Society's accounts and forwarded to the Society quarterly. Kroger allows linkage to only one charity; Randall's to several charities.

Imagine! If 250 families spend \$100 every week in conjunction with these programs—we could raise \$13,000 in one year for Society programs! For those across the country who have friends and relatives in Texas, alert them to these programs that will benefit our PSP families. For more information, contact Karen Kennemer in Texas at 281-358-2282 or [KMK1224@aol.com](mailto:KMK1224@aol.com); or call the Society for PSP at 800-457-4777.



**The Society for PSP**  
(Progressive Supranuclear Palsy)  
*Cure PSP - We envision a world free of PSP.*

---

**Here's how the Share Card Program works:**

1. Each time you shop at Kroger, present the card to the checker before they begin to ring up your order.
2. Ask the checker to "scan" the card.
3. Once this is done, your purchase amount is being recorded for **your organization**. A percentage of your purchase is refunded back to the organization listed on the front of this card. **If you have problems or questions call Kroger at 1-800-745-4438 for more information.**

**Checker Instructions:**  
**FS Exception / Scan Card / Ring Order**  
(press "error clear" and repeat steps if card doesn't scan)  
\*\*Fund-raising Gift Certificates CANNOT be used with this order\*\*

SIMPLY TRIM AND FOLD

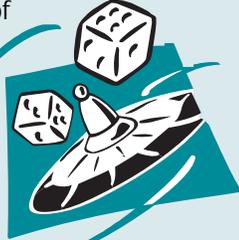
## Special Events

### Hampton Roads, Virginia PSP Casino Night Benefit

Tracie Sansavera of Hampton, Virginia is coordinating a fabulous event that will provide PSP awareness while raising funds for The Society for PSP. The event is "PSP Casino Night," Saturday, October 2, 2004. The doors open at 7:30 p.m. and will feature a variety of gaming such as black jack, roulette, and much, much more. You will think you just landed in Las Vegas!

Scrumptious and decadent hors d'oeuvres will be served throughout the evening. Tickets are only \$35 per person. Tracie is currently seeking sponsors and volunteers. Sponsorship tables are available for \$500. (A real bargain that includes notoriety and tickets for local businesses and even notoriety for those across the nation.)

You may contact Tracie by calling 757-766-8383 or email at [igothands@cox.net](mailto:igothands@cox.net). Your support will bring us closer to finding a cure for PSP. Join us in supporting this event – you're not just rolling the dice, you're making a difference. This is Tracie's Third Annual PSP October Awareness Event in honor of her mother, Marge Peck.



### OCTOBER IS PSP AWARENESS MONTH

Start planning your event today. Plan a walk-a-thon, spaghetti dinner, golf or bowling tournament, auction, writing campaign or dinner in your home. Contact the Society to help you plan your event.

### Join the "Special Event Volunteer" Committee

Come be a part of this team!

For more information contact: Kathy Matarazzo Specca, Director of Development at 1 (800) 457-4777.



*Collinwood Middle School 2nd Annual PSP  
Walk-A-Thon held October 14, 2003,  
raised \$2800 for the Society.*

### Racing For The Cause



In August of 2004, Bob and Cece Griffin of South Heidelberg Township, PA, will be married 50 years. Bob says it is hard to pinpoint when Ceci was stricken with progressive supranuclear palsy since the onset provides many hints that something is changing but it is hard to actually pinpoint the time it began. The Society for PSP has asked the PSP community to go public with this disease to raise awareness and Bob and Ceci have done just that. "It's lonely being the only ones dealing with a disease nobody knows about," Bob says. The Griffins have suffered other personal tragedies in their lives. Three years ago, their daughter Lisa was brutally murdered in her home and to this day, no one has been arrested. The Griffins are an auto-racing family and intend to exploit that for all its worth – both for their daughter and PSP.

Bob has won his class three times at the Duryea Hill Climb in a Volvo he souped up himself. His daughter Diane, driving cars that she built and maintained, dominated micro sprint racing, winning six season championships against an all-male field. Diane's husband, Ronnie Tobias, son of legend, Tobias, died of severe heart failure after finishing a race three years ago. He was 43. Last year, Rob, the youngest Griffin, started racing micro sprints in a car built and maintained by his sister. The car has a new sleek look and been turned into a speeding billboard for PSP.

*When giving a gift to United Way,  
you can designate The Society for  
PSP at 1838 Greene Tree Road,  
Suite 515, Baltimore, MD 21208  
as a recipient.*



### Ask the Doctor

**Question:**

My husband was diagnosed with PSP. We struggled through many difficult years with this disease. He wanted to donate his brain to the Society Brain Bank in hopes that it would help someone in the future. We made these arrangements well in advance. When I got the pathology report, it said corticobasil degeneration instead of progressive supranuclear palsy. How are the diseases alike and how are they different?



*Lawrence I. Golbe, MD*

**Answer:**

On behalf of the PSP community, I thank you and your husband for the brain donation. It will be of great value to research on both PSP and corticobasal degeneration (CBD). The two disorders can be very similar in their appearance not only during life, but at autopsy as well. In fact, the abnormality in the tau gene that has been found to contribute to the cause of PSP contributes equally to CBD. Both disorders have neurofibrillary tangles (abnormal blobs of tau protein) in the brain cells. The main difference at autopsy, aside from some details about the chemistry of the protein blobs, is that CBD affects one side of the brain much worse than the other and affects the cerebral cortex far more than PSP does. The outward result is that CBD causes major difficulty with coordination of limb movement (“apraxia”), abnormal contraction of muscles (“dystonia”), rapid jerking movements (“myoclonus”) and difficulty identifying objects by feel (“cortical sensory deficits”). This all reaches at least a moderate stage of severity on one side before it affects the other side. PSP, on the other hand, is usually symmetric in most of its manifestations. CBD can cause vertical eye movement problems, slurred speech and swallowing problems, but not as severely as PSP. PSP, on the other hand, has more serious balance problems. Both cause general slowing (“bradykinesia”) and have a similar prognosis. While PSP can respond temporarily or modestly to some medications, CBD has not been found to respond to any medication at all, unfortunately. When, with the help of brain donations such as your husband’s, we find the cause and cure of either PSP or CBD, we will probably have the cause and cure of the other.

*When giving a gift to United Way, you can designate The Society for PSP at 1838 Greene Tree Road, Suite 515, Baltimore, MD 21208 as a recipient.*



## Swallowing Difficulties In PSP: A Speech Pathologist’s Perspective

By: Laura Purcell Verdun

It is well known that swallowing difficulties are a hallmark sign of PSP. It is often the earlier onset of swallowing difficulties that discriminates PSP and other Parkinsonian syndromes from Parkinson’s disease. Dysphagia, or difficulty swallowing, can be life-threatening particularly, when it places someone at risk for aspiration or compromised nutrition and hydration. Aspiration is when food, liquid, or saliva goes down “the wrong way” into the airway to the lungs. Therefore, it is important for families and medical professionals to be proactive earlier in the course of the disease process to pursue discussion, evaluation, and management of these difficulties to minimize complications. These complications could include malnutrition, dehydration, and aspiration pneumonia.

A swallowing evaluation consists of a clinical examination and occasionally a swallowing study. A clinical examination is conducted by a speech pathologist, and may include completion of a swallowing questionnaire, an examination of mouth motor and sensory control, examination of speech and voice, and observation of eating and drinking. Patients and care partners must be queried as to concerns and observations regarding swallowing, because the person with PSP may not be aware of changes in swallowing or self-feeding abilities. Questions will be posed regarding speech difficulties, which often precede the onset of swallowing difficulties in PSP. Maintaining a log of swallowing and feeding difficulties for 1-2 weeks preceding the clinic visit is helpful to problem solve and direct therapy efforts. For example, it is important to include which items specifically are difficult to swallow, when it happens, and how often, including observations about self-feeding abilities. Suggestions then can be provided to promote safer and easier swallowing based on the clinical picture, knowledge of normal swallowing physiology, and anticipated changes associated with PSP.

A videofluoroscopic swallowing study, also called a modified barium swallowing study, may be conducted. This is a video x-ray examination of the swallowing passage, from the mouth to the stomach. Various food and liquid consistencies of varied amounts are presented. The goal is to replicate the home eating environment of the person with PSP, document swallowing function, and exhaust all strategies to enhance the safety, ease, and enjoyment of swallowing. This test is not only to document aspiration, but more importantly to figure out what to do about it. Not all persons with PSP need this examination; the decision is made on a case-by-case basis.

Diet modification is a commonly used strategy. For example, thickening liquids will slow the movement of liquids from the mouth to the throat. This is useful when swallowing is not well coordinated, or there is disruption in timing events. Soft and moist foods may be suggested, thus avoiding dry, particulate foods such as nuts, and highly textured foods, such as meats. Additionally, taking medications with a puree or pudding consistency instead of with water or other liquids will keep pills from catching.

The presence of aspiration does increase the risk for developing aspiration pneumonia. Studies have shown however,

that there are other contributing factors to the development of aspiration pneumonia, including poor oral hygiene, bed dependence, and dependence for feeding. The presence of a feeding tube does not eliminate the potential for aspiration pneumonia. Clearly, the development of aspiration pneumonia is a complicated, multi-factorial process, and attention should be directed not only to swallowing but the other factors mentioned.

There is no right or wrong answer to the question "Is it time for a feeding tube?" This conversation does however need to take place sooner rather than later during the disease process for all persons with PSP, allowing for the patient to participate in decision-making. It is yet undetermined whether early and aggressive nutritional therapy may delay the progression of the disease. Perhaps it would allow that person greater medical stability to cope with and minimize complications.

It is important that expectations be realistic and accurate. Are there anticipated physiologic improvements, and/or in quality of life? There is a need to define for what purpose it is being used, and at what point in the natural history of the illness. It is important to understand the risks for proceeding without a feeding tube, and alternatively, the risks and responsibilities associated with placement of a feeding tube. There are minor and major risks to PEG (percutaneous endoscopic gastrostomy) placement. Criteria for placement have yet to be refined. A nasogastric tube (NGT) for long-term enteral feeding is not indicated in PSP.

All persons with PSP should participate in a clinical swallowing evaluation upon initial diagnosis to allow for monitoring over time, timely implementation of swallowing strategies, and support for making informed decisions. Evaluation and adequate treatment of dysphagia might prevent or delay complications such as aspiration pneumonia, which in turn may improve quality of life and increase survival time.

*Laura Purcell Verdun is a speech pathologist with Otolaryngology Associates, P.C. in Fairfax, VA; and a speech pathology contractor for the NIH Warren G. Magnuson Clinical Center.*

## Swallowing Difficulties In Progressive Supranuclear Palsy: A Personal Perspective

Bertrand L Jaber, M.D.

My father was diagnosed with PSP at the age of 70. He had been suffering from recurrent falls and visual difficulties for four years. At the time of diagnosis, a modified barium swallow study confirmed aspiration of clear liquids into his trachea, putting him at risk for pneumonia. At that time, the dietician recommended that all food and drinks have the consistency of thick-set yogurt. Soon afterward, I painfully discussed with my father the need to consider a feeding tube at some point. He deferred this decision to a later date. Over the following three years, the disease progressed and he became increasingly dependent on my mother who cared for him at home. It is a testament to my mother's determination and

devotion that my father's health and weight were maintained for such a long period of time. I flew back home to find out that he had lost significant weight and feeding him by mouth had become an unbearable and inhumane ritual that neither of my parents could withstand. I felt compelled to revisit the need for a feeding tube, after having conferred with my mother and my two brothers and having obtained their support. I sadly succeeded in convincing him. The feeding tube was placed by a gastroenterologist under local anesthesia without any medical complications. However, this intervention was a major turn in my father's helpless resignation to this new physical handicap. In the next six months, his physical condition continued to deteriorate. He stopped ambulating and became bed-ridden, requiring total care. He continued to lose weight despite tube feeding. In fact, the feeding formula was often reassessed due to excessive diarrhea or constipation. He later died at home following an episode of aspiration.

### FACING THE DILEMMA.

Few people are equipped to deal with the painful ethical decisions that arise when a patient with PSP reaches an advanced stage of the illness. My experience both as a physician and as the son of a patient with PSP instigated me to review the issue of tube feeding. Whereas published literature on issues of tube feeding in elderly patients with dementia is quite elaborate, little is known of the role, timing and efficacy of tube feeding in PSP. The relationship between nutrition, aging and disease is quite complex. Indeed, the normal age-related decline in the host defense systems, coupled to nutritional deprivation, may contribute to the increased susceptibility of the elderly individual to infection.

Whereas most physicians would agree that patients with PSP who have swallowing difficulties (or dysphagia) eventually require a feeding tube through which semi-liquid food has to be administered, few are clear on the timing, benefits and risks associated with this form of feeding, particularly in patients with advanced disease.

One could argue that tube feeding should be reserved for patients with advanced stages of PSP in whom there is a failure to insure minimal nutritional requirements due to severe dysphagia. However, this decision is often delayed due to ethical issues, in particular, the inability of the healthcare provider to confirm whether an intervention (such as the placement of feeding tube) will help or be distressing to a patient close to death. I propose that the need for a feeding tube should be discussed with the patient, and its placement pursued aggressively as soon as the diagnosis of dysphagia has been confirmed. If the patient is comfortable with this decision, I believe that early and intensive nutritional therapy can actually delay complications related to immobility and aspiration pneumonia.

In conclusion, since aging and nutritional deficiencies may severely compromise an elderly individual's potential to confront PSP, it remains to be determined whether early and aggressive nutritional therapy, once acknowledged by a patient in the early stages of the disease, may delay its progression.

*In memory of Toufic S. Jaber*

## Your Guide to Making a Decision Regarding a Feeding Tube

Ame Golazewski, MS, RD, CNSD  
Clinical Nutrition Support Services  
Hospital of the University of Pennsylvania  
Philadelphia, PA

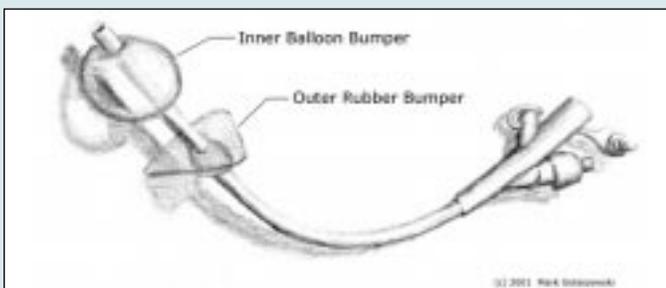
One of the most difficult decisions you may face while living with progressive supranuclear palsy (PSP) is whether or not to have a feeding tube placed. Before you can determine if a feeding tube is right for you and your caregivers, you need to know the facts. More often than not, many people discard the thought of a feeding tube before they even know what it is, or how it is used. The following is a detailed description about feeding tubes to assist you in making a decision as to whether a feeding tube is right for you.

### What is a feeding tube?

A feeding tube is a silicone or polyurethane catheter or tube that is inserted into the gastrointestinal (GI) tract to provide an alternate route for nutrients, liquids or medications. Most commonly in patients suffering from PSP, the feeding tube is inserted into the stomach. There are two types of stomach feeding tubes: 1) Percutaneous Endoscopic Gastrostomy (PEG tube) and 2) Gastrostomy (G-tube).

### How is a feeding tube inserted?

The PEG TUBE is placed while you are under "conscious sedation" (you are medicated so that you will not feel any pain). The doctor places a tube in your mouth, passes it through your esophagus and into your stomach. This tube contains a very small camera which enables the doctor to visualize the inside of your stomach. A small incision is made into the outside of your abdomen leading to the inside of the stomach. The PEG tube is then inserted into the incision into your stomach. A small balloon-type bumper is inflated with sterile water and air to hold the tube close to the stomach wall. Another rubber bumper, located outside the body, is placed on the skin to hold the feeding tube in place. There are no sutures or stitches involved in the placement of a PEG tube. A PEG tube is pictured below.



A G-TUBE is placed while you are under general anesthesia. This differs from the PEG tube procedure in that it requires that you be put temporarily on a ventilator while the tube is surgically placed. Like the PEG tube, there is a balloon-type bumper on the inside of the stomach to keep the tube tight to the stomach wall. The G-tube is secured to the outside skin with a few stitches or sutures to hold it in place. If a PEG tube placement is unsuccessful, a G-tube is placed.

### Main reasons a feeding tube are placed:

1. Recent aspiration (food or liquid in the lungs) pneumonia
2. Difficulty swallowing or any change in food/liquid consistency
3. Weight loss (without trying)

### Other reasons to start considering a feeding tube:

1. Difficulty taking medications
2. Difficulty taking enough fluid or water (recurrent dehydration)
3. Increased coughing or choking with food or liquid

### Misconceptions about feeding tubes:

1. "If I get a feeding tube, I will never eat again."
  - For some individuals who can no longer eat or swallow, a feeding tube can act as an alternate means to provide the necessary nutrition to sustain life.
  - However, for those individuals who are still capable of eating, but may not be consuming enough, or are losing weight without trying, a feeding tube can offer a means of supplemental or additional nutrition.
  - Sometimes a feeding tube is placed to offer a means of supplying additional fluid or water to prevent dehydration or to deliver medications, and not for supplying food at all!!
  - For those who are NOT at risk for aspiration, eating IS encouraged after a feeding tube is placed.
2. "A feeding tube is just going to be another burden on me and my family."
  - Daily care of a feeding tube is minimal.
  - A feeding tube can decrease the stress for both you and your caregivers by possibly alleviating the pressures associated with eating or mealtimes to consume adequate food.

**Remember... A feeding tube may be recommended for reasons other than providing nutrition.**

## Society for Progressive Supranuclear Palsy Brain Donation Program

For Diagnosis of and Research on PSP

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

The purposes of the Society for PSP Brain Donation Program are:

1. To provide families with postmortem diagnostic evaluation for relatives suffering from PSP and related disorders.
2. To provide tissue for PSP research to scientists at medical institutions or other research centers.

To obtain informational packets about brain tissue donations, please contact the Society for PSP.

Phone: (800) 457-4777, (410) 486-3330 / E-mail: SPSP@psp.org  
The Society for PSP, Woodholme Medical Building, Suite 515  
1838 Greene Tree Road, Baltimore, MD 21208

**If you are considering brain donation, it involves a great deal of preparation – So the time to plan is NOW!**

## Keeping Active – What Can I Do At Home?



Heather J. Cianci, PT, GCS  
The Dan Aaron Parkinson's  
Rehabilitation Center  
Philadelphia, PA

Progressive supranuclear palsy can cause slowness of movement, muscle rigidity and changes in one's posture, walking and endurance. Many individuals have been encouraged to perform exercise on a regular basis to better deal with these issues. Exercise and early intervention by a physical or occupational therapist can improve your ability to perform certain functional activities for a longer period of time. Certain exercise can even help reduce stress and promote relaxation.

With your physician's approval, here are some basic exercises that you can do in your own home to get started. Happy exercising!

### RELAXATION EXERCISES

These exercises can decrease muscle tension and improve the ability to perform activities of daily living and other types of exercises.

- DEEP BREATHING - SITTING

Close your eyes and gently place your hands on your abdomen. Slowly breathe in through your nose and feel your hands move out as your abdomen rises. Exhale slowly and fully through your nose. Repeat 10 times.

- RIB CAGE EXPANSION - SITTING

Begin with arms at your sides in a relaxed position. Slowly take in a deep breath through your nose as you lift your arms up above your head and reach for the ceiling. As you exhale, gently bring your arms back down. Repeat 10 times.

### STRETCHING EXERCISES

These exercises help to maintain the flexibility of muscles. This way, muscles will not tighten so easily and will work more efficiently.

- HEAD TURNS - SITTING

Slowly turn your head from side to side and look over each shoulder. Hold each turn for 3 deep breathes in and out. Repeat 5 times.

- SHOULDER SHRUGS - SITTING

Slowly shrug your shoulders up and then roll them backward, feeling your shoulder blades pull together. Repeat 10 times.

- WRIST CIRCLES - SITTING

Place your arms straight out in front of you and make slow circles in and out with your wrists, ten times in each direction.

- ARM STRETCH - SITTING

Hold arms straight out in front of you, move arms to



straight out to your sides, and then behind you. Hold this pose for 5 deep breathes in and out. Return arms in front of you always keeping your elbows straight and head upright. Repeat 10 times.

- ANKLE CIRCLES - SITTING

Straighten your knee and make slow circles with your ankle. Repeat 10 times in each direction. Do the same with other ankle.

- WAND EXERCISE - LYING DOWN ON BED

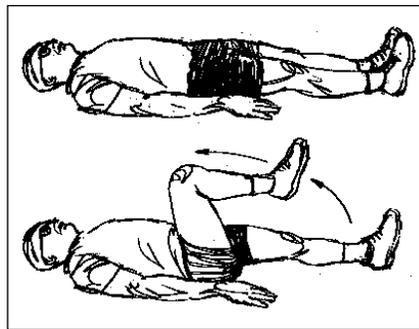
While on your back, lift a cane or stick to the ceiling with both hands. While keeping the elbows straight, slowly allow the cane to fall backwards, over your head. Hold this pose for 5 deep breathes in and out. Repeat 10 times.

- KNEE TO CHEST - LYING DOWN ON BED

While on your back, gently hug one knee up toward chest while keeping the other leg flat on the bed. Hold this pose for 5 deep breathes in and out. Repeat with each leg 5 times.

- TRUNK ROTATION - LYING DOWN ON BED

While on your back, bend both knees up so that your feet are flat on the bed. Make sure knees and ankles are touching. Slowly allow both knees to fall to one side so that your lower trunk is twisting. Try to keep your head and top trunk flat on the bed. Hold this pose for 5 deep breathes in and out. Now allow legs to fall to the other direction. Perform 5 times in each direction.



### STRENGTHENING EXERCISES

These exercises will help to keep muscles strong so that transferring and walking are easier to perform.

- SITTING KICKS - SITTING TALL IN A CHAIR

Slowly kick one leg straight out in front of you. Make sure your knee is straight. Hold this position for 10 seconds. Repeat with each leg 10 times.

- SHOULDER SHRUGS - SITTING

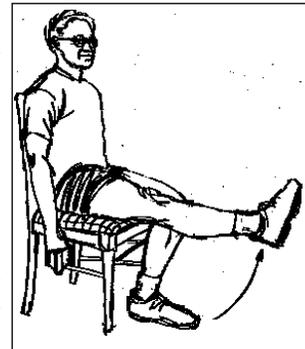
Bring your shoulders upwards towards your ears, count to 5 and relax. Repeat 10 times.

- SHOULDER SQUEEZES - SITTING

Bend your elbows to 90 degrees and hold them at you sides. Gently pull elbows back and squeeze shoulder blades together. Hold for a count of 5 and relax. Repeat 10 times.

- BRIDGING - LYING DOWN ON BED

While on your back, bend your knees up so that your feet are flat on the bed. Slowly lift your bottom up off of the bed



# Education

as high as possible. Hold this position for a count of 5 and relax. Repeat 10-20 times.

- **STRAIGHT LEG RAISE - LYING DOWN ON BED**

While on your back, bend one knee up so that your foot is flat on the bed. Keep the other leg straight. Slowly lift the straight leg a few inches up off of the bed. Be sure to keep the knee straight. Hold this for a count of 5 and relax the leg straight down. Repeat with each leg 10 times.

- **HIP SLIDES - LYING DOWN ON BED**

While on your back, slowly slide one leg out to the side as far as you are comfortable. Slide leg back in and repeat on the other leg. Be sure that toes are pointing to the ceiling and one knee is straight the whole time. Perform 10-20 times on each leg.

*For more information or help in developing an individualized program, contact your local physical or occupational therapist. Heather can be reached at [hjcianci@yahoo.com](mailto:hjcianci@yahoo.com) or 215-829-7275.*

## PSP and the Bladder

Lawrence I. Golbe, M.D.

Chairman, Society For PSP Medical Advisory Board

Many brain disorders, including all of the parkinsonian disorders, can affect the urinary bladder. The normal nerve circuitry linking the bladder to the spinal cord perceives stretching by a large quantity of urine. These circuits normally set in motion a reflex, not unlike the knee jerk reflex, that stimulates the muscle in the bladder wall. This squeezes the bladder, causing it to empty. It is the job of the normal brain to inhibit this function. When we voluntarily initiate the act of emptying the bladder, we temporarily suspend this inhibitory brain function. Patients with PSP have difficulty inhibiting reflex bladder emptying. As the bladder slowly fills with urine from the kidneys, this produces sudden urinary urges ("urgency") and in many cases, incontinence—a condition sometimes called "irritable bladder." In PSP, degeneration of a small cluster of nerve cells near the lower end of the spinal cord (the "nucleus of Onuf") contributes to the problem.

Urinary urgency and incontinence can be treated in a variety of ways. First, it is wise to check for a bladder infection. The inflammation caused by infection can irritate the bladder lining, fooling its sensory nerves into perceiving that they are being stretched. This stimulates the reflex contraction of the bladder wall muscle. Treating the infection with antibiotics and fluids can correct this problem. There are many possible causes of bladder infections, including enlargement of the prostate in men, which can be treated by medication or surgery, and "dropped bladder" in women, which can be treated with surgery.

The overall disability of PSP can cause a bladder infection by making trips to the bathroom difficult and infrequent, allowing urine to accumulate in the bladder excessively, which permits bacteria in the urethra (the tube from the bladder to the outside) to spread into the bladder and grow. Many people with PSP drink little fluid, either because they cannot swallow easily or because they cannot easily walk to get a

drink. This reduces the frequency of urination and the natural cleansing of the urethra by regular flows of urine.

If bladder infection is not the cause of urinary urgency and incontinence, the symptom often responds to drugs that stimulate the muscle at the neck of the bladder. Even when the bladder wall muscle contracts abnormally, the ability of the bladder to empty, and the sensation that it needs to do so, can be inhibited in this way. Two of the more popular drugs are oxybutinin (Ditropan) and tolterodine (Detrol). Both drugs can also cause dry mouth and constipation. The latter is often already a problem in PSP and can be treated by fluids, fiber and stool softeners and in more severe cases, laxatives.

These drugs must not be overused, as they can actually worsen the urinary problem by making it so difficult to empty the bladder that it overfills, weakening the bladder wall muscle. Some drugs used to treat the movement disorder of PSP, such as amantadine and amitriptyline, can share this side effect.

Incontinence during the night is especially common because of the reduced availability of a caregiver to aid the trip to the bathroom and because the recumbent position increases blood flow to the kidneys, producing more urine per hour. Nighttime incontinence can be reduced by avoiding drinking fluids after supper. This must not be accomplished at the cost of reducing the total daily fluid intake and causing dehydration.

If urinary incontinence in PSP fails to respond to these measures, it may be necessary to use an absorbent pad or adult diaper. Advice of a visiting nurse is often useful in choosing between this method and a urinary catheter and for instruction in avoiding skin irritation. For men, a condom ("Texas") catheter is usually preferable to an indwelling ("Foley") catheter because the latter allows bacteria to ascend the urethra and gives them a surface in the bladder on which to grow and cause infection.

### One Day At A Time

*Just for today I will try to live through this day only. I will not think about the future. I know I can get through just one day.*

*Just for today if I feel angry I will find a safe way to express it. I may scream and beat a pillow, but I will not hurt anyone.*

*Just for today I will remember the good things and go of blame and regret because no one can change the past.*

*Just for today I will have a plan to fill the time. I will avoid idle hours which can lead to depression and despair.*

*Just for today I will set aside time to relax and I will plan a short term goal to work toward.*

*Just for today I will have hope that life will get better because love never dies and love can sustain us through the most painful tragedies.*

*Just for today I will be unafraid. Especially I will not be afraid to enjoy what is beautiful because my life must go on.*

*Just for today I will have faith that even though life is not always fair, it is still worth living. In time, with faith and the grace of God, I will find new meaning in life.*

# Education - Helpful Hints

## Home Healthcare Products

### Series III

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#### Products From Functional Solutions

1-800-235-7054 or www.healthcraftproducts.com



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Move from the chair without removing the armrest

The Flip Away Armrest pivots upward, allowing easy entry and exit from a wheelchair. Features a convenient built-in beverage holder. Thick vinyl-covered padding provides comfort.

Accommodates almost any wheelchair with a 2 1/2" x 1" (6.4 x 2.5cm) armrest. The wide armrest measures 13 1/2" (34cm) and the narrow armrest measures 10" (25cm) wide.

Wide

NC94138 (Left) NC94139 (Right)

Narrow

NC94140 (Left) NC94140 (Right)

Each armrest \$159.95

#### WHEELCHAIR DAY PAC™

Sporty and convenient wheelchair pack. This exceptionally roomy pack fits and wheelchair with or without push handles. Adjustable straps allow the pack to slip loosely or snugly over the back of any wheelchair seat, making it simple for the user to remove it from a seated position. Dual zipper system opens the pack from either side and includes large pull rings for persons with limited grasping ability. Measures 12" x 12" x 4" (30 x 30 x 10cm) Made of waterproof nylon.



NC84500-1 Black \$36.95

NC84500-2 Blue \$36.95

NC84500-3 Purple \$36.95

#### CARE COVERS

Cushions hard walker handles for a comfortable hold. These pads attach easily with a hook and loop closures. Made of synthetic sheepskin. Machine wash and dry. Sold in pairs.

NC94342 \$16.95



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Safely move a person between bed and chair with minimal lifting. This finely crafted transfer board is tapered from 3/4" (19mm) thick in the center of the board to 1/8" (3.2mm) thick at the ends. Board measures 8" (20cm) wide and has several coats of lacquer for a smooth finish. Supports up to 200 lbs. (91kg).

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- Ideal for sofas, theatre seats, pews, etc.
  - Comfy foam cushion with washable cover
  - Video guides you through the easy set up
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#### FOLD-AWAY WALKER TRAY

- Snaps on almost any walker with adjustable clips
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- High edges, beverage holder prevents spills
- 16" x 15 1/2" x 7"

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These soft fleece pads cushion your arms to prevent soreness, bruises, and skin irritation. Easily attach them to your armrests with their Velcro® tabs. Washable. Two sizes.



AL 0302

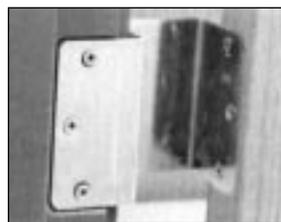
10" Armrest Covers

\$18.99/pair

AL 0303

14" Armrest Covers

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#### OFF-SET DOOR HINGES

Widen your doors economically. Ingenious design makes use of existing hinge holes and screws – no remodeling or door resizing required! Adds an extra 2" clearance space so you won't have to "squeeze through" your home!

- Brass-plated steel
  - Two per package
  - Hinges measure 2" x 3 1/2"
- CG 2006B Off-Set Door Hinges \$19.99

#### 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.

# Support Groups As Of March 1, 2004

*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. For information about support groups please contact: Jessica Quintilian, Director, Outreach and Education at 1-800-457-4777.*

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\*PHONE/EMAIL GROUP

*Let us post your support group news and announcements in the PSP Advocate. Deadline dates are Jan. 15, March 15, July 15, Oct. 10. Please send your support group news/photos to The PSP Editor at NancyB501@cs.com or to the Society office.*

## PSP Forum

These messages were posted on the Society's Web site.  
Visit the PSP Forum today at [www.psp.org](http://www.psp.org)

I would like to say hello to everyone out there. I have been reading all the messages for some time now. I would like to tell you about my husband and PSP. He retired after working with a power company. One of the first sign that I noticed something different was when we took our evening walks together. The year was 1997. His gait became slower. He is a large man, 6'2" and weighed about 250 at that time. I am very short, 5'. But my steps were getting larger than his. The next day after he actually had retired, he sat in his recliner all day. That was the beginning of him doing absolutely nothing all day. I couldn't believe it. He had always worked at least 10-13 hours a day. He seemed to be completely satisfied in doing nothing.

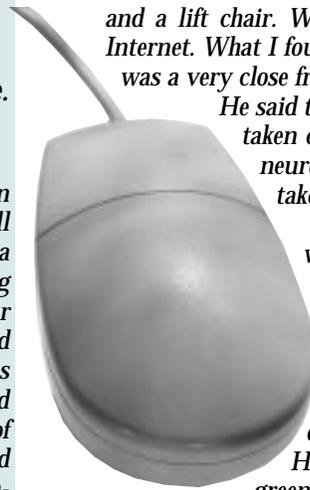
We soon moved to NC and began a life of retirement. After several months, our son became concerned about father's sedentary lifestyle. He talked him into taking a part time job with our local telephone company. He bought about \$500 worth of equipment and worked about one week. He came home and told me he could not remember the steps of the procedure he was doing and just gave up. He gave away the new equipment to the man that was training him and came home. I thought how strange, this man that had worked many years supervising the construction of underground and aboveground power lines for a large district, could not pick up a simple procedure and remember how to do it.

More strange things started happening. He began to forget things, his driving became very hazardous, and he began falling backwards coming up the steps. Many times he had fallen backwards with things in his hands, not holding on the railings, then get up and do the very same thing. He was having problems with his eyes. Always tearing, he complained to the doctors about his eyes all the time.

The Christmas of 2000, we had discussed and planned on what we would be serving at our big Christmas dinner with his family. A few days before the party, I came home from the grocery store with many bags of groceries. He asked "What did you buy all that food for?" I said for our party with his family. He said "Well thanks a lot for telling me about it." He had forgotten about it that quickly!

He has had high blood pressure and diabetes for about twenty years. He was rushed to the hospital and found to have had a mini stroke. We were later to find out through MRI's and CAT scans that he had had several mini strokes before, but we did not know at the time. It was also found that he had a recent fractured tail bone. When he had fallen one time, he did complain of hurting his tail bone, but did not ever tell his doctor about it. I bought him a doughnut pillow and he sat on it for over a year.

During his hospital stay we saw a new neurologist. He continued to watch him closely over a period of a few months. At all the visits, he mentioned a disease called PSP. Of course, he said the full name, which we had never heard about and couldn't remember. A doctor that was visiting our neuro doctor took one look at his eyes and gave us a definite diagnosis. She was from The Robert Wood Johnson School. She wrote the name down and gave us some suggestions that might help me take care of him. Things like satin sheets, a walker with four wheels and brakes,



and a lift chair. We came home and I looked up PSP on the Internet. What I found was shocking. Our internist at that time was a very close friend. I took the printed material to his home. He said that he had heard of the disease but had never taken care of anyone with it. He said that with the neurologist, they would both learn all about it and take care of him.

He began choking some, he could no longer walk without a walker, his vision continued to fail him and then he was diagnosed with prostate cancer. He received radiation for the cancer and has done well with that. Last May, he complained lightly that his stomach hurt. I had just put him to bed when he declared that he wanted to go to the hospital. He had emergency surgery for an almost gangrened gall bladder. He again did pretty well with this surgery. All this time, he has deteriorated to sleeping in a hospital bed, using a raised toilet seat. I now have to bathe him, brush his teeth, dress him, etc. I have to feed him his meals. He had so much trouble getting in a regular kitchen chair, could not see the plate and put very large portions in his mouth. Then, of course, began coughing and choking. He has had three swallowing tests done to tell me what kinds of food to feed him.

He cannot stand up without falling over. I use a gait belt around him all the time. I began this after several falls and broken ribs. The lift chair is one of my saving graces—not that he doesn't still fall. You can be right there with him and he will try to do something that I know that he can't do and over he goes. I have put up safety rails in the bathroom. Last January, his internist for over 25 years retired and moved away. Last June, his neurologist moved to Texas. We live in a fairly small town. His new doctors know of the disease, but have never before had a patient.

Most days he does not talk to me at all. He gets the most pleasure out of our dog (a beagle), Snoopy. Some days he will pick up the newspaper and try to read awhile, but mostly just watches TV and sleeps. His weight is now down to 219. I think that right now I am taking very good care of him. I have a sister that lives two hours away. She comes over one day a week so that I can get out and do some errands and maybe once in a while go to lunch with friends. He doesn't like for me to go. We have three grown children, a son that lives five hours away, a daughter that has relocated to the DC area from Boston, so that she can be closer to help. She comes one weekend a month. Our other daughter lives here in town. I could use any ideas that anybody can give me. I know this story is very long but I hope many can relate to my situation. Thanks for listening.

I think everyone on this forum can relate to your situation. My dad was finally diagnosed in August 2002. In November 2002, he started to fall and my mom tried to stop him. They both went down, and as in all of his previous falls, he was not seriously hurt. Unfortunately, my mom wasn't so lucky. She crushed the humerus bone (between the elbow & shoulder) in 5 places and had major radial nerve damage ... all of this on her "good" arm. For the 7 months between Nov 2002 and June 2003, when my dad went into a nursing home, there had to be someone with my parents 24/7. My mom was not able to do anything with her arm, and could in no way handle my dad.

## Support

The decision to place Daddy into the nursing home was not an easy one, and we still carry some guilt for doing so. BUT, we know that this was the only thing we could do, and it was the best move we could have made...for all concerned. From the time of his diagnosis, my dad deteriorated very quickly, and he is now totally dependent on others for all of his care...being dressed, fed, diapered, etc...

The most heartbreaking part of this disease for me is to see my dad struggle to speak...the only thing we can understand is Yes and No. This horrible disease took the wind out of the sails of a truly wonderful, caring, loving man. It is so hard to see a man so frail and non-communicative that used to be so strong and outgoing.

It really sounds like you have had your hands full for the last several years. God bless you for being there to take such good care of your husband. I'm sure if you've been reading the posts here you know that everyone is here with listening ears and open, loving hearts. Lean on us ... vent if you need to ... it's good for you, mind and soul.

This is easier said than done, but if you ever have the chance to "get away", if even for a couple of hours, it will help to re-energize you.

Hmmm...change a few key words and I could have written this. It's my mom and our dog is Molly. Other than that it pretty much parallels my situation. For a while we used an office chair for dining. It was easier for her to slide into the table. Recently, however, she's been in a wheelchair. My greatest suggestion is to check out hospice. There are a lot of posts about it. We entered last March and the people are WONDERFUL!! Hang in there. It's a worthy cause, caring for him

I could have written the entire post, age, size, retirement...only the names of our cats are Bob and Pal. I also am very new to this and this is my first posting on this forum. This is a very lonely illness. I too, am looking for support. My husband is not yet to the stage you talked about, but from all I am reading, that will soon come. The one good thing we have going is that one of the experts on this illness is in our city. She made the diagnosis just a few months ago. This was after searching for several years. He is now in one of her research programs. We see no change, but who knows. My husband feels this is his only hope. Tonight, he fell getting up from the dinner table. This is happening weekly now. I need to find out more on how to deal with this.

Welcome to the Forum! Just a shame that it has to be another PSP sufferer to get to the post. Re: your husband falling; my husband was falling at least daily, and then 2-3 times per day, when I finally, with the insistence of my children, admitted him to a care center (nursing home). At 6-2" and 275 lbs., I just could no longer keep picking him up. The only way I know how to help the falling is the way the care center does it, and that is putting his bed approx. 9" from the floor and they sit him in a giant bean bag chair. They said in his mind he thinks he can get up, but we all know he cannot,

and he cannot get up from that low position. Ron has been ill for approx. 9 years now. He has to be fed now, because he cannot look down to his plate and gets too large of a bite and if he gets it to his mouth, he usually chokes. We just started this Tuesday, not sure how well it is working.

Oh, how I remember those days of my husband falling all the time. He is now in the wheelchair full time, the only time that he does walk is to take a very few steps in the morning. But prior to him being in the w/c the paramedics would be called out to our house so often, that I had him register with the ambulance district. It was nice, because whenever I did have to call 911 they already had a list of his medical history, medications, doctors, and preferred hospital, along with his doctors name and phone number. This saved a lot of time, because the EMT and Paramedics had a computer print out by the time they arrived to the house with all the info.

Which reminds me of a funny story, well it is funny now. The first week of October, Patrick had another TIA and was admitted to the hospital. We had moved in the middle of Aug. and I didn't change from the old address to the new address with the ambulance company. Well, needless to say, when they were discharging Patrick from the hospital, the ambulance company had our old address on file and was going to take him there. Thank goodness I was at the hospital at the time of the discharge, otherwise the people who bought our home would have had a shock.

Patricia, reading your post was like watching an episode of DRAGNET."The story you are about to see is true. The names have been changed to protect the innocent." It's just sometimes weird to hear carbon-copies of my dad's situation. As for ideas, I'll be blunt. Get help. You will need it. I don't mean to strike fear into you, but people can sometimes walk on eggshells, and I don't believe in that. Not many doctors know about this disease. It will be a battle and you probably will get a thousand different suggestions from as many medical people. But, if you keep hope in your heart, you will find what you need. Also, and this is just from my perspective, you might consider hospice. They can take a lot of the burden off of you. Many of the problems that you will deal with will try your patience and your will, but it can be done. My mom is living proof. Also, if you have to talk, vent, yell, or scream, feel free to do it right here. We've all done the same at one time or another. Jim Valvano once said, "Don't give up, don't ever give up." I tell you the same.

### PRIVACY POLICY/DISCLAIMER

The information provided on the Society website is intended to foster the communication of progressive supranuclear palsy, both for health care professionals and the public. It is not intended to take the place of professional medical advice.

*"If you keep hope in your heart, you will find what you need."*

## PSP “Down Under”

We are writing on behalf of our PSP Support Group in Victoria, Australia, to thank the Society for PSP for the support given to us in the formative stages of our group. A large country, small comparative population, but still the same issues when a diagnosis of PSP is made. Our people with PSP, their families and carers find the problems of a slow diagnosis or misdiagnosis of PSP, educating medical and allied health staff about the disease, isolation and grief are major issues. These are universal issues



but in Australia the disease is less recognized. In the USA and UK, PSP is supported by central organizations and regional support groups. In Australia, the situation is far less developed. Our PSP Victoria Support Group was established in April 2002

under the auspices of the Movement Disorders Program at Kingston Centre, Cheltenham – a rehabilitation centre in Melbourne, Victoria. Our group meets bi-monthly with guest speakers, lively discussion and sharing. We are fortunate in that the group, in being associated with the Movement Disorders Program, has access to neurologists and allied health professionals to address meetings. We have produced a leaflet on PSP, have a Web Site, and are planning our first educational seminar in 2004. We are also currently applying for grant funding with the aim of writing a booklet on PSP suitable for the Australian situation. Currently, we are the only PSP support group in Australia. There is a PSP support organization in Queensland – ‘PSP Support Australia’ – [pspsupport@ozwide.net.au](mailto:pspsupport@ozwide.net.au) We hope our links with the Society for PSP will continue to develop.

Yours sincerely,

Barbara Winkler, Speech Pathologist, Occupational Therapist  
PSP Victoria Support Group

Caterina Marigliani

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### PSP EUROPE

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

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## “Dear Friends”

Dear Friends,

I just received the latest *PSP Advocate* and began reading it right away. I want to reply to a woman who is seeking advice regarding botox injections for her husband's eyes. This is what happened to my mom, who has PSP. We were also advised to try botox injections for her eyes. Immediately after the injections, my mom began complaining of “feeling sand” in her eyes. They hurt her tremendously. We took her to several eye doctors and were finally told that the botox had dried out her already dry eyes very badly. (Her eyes were already dry due to the lack of blinking.) It took about 5 months of hourly eyedrops to finally get her eyes to feel better. We also had her tear ducts clogged to retain as much moisture as possible. Although we will never have the injection given to her eyes again, we do have quarterly botox injections given to her neck (both in front and in back). This has relieved a lot of pain and stiffness for her and enables her to hold her head up, which helps her see more and eat a little more comfortably.

I always gain a lot of knowledge and insight in *The PSP Advocate* but I must tell you that the latest issue is wonderful. Although we had to learn a lot through trial and error, the education portion of the newsletter is very informative. It was amazing to me just how much I had to learn about handling a wheelchair and the person in it. We are also so fortunate to live in a time that there are so many home healthcare products available to us for the ease and comfort of the patient. I also found the “support” pages of the newsletter informative and comforting. I must admit that I am not a person who is very interested in support groups. (This may be because we have a very close family and we are all involved in my mother's care). Having said that, I will also say that I really connected with the people who respond to the Web Site. I will visit your Web Site often and I promise to seek and offer advice as much as I can. Thank you again for all your hard work and help.

Gloria Mattero (Alda Mocogni)

### BALTIMORE SUPPORT GROUP

Are you a PSP caregiver or family member living in Maryland? Whether you are new to the world of PSP or have been a caregiver for years, the Society is here to support you! If you are interested in joining our support group, please contact Jessica Quintilian, Director of Outreach & Education, at 410-486-3330 or 1-800-457-4777.

Meetings will be held monthly at the Society headquarters in Baltimore, 1838 Greene Tree Road, Suite 515, Baltimore, MD 21208. Don't travel this road alone!

# Support - Our PSP Stories

Please continue to share your "PSP Stories." Each journey will be unique—but each journey is filled with love, strength, determination and courage of persons diagnosed with PSP and their families. You may email your story to The PSP Advocate Editor at NancyB501@cs.com or mail to Nancy Brittingham, 6 Bramston Drive, Hampton, VA 23666. Please include photographs if possible.

## A Tribute to My Father

God received my father, James Austin Agerton "Jiggs," on December 31, 2003 at exactly 12:01pm. Now, I do not say that God took my Daddy from us. PSP did that. As a thief that knew each item he wanted from his victim, PSP stole bits and pieces of Daddy, day by day, year after year. By the month of December 2003, this thief had taken my father's ability to walk, speak, blink his eyes, and even swallow his food.

PSP stands for Progressive Supranuclear Palsy. Those that are familiar with the movie actor, Dudley Moore, may recall that this is the disease that claimed his life in March 2000. There are no special tests, no blood work that can be drawn, nor X-ray to be done that can diagnose this disease. And if there was something to point to this thief in the early stages, it wouldn't really matter. There is no cure. And we have no idea what causes it. Looking back, knowing the symptoms now, our family sees each sign. Shortly after my father retired, he was diagnosed with prostate cancer. He had surgery and continued to take medication to help prevent the spread of the cancer. Perhaps six months following his surgery, he insisted that "something was wrong in his head." Following CT scans and an MRI, he received a clean bill of health. Yet, he knew something wasn't quite right. He complained of being "swimmy headed" and I'd often see him watching television, holding down one eyelid, watching with just one eye. One symptom of PSP is blurred or double vision. Having an eye exam, even by a specialist, did no good. His vision was fine, as was his prescription for his eye glasses.



Anne Agerton with her father James "Jiggs" Agerton December 9, 2000



50th Wedding Anniversary October 1999 with all five children and first great grandchild

My father was never a very outgoing man. I think he lived through my mother's love of life. She was his life. But I noticed a change in his personality. His sleeping habits changed. He became more withdrawn. We worried about depression. His ability to balance is what PSP took next from daddy. He would stand and drift a bit to the left before heading off in the right direction. Still, no one gave it much thought. It's just his getting older, we supposed. The falls, that we became aware of, started in the spring of 2001, with a lumber fracture in March 2001. That landed us in the ER at UAB Hospital. The orthopedic surgeon referred him to a neurologist also located at UAB, Kirklin Clinic. She finally had an answer to the ongoing question and that answer was progressive supranuclear palsy. There is little known about this disease and she could offer little advice or hope. We left not knowing what to expect for daddy's future and there was no time table. We humans always seem to want to know how much time we have left. So, I came home and headed for the Internet. What I found made me hurt for my father, mother, brothers, and myself. There was one bright spot in the terrible darkness. It was a Web Site called The Society for Progressive Supranuclear Palsy. There I found as much information as is available to the public, but more importantly, I found a host of support people who were dealing with the very same thing. We all have shared tears and small triumphs via the Internet. We've offered each other words of comfort that no others would understand. There are some very strong, determined people in this world, fighting the battle of PSP, feeling very much alone.

Next, the thief took my father's facial expressions. He began to keep a wide-eyed, startled look on his face. He would laugh or cry at inappropriate times. His face finally froze. Because of his inability to blink, artificial tears were used. But, it could have been worse. Some people with PSP have their eyes affected so that they are unable to open them at all. Botox injections are then used to paralyze the muscles. Of course, the use of eye splints are then needed to hold the eye lids open. His ability to talk, form words, and volume control of his voice were also affected. Many times with those who cannot speak, we rely on facial expressions to determine how they feel. We may ask them to blink their eyes if they are hungry, cold, etc. In Daddy's case, that was not an option. Please keep in mind that although his entire body was slowly freezing, PSP taking away every voluntary and involuntary movement, his mind was perfectly intact. He knew exactly where his was, who he was, and what was happening to his body. The last three weeks of my father's life he was confined to his bed. His sitters had to spoon feed him and then remind him to swallow. His last week and a half he lost his ability to swallow at all. At the beginning of this downhill fall, he made

## Support - Our PSP Stories

decisions regarding the end of his life and we abided by those decisions. We made one last trip to his hospital December 20, 2003. I made him two promises that night. One, that we'd bring him home to die, as he'd wished, and that he would not hurt. My father came home on December 29, 2003. And God received him at exactly 12:01 December 31, 2003, on one of his son's birthdays. That son was at his father's side to say goodbye and I'd kept my promises to my daddy.

Anne Agerton Burns

Jan. 11, 2004

### A Star in the Evening Sky

Dear Nancy,

I recently lost my mother, Marcy Zingler (65) to PSP and it has been one of the most challenging years in my life. In May of 2002, my son had just turned three months old and we attended a neurology appointment with my mother to find out she was diagnosed with Parkinson's disease. I called my friend in Oregon, who is working on her Ph.D. in Neuroscience and explained the news to her. Her father has been diagnosed with Parkinson's disease for the last 25 years and she said we would get through this. I explained that there was a follow-up appointment in a week and I would share the details with her.

A week had passed and we were informed that mom was diagnosed with PSP and has probably had it now for 4-5 years. I called my friend in Oregon back and explained that it was not Parkinson's, yet rather, PSP. There was a long pause – and then "I'm so sorry to hear that." She began to cry. I was so scared for mom and me that I, too, began to cry.

Shortly thereafter, my mother took a nasty fall and I soon had to place her in a nursing home. Through The Society for

PSP, I educated myself on this disease. I also had to repeatedly educate others including the nursing home staff, friends, family and even many physicians that we would come in contact with.

When my son turned a year old in February 2003, mom's health was really failing fast. She felt so badly for not being able to be the grandmother she always dreamed of being and the mother to me during the years of my son's life-the years we would have shared together. I felt like my son was robbed of his grandmother and he would never get to know her. Mom decided that for his first birthday, she would purchase a star in his name through Star Registry. She told me to tell him that whenever he felt down or needed his grandmother, he could always look up in the evening sky and know that Grandma was there shining upon him. I turned to tears and thought to myself, what greater gift could someone give than that. Once again, my mother surprised me even more with her generosity and decided to give the "Gift of Knowledge" and donate her brain to the Society Brain Bank at the Mayo Clinic in Jacksonville, FL. My mother's thoughts were she wanted to do whatever she could to help prevent any family from going through what she and her family had gone through.

My mother passed away on July 28, 2003. My son is now 18 months old and even though it saddens me greatly that she is gone, I cannot say enough how important family is and the memories that will be passed on to the next generation. I love you so much mom – thank you for being an angel and inspiration to all of us.

Love, your daughter,  
Laurie

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Friends & Family of Emily Zigarelli In Memory of Emily Zigarelli  
Friends At Ford In Memory of Marguerite R. Boerger  
Friends of Sylvia, Maureen, Jeanine, Andy & Renee In Memory of Jeanne R. Dunham  
John P. & Audrey R. Furfaro In Memory of Irving Kraus  
Anthony Gallo In Honor of Anna Maria Gallo  
Carl & Barbara Gardella In Memory of Robert Gardella  
Barry Garfinkel In Memory of Irving Kraus  
Jim & Harold Garrison In Honor of Olza Flynt Roberts  
Mildred Gauss In Memory of Floris Gauss  
Robert & Darcy Gelber  
GEM Specialty Companies In Memory of Calvin Kuter  
General Carbide Corporation In Memory of Walter J. Greenleaf, Jr.  
David & Blair Gerdes In Memory of Dorothy Barnett  
Harold H. & Deborah A. Geurtze In Memory of Louis E. Godfroy  
Angie I. Gianopolus In Memory of Pauline Abraham  
Aleks & Dorothy Gilbert  
Judy Gilbert In Honor of Linda Gilbert Boes  
Orville Glaesmann In Memory of Doris Glaesmann  
Jeffrey & Norma Glazer In Memory of Marvin Glazer  
Stephen P. Glick In Memory of Karl F. Mautner  
Richard & Reatha Godwin  
Thomas & Barbara Goetz In Memory of Eileen Goetz  
Mel Goldberg In Honor of Myra Goldberg  
Sidney Goldberg In Memory of Arthur Goldberg  
Bonnie Goodhart In Memory of Vivian Cioe  
Louis & Phebe Goodman In Memory of Irving Kraus  
Norman & Isabell Goodman In Memory of Patsy Goodman  
Nancy Gormley In Memory of Irving Kraus  
Don & Nancy Graffis  
David & Kelie Grassie  
Todd & Lynne Gravois  
Nancy D. Gray In Memory of Pauline Abraham  
Walter & Mary Gray In Memory of Alfred J. Coffin  
Bonnie J. Greeger In Memory of Kenneth Greeger  
Mark Green In Memory of Joan Bay  
David & Maty Beth Greenslade In Memory of Robert Burns  
Marie A. Grega In Honor of George E. Grega  
Glenn & Brenda Gregory In Memory of James E. Gregory  
Robert D. Griffin In Honor of Cecilia R. Griffin  
Michael D. Griffith In Memory of Donald Deadmond  
Ruth Grimm  
John H. Growdon, MD  
Joseph & Mary Guarino  
Betty Jo Gulish In Memory of Fred Gulish  
Roderick G. & Michelle S. Gumz In Honor of Alda Mocogni  
Vinay & Sanjay Gupta  
Chuck & Sandra W. Haase In Memory of Jett Riley  
Michael & Mary Hales In Memory of Henry and Jane Ogiba  
Warren K. Hamburg In Memory of Lola Hamburg  
Arnie & Janet Hammerman In Memory of Joan Lees  
Jack & Rose Hammett In Honor of Jack M. Hammett  
Hammock Dunes Ladies Golf Association In Memory of Irving Kraus  
Leo & Terry Handerman In Memory of Jeanne R. Dunham  
Douglas & Ann Happe In Honor of Mary Rose Hausman  
Harbormaster Friends In Memory of Marvin James Williams  
Patricia Harden  
Margaret M. Hargraves In Memory of Eleanor McCarthy  
Joan Harkleroad In Memory of Douglas Harkleroad  
Nick & Ellen Harmansky In Honor of Mildred Karel  
Kelley Harrison Pistacchio  
Jeff & Janice Hausman  
Richard Hausman  
Greg & Beth Hazlitt  
HeartCare Midwest In Memory of Harold J. Butler  
James F. Heegan In Memory of Florence Heegan  
Valeria Heikes In Honor of Arthur C. Heikes  
Sarah Hellebush In Memory of John C. Hellebush  
Sue E. Hellebush In Honor of John C. Hellebush  
James & Miriam Herndon In Memory of Lilaree Crawford Freeman  
Mary Ann Herrington In Memory of Walter J. Greenleaf, Jr.  
Anne Higgins In Memory of George Higgins  
Virginia High In Memory of LeRoy B. High  
Highland Carbide Tool Co., Inc. In Memory of Walter J. Greenleaf, Jr.  
Hill, Ward & Henderson In Memory of Arnelio Castells  
Joseph & Constance Hines In Memory of Vera M. Nicol  
Winifred Joyce Hinz In Memory of Robert W. Hinz  
Joanne L Hodgson In Memory of LaVerne E Johnson  
Barbara & Alan Hogan In Honor of Donna Eacott  
Jack & Barbara Holley In Memory of Irving Kraus  
Lynn & Marian Holroyd In Honor of Marian Holroyd  
Emily Honigberg  
Lee, Lisa & Nadine Honigberg  
William S. & Jane A. Hopewell In Memory of Kenneth Fowler  
Lois Hopkins In Memory of Donald Deadmond  
Verda Horsfall In Memory of Richard Horsfall  
Betty Houtchens In Memory of Jean Bullard  
Alexandra M. & George H. Howard, III In Memory of Eleanor McCarthy  
Clarice Howe  
Sharon, Joseph & Ben Huber In Memory of Philip Jackson  
Jacqueline Huesing In Memory of William C. Huesing  
Edward C. & Dorothy E. Hughes  
William & Patricia Hulbert In Memory of Carol Rayworth  
Fred & Nancy Hull  
John & Jacqueline Hunter In Memory of David C. Donohue  
Pamela & William Hussey In Memory of Ruby P. LeBleu  
Ann M. Iacovino In Memory of Frances Holec  
Susan Imke, MS, CRNP  
Imo Pump  
Insert Manufacturing Division of Greenleaf Corporation In Memory of Walter J. Greenleaf, Jr.  
Barbara Iocca Mueller In Memory of Marie Iocca  
Noreen Irving  
Marcia Jackson  
Pearl Jackson In Memory of Clarence Jackson  
Wesley Jackson  
Joseph Jankovic, MD  
Bobby Lee Jenks  
Charles Jilcott In Memory of Ruth Jilcott  
John J. Demarest Supply Co. In Memory of Gloria Pangione

# Report Of Gifts

Daniel & Laureen Johnson In Memory of Edwin Johnson  
John Kennard & Mary B. Johnson In Memory of Hattie Bizzell  
Robert A. & Catherine B. Johnson In Memory of Kenneth Fowler  
Sandra Johnson In Memory of Edwin Johnson Sue Johnson  
Evelyn Jordan In Memory of Richard A. Jordan  
Prem S. Juneja In Honor of Vandana Juneja  
William E. Kahle In Memory of Bettye Kahle  
Irene Karle In Memory of Harley Marksiyan  
Gerald & Carol Kaufman In Honor of Sandra Stern  
Donna Keller In Memory of Bruce Sanderson, MD  
Elaine Kend In Memory of Irving Kraus  
Thomas Kennedy In Memory of Irving Kraus  
Tim & Beth Kerr In Memory of Margie Thompson Wade  
Joan Kerssenbrock In Memory of John P. Clements, MD  
Wayne & Darlene Kessling In Memory of Grayce Kraus  
Keystone Manufacturing, Inc. In Memory of DeWayne L. Henderson  
Lori J. Khan In Memory of Dalf Hammerich  
Carol E. & Joseph C. Kientzy  
Miriam S. Kindred In Memory of Lilaree Crawford Freeman  
George M. King In Memory of James & Louise Stewart  
Richard & Jo Ann King  
Helen and John Kingery In Memory of Judy Littleton  
Dale & Shari Kirchner In Memory of Elizabeth McNeely  
Kenneth H. Kirshenbaum In Memory of Irving Kraus  
Lewis V. & Catherine J. Kitchens In Memory of Henry Austin Jenkins  
Joel Klass In Memory of Selma Klass  
Gary & Donna Klein In Honor of Edith Sosin  
William & Susan Klein In Memory of Fern Beebe Mayhue  
Florence K. Kline In Memory of George F. Kline  
Nancy Kliza In Memory of Donald W. DeMasellis  
Catherine & Steven Koffs  
Dan & Mildred Koster  
Kathleen Kovach In Memory of Boo Gaik Sim  
Kowalski, Tim & Cathy In Memory of Calvin Stambaugh  
Edward M. & Christine M. Krajewski In Memory of Walter J. Greenleaf, Jr.  
Dorothy A. Kretzer TTEE In Memory of Alfred J. Coffin  
Andrew Kriegman  
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Kathy & Dillian Lafferty In Honor of Kathryn B. Keener  
Tim & Janet LaFramboise In Memory of Mary Elizabeth Owen  
Richard Lambert In Honor of Louise Lambert  
David Lamm  
William & Gladys Lance In Honor of William Lance  
Alan & Julie Landreville In Memory of Philip Strobel  
Dennis LaPoint In Honor of Clara Mae LaPoint  
Nora Larson In Honor of Christopher Ludwig Mengis  
Leonard & Deloris LaRue  
Ramsey N. Lay  
Ruby Leak In Memory of DeWayne L. Henderson  
Sachiko Lenk In Memory of John Lenk  
Tim & Elaine Lesnik In Memory of Mary Owens  
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Kenneth & Laura Levine In Memory of William C. Huffman  
Milton Levine In Memory of Betty B. Levine  
Will & Joanne Light  
Bruce J. Lipstein In Memory of Leonard Lipstein  
Littlestar Plastics In Memory of Patsy Goodman  
Adolph V. & Anne T. Lombardi In Memory of Calvin Stambaugh  
Adam & Cynthia Lourie In Memory of Isadore Lourie  
Darren Loveless  
Betty C. Lowder In Memory of David F. Lowder  
L-T-L Company In Memory of Patsy Goodman  
Beverly A. Ludeman In Memory of Loren Ludeman  
Thomas & Mary Tuomi Lundsten In Memory of William Tuomi  
Richard & Denise Lunoe In Memory of Catherine E. Souder  
Josephine Maguire  
Maine Innkeepers Association In Memory of Pauline Abraham  
Martin J. & Elizabeth A. Maldonado In Memory of Irving Kraus  
Matthew J. Mallow In Memory of Irving Kraus  
John E. Jr. & Lori Mann In Memory of John E. Jack Mann  
Joe & Teresa Manuel In Memory of Kathryn Turner  
Alexander & Marie Marchese In Memory of Carol Rayworth  
Alesia Marinelli In Memory of Irving Kraus  
James & Megan Marinis In Memory of Dr. William J. Marinis  
Kevin S Marshall In Memory of Kathryn B. Marshall  
Mr. & Mrs. Hugh C. Keenan In Memory of Christopher Ludwig Mengis  
John & Patricia Mulkerin In Memory of Jeanne R Dunham  
Betty Murtagh  
Stephen Muskiewicz  
Beverly J. Myers, MD In Memory of Willa Budge  
C. Stuart & Joan A. Nahles In Memory of Eleanor McCarthy  
Carolyn Natale In Memory of Florence J. Becker  
Parvoneh Navas, PhD  
Marcella Nelson In Memory of James A. Nelson  
Timothy A. Nelsen In Memory of Irving Kraus  
Helen E. Newell In Memory of Warren Newell  
Shelly Newman In Memory of Rose Newman  
Jane Ellen Nickey  
Russell & Linda Nippert  
Nissan North America, Inc. In Memory of Bruce Sanderson, MD  
Nissho Iwai American Corporation In Memory of William Duncan  
Gregg & Linda Noel In Memory of Irving Kraus  
North American Steel Corp. In Memory of Carol Rayworth  
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Mary Ellen O'Hara In Memory of William R. Tamke, Sr.  
David & Ellen Olson In Memory of Virginia Koallick  
Jane Oppenlander  
Oracle Corporation Matching Gifts Program  
In Memory of Alice Marie Joyce  
Virginia & Juanita Orr In Memory of Marian Orr Jenkins  
Otho Neuro In Memory of Calvin Stambaugh  
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Captain David L. Osburn In Memory of Marvalyn F. Strohsahl  
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Kathy Ozlowski  
David A. & Janet Packard In Memory of Oliver H Grotelueschen  
Vincent & Geraldine Palmieri In Memory of Emily Zigarelli  
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Lorraine B. Pappafava In Memory of Walter J. Greenleaf, Jr.  
Louis E. & Dolly F. Pardi In Memory of Carol Betterbed  
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Donald & Joan Pennington In Memory of Margie Thompson Wade  
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Robert & Judith Peters In Memory of Walter J. Greenleaf, Jr.  
Annette Peyser In Memory of Ralph Peyser  
Kurt & Pauline Philipps-Zabel  
Kenneth & Bettina Plevan In Memory of Irving Kraus  
Robert & Gilberte Poisson In Memory of Irving Kraus  
David R. Poulin In Memory of Carol Rayworth  
Jack Powell In Honor of Mary Powell  
Mary-Ellen Prescott In Memory of Carol Rayworth  
Donald & Coralee Presley In Honor of Donald E. Presley  
Kathleen Presley In Honor of Donald E. Presley  
Kevin C. Preuss & Lisa A. Duret In Memory of Marguerite R. Boerger  
PSP Network of Houston  
Vall Pulliam  
Mary L. Quarles In Memory of James C. Quarles, Jr.  
Gloria Rand In Memory of Stephen S. Levitt  
David Rayworth In Memory of Carol Rayworth  
Douglas & Kathleen Rayworth In Memory of Carol Rayworth  
Vernon J. Reed, Jr.  
Dr. Alan Reich In Memory of Dalf Hammerich  
E. L. Reid In Memory of Charles H. Hamilton, Jr.  
Joan Reifler In Memory of Norman Reifler  
Ken & Lisa Reisen In Memory of Gerald Zimmerman  
Susan Reisser In Honor of James Evertz  
Kenneth E. & Kathy J. Reiter In Memory of Ivey Lamar Garren  
Jeanne E. Reith In Memory of Jeanne R. Dunham  
Don & Marie Rennie In Memory of Dorothy Ann Kimball  
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In Honor of Juanita Micki Wesche  
Esther Robinson  
Rodrigue Family In Memory of Claudia P. Rodrigue  
Michael & Deborah Rodriguez In Memory of Dora Salazar  
Michael P Rogan In Memory of Irving Kraus  
Joy Rogers In Memory of Fred Rogers  
Thomas J. Romanello, Sr. In Memory of Vincent Romanello  
Vivian Rosenberg In Memory of Anuita Blanc  
Charles W. Roska In Honor of Constance Roska  
Russound In Memory of Pauline Abraham  
Mary F. & Joanne M. Sala In Honor of Julia La Magna  
George & Jeanne Samaras In Memory of Robert Burns  
Elizabeth Santucci In Memory of Julia V. Waldron  
Horace Sarter In Memory of Sondra Sarter  
Michael & Denise Saul In Memory of Irving Kraus  
Charles R Schaller In Memory of Jean S. Schaller  
John & Holly Schenck In Honor of Jane Addison  
Alice Scherer In Memory of David Scherer  
Edward & Marjorie Schieber In Memory of Norman O. Thomas  
Stephen W Schmaltz In Memory of Marian E Schmaltz  
Michael Schneider & Mary Kelly In Honor of Alda Mocogni  
John E. Schoenecke In Memory of June Clarice Schoenecke  
Edward & Joni Schroeder In Memory of Sally Schroeder  
Seth & Carolyn Schwartz In Memory of Irving Kraus  
David & Sandra Sciarrone In Honor of Alda Mocogni  
Carol Sebastian In Memory of Jeanne R. Dunham  
Myron Sedorowitz In Honor of Anita Nastuk  
Ernest C. Segundo, Sr.  
Sewickley Car Store In Memory of Vernon A. Kean, Sr.  
Carol Shap In Memory of Sidney Rosenberg  
Honey Shara  
Robert C. Sheehan In Memory of Irving Kraus  
Stuart & Marjorie Shepard In Memory of Vivian Elliott  
Robert J. & Margaret C. Sieber In Memory of Myers Y. Cooper, II  
Ronald & Lynn (Penny) Siegel In Honor of Lynn Seigel  
Lloyd Silverman In Honor of Majorie Silverman  
Scott J. Simmons In Honor of Alda Mocogni  
Dana & Jim Simon & L.H. Williamson In Memory of Margie Thompson Wade  
Virginia M. Simpson

# Report Of Gifts

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Donna & Chuck Sisney In Memory of Robert Evans  
Phyllis Slade In Memory of Harold H. Georgens  
Esther Sloan In Honor of William H. Foster, Jr.  
Laurie Slobody In Memory of Evelyn Towne Slobody  
Robert Slominski In Honor of Mary Slominski  
James L. & Claudia Smith In Memory of  
Carol Rayworth  
Ruth R. Smith In Memory of Kenneth R. Smith  
Steven & Sue Smith In Memory of Josephine Smith  
Mary Smithers In Memory of Mary Mickey Smithers  
Nicholas & Roxanne K. Smyrniotis In Memory of  
William B. Sheridan  
Philip N. & M. Eunice Smyrniotis In Memory of  
William B. Sheridan  
Societa Modenese DI M.S. In Honor of  
Aida Mocogni  
Pauline Sodermark In Honor of Linwood Hildreth  
Emanuel Sosinsky In Memory of Terrie Sosinsky  
Gerald Souder In Memory of Catherine E. Souder  
James B. Sparks In Memory of Marie C. Sparks  
Sandra Spicer In Memory of Rita Perez  
Clyde A. Spooner In Honor of Leslie E. Spooner  
Stephen & Mary Spross In Honor of Catherine Kelly  
Ruth Stanger In Memory of Carol Rayworth  
Ronald Steiger In Memory of Julia Poling  
Walter & Sandy Stern In Honor of Sandra Stern  
Dorothy L. Stevens In Memory of  
William Tris Stevens, Jr.  
Mary Ellen Stix In Memory of Robert Stix  
Karen Stockman-Givens  
Edna Story In Memory of Richard J. Story II  
Alan G. Straus & Katherine W. Schoonover  
In Memory of Irving Kraus  
Betty J. & Wayne Strickland In Memory of  
Lilaree Crawford Freeman  
Mark Strickland In Memory of Carl C. Strickland  
Ann Stupak  
Charles Bud & Eivor W. Swain  
Mark & Kimberly Swain  
Della Swallow  
Sallie Swank In Memory of Darlene Boyer  
Shirley Sweeney In Memory of Myles Bert Sweeney

Alice I. Tahaney In Honor of James Tahaney  
Wendell Taylor  
Christina M. Tchen In Memory of Irving Kraus  
The Herff Jones Company In Memory of  
Jack K. Molz  
The Norfolk General Dynamics Family In Memory of  
Marvalyn F. Strohsahl  
The Prettys In Memory of Jeanne R. Dunham  
Kathy Thomas In Memory of Dorothy Hart  
L. Thomas & Carolyn Conlin  
Thad O. & Elizabeth T. Thomas In Memory of  
Norman O. Thomas  
Marion Thompson In Memory of  
Malcolm Thompson  
Merilyn Timmons  
Margo Todd In Memory of Dr. William R. Todd  
Trace Tomich In Honor of Ed Tomich  
Peggy Toomey  
Henry Torre In Honor of Mary Torre  
Russ Townsend In Memory of Mary F. Townsend  
Robin Tragger  
Ann Tropeano In Memory of Rita Tropeano  
Mary Trotta In Memory of Jerome Trotta  
Lorna Trowbridge  
B. Lawrence Tull In Memory of Delores Tull  
Nancy & Nancy Lee Tyler In Memory of  
George Detterbeck  
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Fred Becker, and Florence J. Becker  
Lisa Vallance In Memory of  
Marjorie Frances Sawtelle  
Anthony H. & Emmi Vernon  
Richard & Barbara Vinciguerra In Memory of  
Gloria Mitchell  
Paul & Mary Virtue In Honor of Mary A. Virtue  
Diane Vollmar  
Joseph & Barbara Volpicelli In Memory of  
Evelyn J. Faretra  
Beverly Wagner In Memory of Ed Tomich  
Gaylord W. & Norma L. Wagner In Memory of  
Howard Nutter

Herman Waid In Memory of Lois Jane Waid  
Doris Walker & Margaret Clark In Memory of  
Marjorie Frances Sawtelle  
Jack F. & Caroline S. Waltz In Honor of Jack Waltz  
Wei Wang In Memory of Yang Ling Suet Tse  
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Norris & Bettie Watson  
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Anne Collins  
Carol Webster In Memory of Charles Colpitt  
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Doryce Hills-Wells In Memory of Patricia Costello  
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Susan Williford  
W. Thomas Wilson II In Memory of C. Palmer Ruth  
Anne S Wilson In Memory of Marie C. Sparks  
Lana Withee In Memory of June Hamilton Boyer  
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World Headquarters In Memory of John W. Pavey  
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Donald E. & Eunice J. Wynn  
Mr. Earle Yaffa In Memory of Irving Kraus  
Claudine Z. Yannoni In Memory of  
Nicholas Yannoni, MD  
Thomas E. & Martha K. Yerina In Memory of  
Doris Glaesmann  
Frances H. Young In Memory of  
Joan Hook Cochran  
David Zerfoss In Memory of Allen Zerfoss  
Marie K. Zimmerman In Memory of  
John G. Zimmerman

## How To Make A Bequest To The Society for Progressive Supranuclear Palsy

To make a bequest of cash or property to The Society for Progressive Supranuclear Palsy, your will or supplemental codicil should state:

**"I give and bequeath to The Society for Supranuclear Palsy, a non-profit corporation, organized under the laws of the State of Maryland and having its main office at Woodholme Medical Building, Suite 515, 1838 Greene Tree Road, Baltimore MD 21208, the sum of \$ \_\_\_\_\_ or \_\_\_\_\_ % of the residue, rest and remainder of my estate to be used for the general purposes and mission of the organization."**

A bequest to the Society is fully deductible for estate tax purposes. To learn more about opportunities for giving, consult your attorney, accountant, estate planner or call the Society for PSP office, 1-800-457-4777.

## How To Make A Donation Of Securities To The Society for Progressive Supranuclear Palsy

Contact: • The Society for PSP  
Woodholme Medical Building, Suite 515  
1838 Greene Tree Rd., Baltimore, MD 21208  
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FAX: 1 (410) 486-4283 • email: SPSP@psp.org

Or • Ann Wilson, Regional Investment Manager,  
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Send me copies of:

- #1 PSP Some Answers (Overall guide To PSP)
- #2 Aids for Daily Living Catalogs/Thickening Agents/Personality Changes/Helping the Helpers - four page pamphlet.
- #3 2002 National Symposium Video Tapes - 3 Pack \$75, plus \$7 shipping in US and \$10 outside the US.
- #4 *The PSP Advocate* Newsletter
- #5 Thickening Agents
- #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 the US.
- #11 PSP Fact Sheet (1 page summary can be duplicated and distributed)
- #12 Aids for Daily Living Catalogs Listing
- #13 Publications Resulting from Society Funded PSP Research
- #14 Brain Bank Information Packet
- #15 Physician Referral Cards
- #16 Giving Envelopes
- #17 The Society for PSP/National Institutes of Health PSP Brainstorming Conference/Dr. John Steele meeting with the Maryland Support Group \$25, plus \$3 shipping in US and \$5 outside the US.
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- #22 Challenges in the Management of PSP
- #23 Support Group List

Mail to: \_\_\_\_\_

Fax to : \_\_\_\_\_ Email to: \_\_\_\_\_

FOR PHYSICIANS ONLY:

- CD "The Diagnosis of PSP" by Lawrence Golbe, MD (Recommended for clinicians and faculty)
- Medical Professional Packet (Grant Award Information/PSP Rating Scale/copies of all other info.)
- I no longer wish to receive the *The PSP Advocate* and by sending this will save expenses for the Society.
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PSP Advocate, First Quarter 2004

You Can Help By Becoming A Volunteer

## VOLUNTEER PROFILE

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

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

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

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

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

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

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

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

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

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

Social Affiliations/Clubs & Organizations: \_\_\_\_\_

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

Areas of Experience or Expertise:

- |   |   |   |
|---|---|---|
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| <input type="checkbox"/> Legal              | <input type="checkbox"/> Special Events   | <input type="checkbox"/> Computer Technology        |
| <input type="checkbox"/> Accounting         | <input type="checkbox"/> Foundations      | <input type="checkbox"/> Web site/Internet          |
| <input type="checkbox"/> Investing          | <input type="checkbox"/> Corporations     | <input type="checkbox"/> Newsletter                 |
| <input type="checkbox"/> Government Affairs | <input type="checkbox"/> Writing          | <input type="checkbox"/> Lead a Support Group       |
| <input type="checkbox"/> Personnel          | <input type="checkbox"/> Media            | <input type="checkbox"/> Social Services            |
| <input type="checkbox"/> Research/Marketing | <input type="checkbox"/> Graphic Arts     | <input type="checkbox"/> Allied Health Professional |
| <input type="checkbox"/> Non-Profit Mgmt.   | <input type="checkbox"/> Meeting Planning | <input type="checkbox"/> Counseling/Social Work     |
| <input type="checkbox"/> Public Speaking    |   | <input type="checkbox"/> Other (specify) _____      |

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