

"Nothing Better To Do"

By: Larry Engstrom

We ran into one of my mother's friends at the grocery store. After chatting with her for a few minutes, the friend turned to me and told me how nice it was that I was here to help.

"Well, I've got nothing better to do," I replied. Hey. Don't waste words. Tell it like it is. There wasn't anything better I could have been doing. Or for that matter, would have wanted to do. So here is the story.

Why I Came Back

In the mid-1980's my father began to exhibit symptoms of Alzheimer's disease. By late 1990, his condition had deteriorated to the point where it became painfully clear to my mother that she could not handle the situation alone. She faced the prospect of putting him in a nursing home. That was breaking her heart.

So in early 1991, I loaded my belongings into a rental truck and moved back to Texas. Leaving Washington, D.C. wasn't difficult. I had been divorced several years earlier, had a career that was going nowhere and had no strong ties to the area.

There were more important reasons, of course. I thought I could help. Also, I remembered when, 30 years earlier, my grandfather had come to live with us after my grandmother died. As his health deteriorated, he became bedridden. The strain was almost too much for my mother. She was working full time to put me through college, maintaining the household and spending half the night caring for my grandfather. Eventually, she did have to put him in a nursing home. She didn't need to go through that again.

Alzheimer's Disease

One has no way of knowing how Alzheimer's torments its victims, but the anguish and despair suffered by those closest should not have to be borne alone.

My father was a kind and gentle person. The disease never robbed him of that. But he couldn't be left alone. He had lots of nervous energy. He would, alternatively, stick like glue to one of us as if for comfort or security; or at other times seem compelled to wander off, convinced that the place where he really lived or perhaps his boyhood home was somewhere just down the road.

I didn't do much. Mostly, I just filled in and allowed my mother a little free time for herself.

He never could quite grasp the fact that I was his son, although he seemed to accept the idea that I had a good reason for hanging around the house. Often, he would pretend to know me, but it was more like I was a vaguely familiar face that he couldn't quite place and he didn't want to embarrass me by asking who I was. However, he did learn (or re-learn) my name and that I would respond when he called.

Sadly, a few short months after my return, my father had a stroke and died shortly thereafter. His death left a great void in our lives. My father was a good parent and a wonderful person. There is much more to tell, but this is not really his story.

Adjusting

With time, our life settled into a routine. I eventually found gainful employment in South Texas. My mother resumed her activities. Her interests and commitments were extensive. For the record, here are some of them:

One day a week she volunteered at the local hospital.

Much earlier she had developed an interest in genealogy and did considerable research tracing our ancestors. That led to active involvement in the local genealogical society.

Another activity was volunteering as a reading mentor twice a week at an elementary school.

Church life always had been of great importance to both parents. That meant Sunday school and regular church service

every week. In addition, she participated in bible study groups and other church related activities.

During this period I think my mother, no longer under the constraints of caring for my father, relished the opportunity to resume doing things that interested her. Also, with me around, the house was less of a concern. So, she took a couple of international tours and made a number of trips to visit friends and relatives.

Where Did That Little Old Lady Come From?

As I followed her car home from church one Sunday, I saw my mother make a wide sweeping turn across the front yard and take out part of the sago palm growing next to the driveway.

My sister and I grew up secure in the knowledge that our mother could and did do just about anything. So, I was slow to perceive that her strong independent

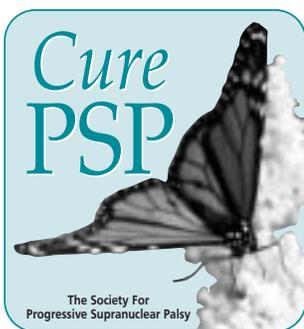


Larry Engstrom with his father, Howard and mother, Teresa.

INSIDE:

**PSP RESEARCH
UPDATE**

**HOSPICE
CARE**



The Society for Progressive Supranuclear Palsy

FOUNDERS

Reba and David Saks

HONORARY CHAIRMAN*

John C. Steele, MD, F.R.C.P. (C)
Fellow, American College of Physicians
Core Director, Micronesian Health Studies

MEDICAL ADVISORY BOARD

Lawrence I. Golbe, MD, Chair
Professor of Neurology
Robert Wood Johnson Medical School, New Brunswick, NJ
Catherine Bergeron, MD, Associate Professor
Department of Laboratory Medicine and Pathobiology
University of Toronto, Canada
James Clements, PhD, Roswell Cancer Institute, Buffalo, New York
Dennis W. Dickson, MD
Neuropathology Consultant, Mayo Clinic, Jacksonville, FL
John H. Growdon, MD
Professor of Neurology, Harvard Medical School, Boston, MA
Joseph Jankovic, MD
Professor of Neurology, Baylor College of Medicine, Houston, TX
Virginia M.Y. Lee, PhD
The John H. Ware 3rd Professor in Alzheimer's Research
University of Pennsylvania School of Medicine, Philadelphia, PA
Andrew J. Lees, MD, Consultant Neurologist,
National Hospital for Neurology & Neurosurgery, London
Irene Litvan, MD
Raymond Lee Leiby Professor of Parkinson Disease Research
University of Louisville School of Medicine, Louisville, KY
David E. Riley, MD, Associate Professor, School of Medicine
Case Western Reserve University, Cleveland, OH
Gerard D. Schellenberg, PhD
Research Professor of Medicine and Neurology
University of Washington School of Medicine, Seattle, WA
Maria Grazia Spillantini, PhD
William Scholl University Lecturer in Neurology
MRC Brain Repair Centre and Department of Neurology
University of Cambridge, Cambridge, U.K.
Eduardo Tolosa, MD, Professor of Neurology
University of Barcelona Hosp Clinico, Barcelona, Spain
David S. Zee, MD
Professor of Neurology, Ophthalmology & Otolaryngology
Johns Hopkins University School of Medicine, Baltimore, MD

BOARD OF DIRECTORS

Stephen Hamer, President
Kenneth A. McKusick, MD, Vice President
James E. Koehnlein, Treasurer
Janice Clements, Secretary
Joanne Armstrong
Bruce Barnett, PhD
James Barron, PhD
Barbara Boyle
Liz Brisson
Lawrence I. Golbe, MD
Robert Hamill, MD
Susan Imke MS.N, CRNP
Sharon Pratt
Joan Reifler
Russell Swerdlow, MD
Stephen G. Reich, MD, Chairman Emeritus

**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.

Phone (410) 486-3330
Toll Free (800) 457-4777, FAX (410) 486-4283
Canada 1-866-457-4777

The Society for PSP
Woodholme Medical Building
Suite 515
1838 Greene Tree Road
Baltimore, MD 21208
email-spsp@psp.org
Web site-www.psp.org

The PSP Advocate is a newsletter published by the Society that informs readers of findings in the area of PSP. There is no copyright. Newsletters and other publications can disseminate any information in *The PSP Advocate*. Please cite attribution to the Society and the author.

EDITOR

Nancy Ogiba Brittingham
NancyB501@cs.com
(757) 838-0777 • FAX (757) 838-6086
(In memory of Henry and Jane Ogiba)
Assistant to the Editor: Debra Thompson
(In memory of Lois Croft Davis)
Graphic Designer: John Hargett
(Sammons Commercial Printer)

TABLE OF CONTENTS

President's Message	3
Research	4-5
Fundraising	5-6
Ask the Doctor	6
Communication Practice	7
Living Day to Day with PSP	8
Doctors are People, Too	9
Hospice	10-11
Baltimore Support Group Meeting	12
PSP Fact Sheet Pull Out	13-14
Support Group Listing	15
PSP Forum	16
Nothing Better to Do con't.	17-20
Report of Gifts	21-22

President's Corner

Dear Society Friends,

In the late 1980's, my father fell on a sidewalk near his home. It was a flat stretch he had walked many times before. At the time, nobody thought it was unusual. He just wasn't paying attention.

That was the beginning of a long journey you are all only too familiar with. By the time a proper diagnosis had been made, his condition was quite advanced. My father died on June 24, 2001. Ironically, I was attending a Society for PSP board meeting at the time.

When my mother called to tell me the diagnosis, she didn't have the name quite right. We did piece it together using the Internet. I found the Society online and called immediately. What a relief to finally have someone to talk to about this mysterious disease which was essentially unknown.

My father always believed in volunteer work. He was always after me to get involved in charitable work. He had spent most of his adult life involved in one charity or another. When I started on the board of the Society for PSP, I told him he didn't have to go to such great lengths to get me involved as a volunteer. He laughed.

For a number of years, my father helped out at a stroke clinic. As chance would have it, one of his diagnoses was that he had a stroke. The director told my father that he would now be a patient instead of a caregiver. Later, when the diagnosis changed to PSP, the director said my father would always be welcome. I guess it is true that whatever goes around does come around.

While I began serving on the Board of Directors. I learned that in the early 1990's, when the Society for PSP came into existence, most people would send in checks and get back a receipt. They could either phone in or write and ask for information. The information would then be gathered up and sent out. It was very labour intensive. Now the Society gets 17,000 hits per month on the Web site. Most of the people who call in have found out about us through the Web site. It would be fair to say that the Web has helped many organizations transform themselves. Most of the documents we have can be accessed on our Web page. There is also a schedule of events.

However, the preferred method of contacting the Society is still the phone. Like me, most people want human contact.

Why are people calling? They want to know what is next. They ask about support groups, healthcare professionals, and the latest in research. People could do much of this over the Internet but in this world where high tech rules, people want high touch and that is what the Society strives to give them.

Every year, when we go through the budget process, one topic always comes up. How can we cut costs? Invariably, someone suggests that we reduce the number of people in the office. However, that would reduce personal contact. It would take longer to answer the phone. Callers would be put into voice mail jail. We remind each other about the mission and remember why we volunteered for this assignment. That ends the discussion.

Technology revolutions occur all the time. Whenever we shop, we encounter bar codes. Who hasn't heard of the genetic code or the human genome project? Now, the Society for PSP is funding proteomic research or the study of proteins and how they could impact our understanding of PSP. On the other hand, the answer may come from studying a now extinct fruit bat from Guam or a type of tea from a fruit from the French West Indies.

The Internet and email allow researchers to communicate better than ever before. However, what really counts is the

dedication and enthusiasm of volunteers, employees, and researchers who know that they are making a difference. Finding new and faster ways to connect is all well and good, but what really counts is giving PSP families the information they need in a friendly, professional, and caring way. We are the only ones on this continent doing that and that remains our promise. I am honored to be the newly elected President of the Society for PSP's Board of Directors. Together, we can make a difference.

Warmest regards,

Stephen Hamer
Stephen Hamer



Stephen Hamer thanking George Jankiewicz and Kelley Ann Pistachio for their years of service on the Board.



Past President, Liz Brisson, handing over the gavel to the new Board President, Stephen Hamer.



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.

PSP Research Update

Lawrence Golbe, MD
Chair, Society Medical Advisory Board

The Eighth International Congress on Parkinson's Disease and Movement Disorders was held in Rome, June 14-17, 2004.

Of the 1,338 original research presentations, 21 directly concerned PSP. Here are brief summaries of each.

CLINICAL DEFICITS

N. Cordato et al of Sydney and Melbourne, Australia found that "frontal" behaviors, which are extremely common and often disabling in PSP, correlate closely with loss of frontal cortex tissue as assessed by a new MRI technique. This shows that in PSP, frontal behavioral is probably not caused by loss of deeper brain centers that connect to the frontal cortex. This has implications for future use of stem cell implants in PSP.

Y. Osaki et al from Kochi, Japan; Bristol and London, UK; Rome, Italy and Innsbruck, Austria determined that by most measures, informal assessments by experienced neurologists were better than formal, published diagnostic criteria at predicting PSP at autopsy. The explanation for this is probably that experienced neurologists observe more features and subtler abnormalities than any convenient set of criteria can specify.

P. Soliveri et al from Milan, Italy studied apraxia, the loss of a previously learned, complex motor action. They found that in PSP, patients had not lost the mental conception of the movement, just the ability to perform it. The difficulty arose from difficulty sequencing, not performing, the movement components. The apraxia correlated with the decline in thinking ability.

TREATMENT

C. H. Schrader et al of Hannover, Ulm and Dresden, Germany attempted to treat retrocollis (backward extension at the neck) of PSP with Botox injections into the muscles of the back of the neck. Of 5 patients treated, 4 responded very well, particularly with regard to pain caused by the neck position. Three developed the side effect of weakness of the injected muscles causing uncontrolled forward lolling of the head.

GENETICS

D. Healy et al from London confirmed the association of the tau H1 haplotype with Parkinson's disease. This genetic variant was first described in PSP, with which it is slightly stronger than in PD. This suggests that there is an interaction of alpha-synuclein, which is the protein that aggregates in PD, with tau, the protein that aggregates in PSP.

R. de Silva et al from London and Bethesda, MD found that the segment of chromosome 17 that includes the tau gene and travels as a unit includes many genes on either side of tau itself. Therefore, the explanation for the association of the tau H1 haplotype with PSP may not be in tau itself. The authors discuss other genes near tau that are candidates for this role.

D. Nicholl et al from the UK and the Netherlands described a family from Shropshire, England with a PSP-like illness in three members. Interestingly, the age at onset declined with successive generations, a phenomenon that occurs in Huntington's disease. The gene has not been identified and

no autopsies have been performed to confirm an affinity to PSP.

E. Gasparoli et al from Padua and Milan, Italy found another family with a PSP-like illness with onset in the 30's to 50's, this time with a highly deleterious mutation in the tau gene that results in the deletion of one amino acid at a critical position. One of the affected gene carriers had what appeared to be typical PD, not PSP. The authors plan to follow several young, healthy carriers of the mutation.

BIOCHEMISTRY

J. Fukae et al of Tokyo and Fukuoka, Japan found increased levels of an enzyme, 8-oxoguanine DNA glycosylase (OGG1) in the areas of brain in PD and PSP that degenerate first and worst. This is evidence that oxidative stress that damages mitochondrial DNA contributes to the brain cell death in both disorders.

EPIDEMIOLOGY

L. Donker Kaat et al from Rotterdam and Amsterdam, the Netherlands presented the design of an ambitious effort to study environmental and genetic factors in PSP throughout their country. eighty-seven patients have entered the study so far. All have been asked to donate their brains after death.

D. Williams et al from London, UK found that in PSP, certain signs and symptoms tend to cluster together and that this can be used to divide PSP into what they call "PSP-parkinsonism," which is in many ways like PD, and "Richardson's syndrome," which is more like "classical" PSP. The former had a longer survival, fewer falls, less dementia, more tremor, more asymmetry and better response to levodopa/carbidopa. There was no difference at autopsy.

IMAGING

Y. Rolland et al from Rennes and Paris, France used conventional MRI to measure the surface area of the midbrain, an area of brain profoundly affected in PSP. The average figures differed between PSP and the multiple system atrophy/Parkinson's disease group. This new technique could assist in diagnosis.

C.R. Blain of London, UK used diffusion tensor imaging, a new MRI technique, to reveal abnormalities in the middle cerebellar peduncle and other, smaller brainstem areas that have been detected at autopsy but not on conventional MRI. This offers promise as a diagnostic tool for PSP.

Y. Morita et al from Kochi, Japan used transcranial magnetic stimulation to distinguish PSP from Parkinson's disease (PD). Differing were the magnetic evoked potential amplitudes and resting motor thresholds.

A. Kreisler et al from Lille, France did a statistical analysis of how HMPAO SPECT, a radioisotope technique available at most hospitals, can differentiate PSP from PD and corticobasal degeneration. They caution, however, that further studies will be needed to distinguish early, mild cases.

O. Morsi et al from Barcelona, Spain used a different SPECT technique to image dopamine-producing brain cells in patients with PSP with little or no "parkinsonism" (slowness and stiffness). Those cells proved to function poorly, as in most cases of PSP. The authors suggest that this can be used as a diagnostic test for atypical cases of PSP.

D. Jennings et al from New Haven, CT used another SPECT technique, beta-CIT, to evaluate patients with early, mild, diagnostically equivocal parkinsonian conditions. Using 1-year

Research

followup showed that the scan was more accurate at the outset than specialists' diagnosis in distinguishing parkinsonism (including PSP) from non-parkinsonian conditions.

UNUSUAL PSP MIMICS

J.-H. Tan et al of Singapore described a 75-year old man who developed a PSP-like illness that progressed to a bed-bound state over only 5 months. He was subsequently found to have a non-Hodgkins lymphoma. Autopsy was not reported. Other "paraneoplastic" (i.e., caused by cancer in a distant organ) neurological conditions are well-known, but this is the first report of a PSP-like illness apparently caused by cancer.

J. Lewerenz, et al of Hamburg, Germany report a 38-year old man with a malignant tumor of the dorsal (top or back) part of the midbrain that spared the dopaminergic part of the midbrain, which is in the ventral (belly) area. It also spared the basal ganglia of the cerebrum. Nevertheless, it reproduced most of the features of PSP. This suggests that damage to the dopaminergic circuits of PSP does not contribute importantly to that condition's outward features.

UNUSUAL PRESENTATIONS OF PSP

B. E. Murray and T. Lynch of Dublin, Ireland reported on two patients whose illness started with prominent cerebellar signs and progressed to otherwise typical PSP. This is extremely rare, even though PSP nearly always damages the cerebellum. This shows that any aspect of PSP brain cell loss can cause the first and worst clinical feature.

T. Scaravilli et al from Padua, Italy and London, UK reported a man who at age 39 developed PSP along with much more severe spinal cord abnormalities than occur in typical PSP. Autopsy was nearly typical for PSP except for the spinal cord changes. The authors conclude that PSP comes in a wider variety of forms than we have appreciated.

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 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.

Pls 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 please refer to back issues of our newsletter, *The PSP Advocate* http://www.psp.org/press_room/newsletter.asp

Fundraising

Development Update

Kathy Matarazzo Specca
Director of Development

Hello Everyone,

As always, please know that we truly appreciate all you do to help the Society for PSP. Because of your support, we are able to provide vital services to those affected with PSP. Please know that we are here to help you through your journey with PSP. We are just a phone call away.

Listed below is an update of the special events that have been organized as well as some that are still "in the making." As you will see, there are plenty of good things happening to get the word out about PSP as well as raise money to find a cure.

- Walkathon – Florida – January 16, 2005
- Father's Day Race – California – 2005 – Date TBA
- Golf Tournament – Texas – Date TBA
- Jean's Day – Connecticut – Date TBA
- Craft Show – Date TBA
- Fishing Tournament – Date TBA
- Writing Campaigns (three) – Date TBA

If you would like to coordinate a fundraising event, please give me a call. I'll help you with ideas and even walk you through all the steps. I can also send sponsorship, advertising and public relations packets that will guide you. One event that is easy and most popular is hosting a dinner or cocktail party in your home. Or, perhaps you could write a letter to 10 or more of your friends. Tell them about PSP and ask them to make a donation. Both events are quite successful and easy to organize.

RIDES AND RODS EVENT

LAWTON, MICHIGAN • SEPTEMBER 4, 2004



Patti and Jimmy Downs with Kathy Specca, Director of Development and Jackie Allison, Society Deputy Director.

Hundreds of hot rod and motorcycle enthusiasts attended the second annual "Rides and Rods" event held on Saturday, September 4, 2004, in Lawton Michigan. This event was hosted by the family of Downs Manufacturing Company. Jimmy Downs, (founder) who has PSP, along with his wife Patti, son Jamie and daughter Angie, were the gracious hosts along with the help of their fabulous friends, family members, employees and volunteers. (The Downs Manufacturing

Fundraising



Company is the only group in the United States that is true one-stop-shopping facility for street rod fans. They have over 56 body styles to choose from. With 25 years in

the industry you are sure to get the best quality and design. So, if you're a street rod fan, check out their Web site at www.downsmfg.com)

Guests from various states drove their hot rods and cycles to "show off" their wares to the crowd. It was so exciting to see cars from the past—red corvettes from the 50's and 60's, a Porsche from the 30's, and let's not forget the Model T Ford also from the 30's. The Model T Ford was one of my favorites. I guess it is because my father just loved that car. I then fell in love with another old car that had a rumble seat. I remember my mom saying that someone would have to ride in the rumble seat because the inside of the car would fill up fast with passengers. She said that the ride in the rumble seat was very bumpy but fun because you could really feel the cool breezes. Ah, the good old days! As I looked at the rumble seat, I thought how nice it would be if mom was here and we could sit in the seat together. However, I know she and my dad were looking down enjoying the event with me.

Two bands and a DJ provided the entertainment for the day. A clown made balloon animals for the kids and a dunking booth was adorned with fun-loving and dedicated volunteers. Jamie Downs and his wife Vicky decided to volunteer and take turns in the booth. Both drew a large crowd. I myself threw a couple of good balls and actually dunked Jamie—all for the good of the Society, of course! There was even a pig roast! Pulled pork, salads, cookies, snacks and lots of beverages. Scrumptious food.

Tons of door prizes were given every hour on the hour. I was able to make a brief announcement about PSP on stage, every hour. Info packets were given at the time of registration. A great public awareness event!

Hats off to the Downs Family and their wonderful crew of friends, family, employees and volunteers. Lots of hard work went into this event. The event was enjoyed by everyone. Final proceeds should be available by the next issue of *The PSP Advocate*.

Our Annual Campaign will "kick off" in November. Please remember to support the Society. Your generosity brings us closer to finding a cure for PSP.

Thank you again for all you do to help the Society. We truly appreciate your support.

Education

Ask the Doctor

Question:

I live in Fort St. John, a city of 20,000 people in northeastern British Columbia. It is my understanding that PSP is a rare disorder; however, there have been four cases here in the last 20 years.

A brief history. My father was diagnosed in the mid 80's with PSP. At that time, one of the health unit nurses told us of a previous case. My father died in 1990. A friend's mother who lived here in the late 60's, early 70's and then moved to Manitoba, was diagnosed with PSP and died in the late 90's. I just saw an obituary in our local paper of a man who died this May and suffered with PSP.

This seems strange to me and thought I should bring it to someone's attention. Why four cases in one town of a supposedly rare disorder? Not sure if your organization is the right place to direct this question, but maybe there's a common denominator somewhere.

Glad to see you have such a great Web site.

Answer:

The annual incidence of PSP (i.e., the number of new cases that develop in one year) is approximately 1 per 100,000 population. That means that in a city of 100,000, you would expect one case to develop each year, on average. For a town of 20,000, it would take about 5 years to see one case. The period of time over which the four cases you know of lived in Fort St. John was about 35 years (late 1960's to the present). That means that you would expect 7 cases over that period of time (35 divided by 5 years), assuming that the town's population has remained stable. The "shortfall" of 3 cases occurred because no neurologist carefully investigated the medical status of everyone in town, while the researchers who formulated the incidence figure did just that in their city. Also, you may not be in a position to know of every person in town who has had the diagnosis. Still, I am very glad that you brought your suspicions to our attention, and maybe if you continue to keep your "antennae up" you might learn of more cases that might truly constitute a statistically unexpected cluster. Understanding of many diseases has benefited from such "amateur" observations with followup by professional researchers.



Lawrence I. Golbe, MD

GIVE A GIFT ONLINE

www.psp.org



Communication Practice Sets

Clues for Friends and Family

Family members are usually the best ongoing support system for individuals living with PSP. There are several things caregivers, family members, and friends can do to assist the person with PSP to communicate more effectively.

The first and most important thing is to encourage the individual to agree to speech therapy when changes in voice and speech production are noticed. In addition, simple yet effective environmental and behavioral modifications can be implemented to greatly improve communication.

Communication Boosters

Establish the habit of looking at one another while having a conversation. The element of lip reading greatly enhances comprehension.

Eliminate background noise while speaking. Turn off radio or TV, close car windows, doors to noisy areas, etc.

Be aware that facial masking is a feature of PSP. Individuals with PSP may feel emotions that do not show fully because of rigid facial muscles. Don't assume that the individual does not understand your message. "Blank" expressions may be due to facial rigidity. Avoid depending on facial cues to determine if the message was "transmitted".

Encourage and practice the use of shorter sentences when speaking. The individual with PSP can put more breath support behind shorter statements. Ask questions that can be answered in short sentences. Choose questions that give the person a limited choice of answers:

i.e., "Do you want eggs or pancakes for breakfast?"

Be patient. Don't rush or force conversational responses. Allow ample time for the person with PSP to communicate. Patience encourages an accepting climate in which the individual who is slow or soft of speech can respond and feel more comfortable.

Encourage your PSP partner to regularly practice a home exercise regimen that can be tailored to his or her needs by a speech-language pathologist. Some components of such a program are included in the exercises that follow....

Vocal Strategies

It is important to develop a homework routine that can be completed consistently. Choose a time of day to practice these maneuvers for 10-15 minutes daily without interruptions.

- 1) Take a deep breath and say the "ah" sound in a loud voice. Try projecting your voice across the room; hold the "ah" for as long as you can..
- 2) Sing musical scales on "la" both going up and coming down. Make sure to take a deep breath before starting, and sing in a loud voice.
- 3) Try talking in a voice that feels/sounds really loud. This increases overall function of your voice and speech.

- 4) Practice using a loud voice... First in short phrases, then sentences and reading paragraphs, finally in conversation. Although your voice sounds loud to you, it is probably just right for the listener.
- 5) When speaking on the phone or engaged in conversation, count the number of times you are asked to repeat. Now try again in a loud voice, and count the requests to repeat. Doing this helps increase awareness of how you actually sound to others.
- 6) While driving or riding in the car, practice saying aloud the street signs or places you pass. Use a loud voice (and considerable caution if you are the driver!)
- 7) Read short newspaper articles out loud. Read each article as if you were reading to a large group.
- 8) Read children's books to your children or grandchildren in a loud voice. Practice putting extra expression into your voice as you read.

9) Tape record yourself while doing any of the above exercises. It helps increase awareness of how you sound when using a strong voice.



Practice Maneuvers*

Practice the following phrases in a loud, expressive voice:

- "Shut the door."
- "Good night honey"
- "Pass the food, please."
- "Answer the phone."
- "How are you?"
- "I'm fine, thank you."
- "I love you."
- "Who is this?"
- "I need help!"
- "Please sit down."

Practice saying the following sentences in a loud, strong voice.

Use proper breathing techniques as indicated to enhance vocal strength:

- 1) (inhale) "Did I take my medication yet?" (exhale)
- 2) (inhale) "I would love a cup of coffee." (exhale)
- 3) (inhale) "Where are you going?" (exhale)
- 4) (inhale) "I need to go to the bathroom." (exhale)
- 5) (inhale) "It's a beautiful day!" (exhale)
- 6) (inhale) "Where is the remote control?" (exhale)
- 7) (inhale) "Would you like to go out to eat?" (exhale)
- 8) (inhale) "It's good to see you!" (exhale)
- 9) (inhale) "How are you today?" (exhale)
- 10) (inhale) "I went to the doctor's last week." (exhale)

Paragraphs are easy to find...

Try reading out loud anything that you are currently reading: from the newspaper, a favorite book, magazines, or reading aloud to children from their books. Remember to "think loud" and breathe.

* Exercises outlined are part of the Lee Silverman Voice Treatment (LSVT)

Living Day-To-Day With PSP: A Spouse's Perspective

SECOND OF A SERIES

Joyce Munsell is a registered nurse and primary caregiver to her husband of 36 years. Gary was diagnosed in 1998 after experiencing vague symptoms for over 2 years. He is no longer verbal or ambulatory and Gary communicates through the use of a touch screen computer. If you have everyday care questions you wish her to address in upcoming articles, you may contact Joyce at jmunsell1@cs.com



"Activities of Daily Living," (ADLs) to health care professionals, are the most basic abilities we possess. They make up some of the most ordinary "things" we do everyday. ADLs include getting in and out of bed, personal hygiene, dressing, eating, ambulating and performing manual household tasks. To those diagnosed with PSP and their caregivers, these activities become more important and more challenging as the condition progresses.

Let's examine a few of these usual routines and explore some inexpensive modifications which will assist both the family member and help the PSP loved one retain as much independence as possible.

Getting out of bed in the morning can become pretty tricky. A bed which is too soft or too low to the floor may hamper one's ability to rise up to a safe standing position or easily sit in a wheelchair. There are attachments which can be placed next to the bed, not unlike a fireman's pole, to grab and hold on to. Always have attachments tested for stability before allowing someone with PSP to use the aid. We found that a hospital bed equipped with the ability to be raised and lowered to a good height, worked best. Affixed short side rails offer a sturdy grab bar. The bed can be positioned to allow a person to roll on one's side, plant both feet solidly on the floor and then push up safely. Bed heights can be altered as needed. At some point in time, a caregiver should be able to assist without injury as well.

Rising up too quickly can cause someone with PSP to become dizzy and appear to pass out. This is sometimes called orthostatic hypotension. Be sure that adequate time is given at position change to rest for a few minutes. It will help eliminate this dizzy sensation and falls.

Brushing one's teeth may become increasingly difficult. It is much easier and more effective to use a battery-operated or rechargeable toothbrush to do a thorough job. Oral health is important to maintain, especially as the condition progresses. Lemon juice and glycerin swabs are now available, which assist in keeping the mouth fresh, especially when the ability to gargle and move water about the mouth decreases.

Toileting has challenges all its own. The first list of basics (previously mentioned as necessities) include side rails placed about the toilet and a raised seat. The caregiver should monitor both liquid and solid intake and output. It is easier to maintain a consistent routine than to deal with bladder infections or depend on laxatives and enemas because of

constipation. Your health care professionals (physicians, registered nurses, case managers, dieticians etc.) should be able to help you assess your particular situation and modify your routine accordingly.

Showering and bathing must include a handheld shower head and shower chair. You might want to consider a wheeled shower chair, as it will be useful for a longer period of time. Modifying the step-over ledge on a stall shower will probably need to be addressed at some point. Fortunately, prefabricated, inexpensive aluminum ramps are readily available at your local home improvement store. These ramps work great and are easy to install. A ramp allows for the use of a wheeled shower chair that can be directed right into the shower. It also eliminates expensive house modifications or the need to purchase expensive ramps from medical supply houses.

In time you may notice the increased inability to swallow saliva, as indicated by drooling. Using washcloths under the chin will help keep clothes dry and remove excess saliva. To keep them in place at home, you might want to consider using alligator clamps on a ribbon or plastic tape. These are available in the electrical department of your local discount store. If your physician agrees, a couple of drops of ophthalmic Atropine (yes, eye drops) placed under the tongue works great to temporarily stop the excess saliva. But, be sure to get your doctor's OK before using any prescription medication.

Dressing for comfort is also very important. Simple clothing such as elastic waist pants and velcro-strapped shoes help to prolong one's independence. Women will find stretchy garments less confining and more comfortable. If external or internal urinary catheters are used at some point, you can have your tailor or local cleaners place a seven to nine inch invisible zipper in the inseam of the pants. This allows for easy access to the drainage bag without having to undress during the day or while out.

Lastly, take your time and establish a nice routine. Our bodies work better knowing we are taking care of its needs. One of the classic symptoms of PSP is that ordinary tasks take extraordinary time to execute. That's OK. Give plenty of time to carry out your daily routine.

These are only a few of the simple, inexpensive modifications which can be used to keep someone with PSP involved with their ADLs and as active as possible. If you have a perplexing question concerning ADLs, or any area of day-to-day care, I welcome your inquiries. You may reach me at: jmunsell1@cs.com

Joyce Munsell, RN, CCM, MPA

Postscript: Gary Munsell completed his journey quietly at home, surrounded by his family on August 16, 2004. The Society extends it sympathy to Joyce and her family.

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.



Doctors Are People, Too

Jessica E. Quintilian, BS, CHES
Director, Outreach & Education

"Progressive what palsy? Did he say I'm going to go blind?" "How long did she say I had before I'd need a wheelchair?" Upon receiving the initial diagnosis of PSP, patients and their families are often left in a state of semi-shock. They hear and process about half of what the doctor says, if they are lucky. Some things ("there is no cure") come across loud and clear. Often though, a patient comes home from the physician's office feeling frightened, overwhelmed and wondering whether he or she really understands his or her medical condition.

PSP tends to affect people who are in their 60's. Past generations were usually brought up to never question the doctor and follow "doctor's orders." People in this age group may be easily intimidated by physicians and timid about speaking up at appointments. For example, if the physician schedules a medical test, the patient or family may not think to ask why the test is being performed. They may feel like the physician is too busy or doesn't have the time to talk with patients. Doctors often get a "bad rap" for not taking the time to answer all of a patient's questions, but the truth is that with health care the way it is today, doctors too sometimes feel frustrated about not being able to spend "enough" time with each patient. Hospitals may put pressure on physicians to increase their patient loads, and there has been much in the media lately about physicians being forced out of the profession due to rising malpractice insurance costs. While you may occasionally experience a less than ideal encounter with a health professional who doesn't seem to care, most physicians, nurses and therapists entered the field because they really do wish to help people. With a disease like PSP, they may not have all the answers either. It is difficult to tell a family "there is nothing more that we can do."

These days, patients and doctors share responsibility for care. Here is what YOU can do to better communicate with your doctor or health professional:

- Make a written list of questions to bring to your appointment. It is very easy to forget everything that you wanted to ask when you are actually sitting across from the doctor. Write down the answers you receive too. You may even wish to ask about tape recording the appointment.
- Be specific, clear and brief when asking your questions.
- If you have many things to discuss, consider making a consultation appointment to allow sufficient time.
- Educate yourself about PSP (this is where the Society can help!)
- Bring someone with you to the appointment. He or she may hear things you do not or think of other questions.
- Recognize that not all questions have answers.
- Be honest. The doctor may ask embarrassing questions about things like incontinence. Answer honestly so the doctor can accurately diagnose and treat your condition.
- Make sure you understand the purpose and side effects of medications. Make sure your doctor knows about all medications you are taking including over-the-counter and herbal supplements.
- Separate your anger or frustration about not being able to help your loved one as much as you would like from your feeling about the doctor.
- Appreciate the doctor's help and say "thank you."
- Make sure you understand what the doctor has told you – try repeating it back if you are unclear.

- Familiarize yourself with your insurance plan.
- Get to know the nurses and office staff. They can often answer day-to-day questions and provide information or resources.
- Don't be afraid to ask questions or seek a second opinion.
- Remember that you are the consumer and are paying for a service! Caregivers and patients must be advocates for themselves. Be polite, but stand up for your rights!

Doctors sometimes believe that they are effectively communicating information to their patients, yet surveys have shown that many times the information is not heard or not comprehended well. Doctors and health professionals can take simple steps to improve communication with patients:

- Be open and forthright.
- Consider the effect of treatment on the entire family.
- Be as accessible as possible.
- Reach out – a simple touch can mean a lot.
- Be sensitive about where you discuss a patient's condition (away from waiting rooms and hallways).
- Provide caregivers with helpful resources.
- Make sure that patient understands potential side effects of medications or procedures.
- Unless the situation is life-threatening, respect the right of the patient and family to think things over. If the situation is life-threatening, explain all legal ramifications as clearly as possible.

By trying to walk in each other shoes, doctors and patients can improve communication resulting in better care for the patient, more efficient use of the doctor's time, less stress for the caregiver and more satisfaction for everyone.

So, the next time you feel afraid to ask a question during your medical appointment, remember doctors are people too!

Sources:

National Family Caregivers Association, 800-896-3650, www.nfcca.org

CancerCare, Inc., 800-813-HOPE, www.cancer.org

Family Caregiver Alliance, 800-445-8106, www.caregiver.org

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 / email: 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!*

When Should Hospice Be Contacted For Someone With PSP?

As a participant in the online discussion forum, available at forum.psp.org, I've often been asked my opinion as to when is the appropriate time to contact hospice. I receive this question fairly often because of my background and current employment as a Registered Nurse working in Hospice for Healthcare Dimensions, a subsidiary of the Dana Farber Cancer Institute. I also have a family member who has been diagnosed with this awful disease.

People are sometimes taken aback by my most common response, which is often simply "today." The reason I feel this is the most accurate answer is that by contacting hospice today, you have absolutely nothing to lose, but a priceless amount of information, support and services to gain. When contacted, many hospices will give you the option of having a nurse come to your home and explain the benefit. The nurse can often tell you on the spot whether the hospice benefit may be available as an option now or, if not, what criteria would need to be met in order to qualify. I have yet to have anyone tell me, "I think I contacted hospice too soon," I unfortunately have had people tell me, several of them caregivers of those with PSP, "I really wish I had contacted hospice sooner."

In accessing your hospice benefits, which are covered 100% by Medicare and almost all private insurances, you gain access to a multitude of support and services. A registered nurse case manager will be assigned, whose focus will be on controlling the symptoms of the disease and helping to promote the best quality of life possible. The nurse will come to the home on a regular basis for ongoing symptom management. The frequency of the visits will depend on the patient's needs. A social worker will also be assigned who can assist in obtaining any available community resources, as well as helping both the person with PSP as well as the family deal with the emotional aspects of the losses this disease can bring. A non-denominational pastor can also be assigned who can work alone or in conjunction with community clergy to help cope with the spiritual aspects of dealing with a terminal illness.

In addition, nurse's aides can be assigned if needed to assist with personal care such as bathing and dressing. Nurse's aides generally visit from 2-7 days a week depending on need, and stay from 1-1½ hours per visit. Trained volunteers can also become involved. They can help by just making friendly visits to sit and read to the patient, running errands, assisting with rides to doctor appointments, or helping in any other way they can. Other services such as speech or physical therapy can also be included as part of the hospice

plan of care. By invoking the benefit, you gain access to a team of well-trained professionals whose focus will be on providing the person with the absolute best quality of life possible. In addition to the professionals involved in the care, hospice also covers related medications as well as home medical equipment such as walkers, wheelchairs, commodes, and even hospital beds or other related equipment.

William Carroll is a Registered Nurse who is nationally certified in Hospice and Palliative Care that is currently employed by Healthcare Dimensions Hospice, a subsidiary of Dana Farber Cancer Institute. For more information on hospice, please visit <http://www.hcdhospice.org>

What Questions Should I Ask About Hospice Care?

There are a number of questions you might ask when deciding on a hospice program.

ACCREDITATION: Is the agency accredited by a nationally recognized accrediting body, such as the Joint Commission on Accreditation of Healthcare Organizations? This means that the organization has voluntarily sought accreditation and is committed to providing quality care. The JCAHO is an independent, not-for-profit organization that evaluates and accredits health care organizations and is an important resource in selecting quality health care services.

CERTIFICATION: Is this hospice program Medicare certified? Medicare certified programs have met federal minimum requirements for patient care and management.

LICENSURE: Is the program licensed by the state, if required by your state?

CONSUMER INFORMATION: Does the agency have written statements outlining services, eligibility criteria, costs and payment procedures, employee job descriptions, malpractice, and liability insurance?

REFERENCES: How many years has the agency been serving your community? Can the agency provide references from professionals, such as a hospital or community social workers, who have used this agency? Ask for specific names and telephone numbers. A good agency will provide these on request. Talk with these people about their experiences. Also check with the Better Business Bureau, local consumer bureau, or the State Attorney General's office.

ADMISSIONS: How flexible is this hospice in applying its policies to each patient or negotiating over differences? If the hospice imposes upfront conditions that do not feel comfortable, that may be a sign that it is not a good fit. Also, if you are not certain whether you or your loved one qualifies for hospice, or whether you even want it, is the agency willing to make an assessment to help clarify these issues?

Education

PLAN OF CARE: Does the agency create a plan of care for each new patient? Is the plan carefully and professionally developed with you and your family? Is the plan of care written out and copies given to all involved? Check to see if it lists specific duties, work hours/days, and the name and telephone number of the supervisor in charge. Is the care plan updated as the patient's needs change? Ask if you can review a sample care plan.

FAMILY CAREGIVER: Does the hospice require a designated family primary caregiver as a condition of admission? How much responsibility is expected of the family caregiver? What help can the hospice offer in coordinating and supplementing the family's efforts or filling in around job schedules, travel plans, or other responsibilities? If the patient lives alone, what alternatives can the hospice suggest?

PRELIMINARY EVALUATION: Does a nurse, social worker or therapist conduct a preliminary evaluation of the types of services needed in the patient's home? Is it conducted in the home, not on the telephone? Does it highlight what the patient can do for him or herself? Does it include consultation with family physicians and/or other professionals already providing the patient with health and social services? Are other members of the family consulted?

PERSONNEL: If you are dealing with an agency, are there references on file? Ask how many references the agency requires (two or more should be required.) Does the agency train, supervise, and monitor its caregivers? Ask how often the agency sends a supervisor to the patient's home to review the care being given to the patient. Ask whether the caregivers are licensed and bonded.

QUESTIONS: Who can you call with questions or complaints? What is the procedure for resolving issues?

COSTS: How does the agency handle payment and billing? Get all financial arrangements—costs, payment procedures, and billing—in writing. Read the agreement carefully before signing. Be sure to keep a copy. What resources does the agency provide to help you find financial assistance if it is needed? Are standard payment plan options available?

TELEPHONE RESPONSE: Does the agency have a 24-hour telephone number you can call when you have questions? How does the hospice respond to the very first call? Do telephone staff convey an attitude of caring, patience, and competence from the first contact even if they need to return the patient's call? Do they speak in plain, understandable language, or do they use a lot of jargon about the requirements that patients must meet? What is the procedure for

receiving and resolving complaints? How a hospice responds to that first call for help may be a good indicator of the kind of care to expect.

SERVICES: How quickly can the hospice initiate services? What are its geographic service boundaries? Does the hospice offer specialized services such as rehabilitation therapists, pharmacists, dietitians, or family counselors when these could improve the patient's comfort? Does the hospice provide medical equipment or other items that might enhance the patient's quality of life?

INPATIENT CARE: What are the program's policies regarding inpatient care? Where is such care provided? What are the requirements for an inpatient admission? How long can patients stay? What happens if the patient no longer needs inpatient care but cannot return home? Can you tour the inpatient unit or residential facility? What hospitals contract with the hospice for inpatient care? What kind of follow-up does the hospice provide for those patients? Do nursing homes contract with the hospice? Does the hospice provide as much nursing, social work, and aide care for each patient in the nursing home as it does in the home setting?

PATIENT'S RIGHTS AND RESPONSIBILITIES: Does the agency explain these? Ask to see a copy of the agency's patient's rights and responsibilities information.

Excerpt from an American Cancer Society article.



Kate DeSantis, the Society's Administrative Coordinator, and her husband Patrick, joyfully welcomed their first child, Elizabeth Haig, on Friday, June 11, 2004 at 7:43 a.m. "Libby" weighed 8 pounds, 11 1/4 ounces and was 21 1/4 inches.

PSP EUROPE

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

Michael Koe
The Old Rectory
Wappenham, Nr Towcester, Northamptonshire
NN12 8SQ
Telephone 0044 (0) 1327 860299
E-Mail psp.eur@virgin.net
Web site <http://www.pspeur.org>

GIVE A GIFT ONLINE

www.psp.org



Circle of Friends

The Society Hosts an Afternoon Dessert Reception for Local Families

Support groups provide many benefits, as those who have been a part of them well know. Meeting as a group fosters self-help for people who share the unfortunate common bond of living with PSP. Groups provide a safe haven where caregivers can express their true feelings. Caregivers themselves are often the best treasury of information and experience for other families battling the challenges of PSP. What else do support groups provide? A circle of friends.



On September 12, 2004, close to 70 people found that circle at an afternoon dessert reception held at the BWI Airport Marriott hotel in Baltimore, MD. The Society hosted the Sunday reception for two reasons. It wanted to give local families the chance to meet one another and to start meeting again as a support group. Like many groups across the country, the Baltimore support group has had its ups and downs. The group has dwindled during the past couple of years, and the Society wanted to bring families together so that people in the Baltimore area can once again benefit from being part of an understanding and accepting group of persons who are affected by PSP. Secondly, it wanted to provide the latest information to families who are often left hungry for any news that attempts to explain this under-recognized disease. Dr. Paul Fishman, a neurologist and professor at the University of Maryland School of Medicine, provided a PSP update, citing misdiagnosis rates, symptoms, pathology and possible clues to environmental causes of PSP. Dr. Fishman, along with Dr. Stephen Reich, is well-recognized within the PSP community, as he has treated several Maryland patients who have been diagnosed with PSP. Following Dr. Fishman's presentation, Jo Ann Hart told her family's story. Jo Ann lost her father to aspiration pneumonia due to PSP in 2001. Her speech, entitled "Why my Dad?", evoked more than a few tears, as so many families in the room related to the feelings of loss, grief and growth expressed by Jo Ann.

Families also had the opportunity to meet the entire Baltimore-based Society staff and two very special people, the co-chairs of the Baltimore support group, Ruth Goldstein and Bruce Barnett. Both Ruth and Bruce have lost loved ones to PSP and have been incredibly dedicated volunteers over the years. Ruth not only spearheads the Baltimore group, but is always on the lookout for ways to raise awareness about PSP. Bruce is a member of the Society's Board of Directors serving on the Executive, Research and Outreach & Education Committees.

Support groups are not an end-all, but they can provide, through other people who understand what you are going through, invaluable strength for coping with the emotional pain brought on by a disease like PSP. They can provide education, encouragement and information... a place free of judgment or embarrassment, a place where you can be yourself. And who knows? Chances are, you just might make a new friend!

If you would like more information about the Baltimore support group or any of our PSP support groups, please contact Jessica Quintilian, Director of Outreach & Education at 1-800-457-4777 or email: outreach@psp.org. If you would like to consider starting a group in your area, please contact us! The Society is always looking for new leaders.

How To Start A Support Group

Support groups provide an opportunity to meet other people who share similar experiences. Most often, groups provide support and advice on how to deal with common problems. The goal of a support group is to create a warm, non-judgmental atmosphere where members can talk about life's challenges without embarrassment as well as give support and encouragement to each other. A support group is a place for people to come together to share coping strategies, discuss feelings, and make new friends. In addition to sharing, some groups choose to have educational activities by inviting guest speakers who talk about specific issues.

HOW DO I START A SUPPORT GROUP?

There are a number of steps to take when starting a support group.

HOW TO GET STARTED.

- Gather information about other support groups. Attend a meeting if possible to watch, ask questions, and borrow ideas.
- Find a convenient and safe place for a 1- to 2-hour meeting, such as someone's house, church or synagogue, library, community center, or YMCA/YWCA. The place to meet should be accessible to as many people as possible.
- Find other people who are experiencing similar problems and invite them to attend. Ask for referrals from social workers, churches, local officials, and community agencies.
- Promote the meeting through newspapers, flyers or posters.

WHAT SHOULD HAPPEN AT THE FIRST MEETING?

- When you have a list of potential members, you should contact them to confirm the meeting time and place.
- Keep the first meeting simple and start small; 2 to 3 people at first is fine.
- Allow 1-2 hours for this meeting and then let the group decide the time, length, and place of future meetings.
- Introduce yourself and share your story; invite others to share their stories, but do not force anyone to talk before he or she feels comfortable. All information should be kept confidential within the group.
- Ask for volunteers to help plan and run future meetings.
- Provide refreshments, if desired.

WHAT ELSE SHOULD BE DISCUSSED?

- Decide the purpose of your support group and decide what activities and speakers you would like to have.
- Determine who is eligible to attend and if transportation assistance is necessary.
- Plan your meeting schedule—at least monthly is recommended.
- Decide how to handle group expenses. How will refreshments be provided? Will dues be necessary?
- Remember to celebrate the triumphs of members as well as the challenges.

Woodholme
 Medical Building
 Suite 515
 1838 Greene Tree Rd.
 Baltimore, MD 21208
 1 (800) 457-4777
 1 (410) 486-3330
 FAX:
 1 (410) 486-4283
 email:
 spsp@psp.org
 Web site:
 www.psp.org

PROGRESSIVE SUPRANUCLEAR PALSY (PSP)



What is progressive supranuclear palsy?

- ◆ Progressive supranuclear palsy is an under-recognized brain disorder. Symptoms typically begin in one's 60's, but can start as early as the 40's. Those affected usually survive six to ten years after the initial symptom occurs. In people with PSP, gradual loss of certain brain cells causes slowing of movement and reduced control of walking, balance, swallowing, speaking and eye movement. People with PSP eventually become wheelchair bound or bedridden.
- ◆ Loss of balance while walking is the most frequent first symptom of PSP. Many times the falls are described by the person experiencing them as dizziness attacks, prompting suspicion of an inner ear problem. Another characteristic symptom of PSP, and the one for which the disease is named, is weakness ("palsy") of eye movements, especially in the downward direction. Other symptoms that occur in some are emotional or personality changes such as increased irritability, occasional angry outbursts or sudden bouts of laughing or crying, sleep disturbances, slurred speech and intellectual losses such as forgetfulness, mental slowing, apathy, and difficulty with abstract reasoning.
- ◆ PSP is often misdiagnosed as Parkinson's disease because of the general slowing of movement. Less often, it is mistaken for Alzheimer's disease because of its changes in mood, intellect and personality.



What are the complications of progressive supranuclear palsy?

- ◆ The slowed movements, frequent falling and poor visual function can cause physical injury. The patient eventually becomes wheelchair-bound. The visual disturbances also cause difficulty reading, feeding and performing other eye-hand tasks. The inability to maintain eye contact during a conversation can give the mistaken impression that the patient is hostile or uninterested. Those with PSP eventually become totally dependent on others for their activities of daily living. Difficulty in swallowing can lead to aspiration, the entry of food into the airway. This can cause choking, or more commonly, aspiration pneumonia, the most common cause of death for PSP patients. A physician may recommend a feeding tube at this time.



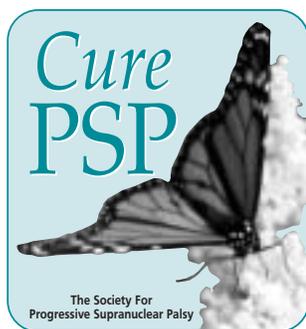
What causes PSP?

- ◆ The cause of PSP is not known, but it is at least partly genetic. A brain protein called tau accumulates in abnormal clumps in certain brain cells in people with PSP causing the cells to die. Exposure to as-yet unidentified chemicals in the food or environment probably also plays a role in the failure of these brain cells and the clumping of tau protein.



Is there treatment for PSP?

- ◆ There is currently no effective medication for PSP. Drugs that may have a temporary or modest benefit are levodopa (as in Sinemet), amantadine, and amitriptyline. Botulinum toxin injections are sometimes used to treat the blepharospasm (involuntary eyelid closure) that occurs in some people with PSP. Artificial tears can be used to help prevent drying out of the eyes due to decreased blinking. Use of a weighted walker can help prevent backward falls. Glasses with prisms can aid the difficulty in looking down.





What research is being done?

- ◆ Research is proceeding on several fronts, but more needs to be done. The most promising leads are: 1) A normal protein called tau forms abnormal clumps in the brain cells in PSP. Much recent work is aimed at determining just what causes the tau molecules to clump. A genetic variation in the tau gene is present in nearly everyone with PSP and in only about half of the non-PSP population. This variant in tau probably causes excessive production of that protein, which clumps when its concentration exceeds a critical level. 2) A clue to why only a few people with the tau variant develop PSP may be diet. Certain tropical fruits have been associated with a PSP-like illness on the Caribbean island of Guadeloupe. The precise nature of this is being investigated in order to determine whether chemicals similar to those in the fruits may be causing PSP in other populations. 3) Animal “models” of PSP have recently been created. Mice and fruit flies with an abnormal tau gene develop the same kinds of tau aggregates in their brains as humans with PSP. Such animals are useful in understanding the development of brain cell loss and in developing treatments.



Is there help?

- ◆ Yes. The Society for Progressive Supranuclear Palsy is a nonprofit organization that is dedicated to promoting and funding research into finding the cause and cure for PSP. Since 1997, the Society for PSP has spent almost two million dollars on nearly 60 research projects. The Society for PSP also offers information, education and support to people with PSP, their families and caregivers and provides advocacy for all. The Society educates physicians and other health professionals on PSP and how to improve patient care and provides a forum for researchers to exchange new information and ideas on PSP.
- ◆ The Society for Progressive Supranuclear Palsy, Inc.
Woodholme Medical Building
1838 Greene Tree Rd., Suite 515
Baltimore, MD 21208
Phone: 1 (410) 486-3330
Toll-free: (800) 457-4777
Fax: 1 (410) 486-4283
email: spsp@psp.org
Web site: www.psp.org
Canadian: (866) 457-4777



What are the Society for PSP's support services?

- ◆ Sponsorship of research through contributions. In the past six years, the Society has funded nearly \$2 million in research grants to investigators in the United States and Europe. But, much more is needed.

- ◆ Formal support groups in many cities across the country as well as informal support through telephone “communicators”
- ◆ Distribution of a quarterly newsletter, *The PSP Advocate*, educational brochures, videotapes, Web site, and forum, www.psp.org
- ◆ Regional conferences for persons with PSP and their families
- ◆ Brain bank for tissue donation to support PSP research
- ◆ Volunteer opportunities

The Society strives to keep famous actor and musician, Dudley Moore's memory alive by acknowledging that he brought his diagnosis before the public so that the world would become aware of PSP.



The Society for PSP

Vision:

- ◆ A world free of PSP

Mission Statement:

- ◆ 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.



Support Groups As Of October 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.

ALABAMA

MIKE & SUE MCINTIRE*

Dothan
334-699-2091
seminole1@graceba.net

ARIZONA

KRISTINA WATTS

Phoenix
602-406-4931 • k2watts@chw.edu

CALIFORNIA

CAROLYN GRIFFITH*

Santa Ana
714-832-3731 • wgriff1@earthlink.net

CERI WILLIAMS

Sherman Oaks
818-343-3259
medianet@earthlink.net

KATHY SCHWAIGER

Thousand Oaks
805-496-7018

MARY MIANO

Laguna Woods
949-855-3972 • mjm941@juno.com

DOTTIE GEORGENS

Encinitas
760-230-1130 • dgeorgens@cox.net

ROBIN RIDDLE

Menio Park
650-233-9277
rriddle@stanfordalumni.org

COLORADO

VICKI SEGRO

Englewood
303-788-4600 • segro@megapathdsl.net

CONNECTICUT

FRANK CADWELL*

Clinton
860-664-9524

FLORIDA

HELEN LAVELLE*

Naples
941-352-2909 • hlavelle@yahoo.com

LINDA IVES*

DeBary
386-668-7130 • L_r_ives@695online.com

BOB KRASNICKI*

Tampa
813-960-5732
robert.krasnicki@med.va.gov

CATHY STERN

Bradenton
941-748-4028

GEORGIA

KATHY THOMAS*

Decatur
770-939-2612

JOAN CARPENTER

Augusta
706-721-9445

ILLINOIS

DARREN LOVELESS

Glenview
847-729-0000
dlovelessmktg@aol.com

INDIANA

STACY WARE

Connorsville
765-825-2148

KANSAS

MARIAN GOLIC

Overland Park
913-381-6972

LOUISIANA

BRENDA GREMILLION*

Kenner
504-467-6658 • bgrem737@aol.com

MAINE

FAYE RYAN*

Whiting
207-259-2152

MARYLAND

RUTH GOLDSTEIN

Baltimore
410-486-2822 • music@comcast.net

MASSACHUSETTS

PATTI RYAN

Swampscott
781-595-4431
parmanagement@aol.com

MICHIGAN

CAROL ANN KLANK*

Commerce Township
248-363-9064

SARA BALL

Mt. Pleasant
989-426-3877
saldon@ejourney.com

NANCY GRIFFIS

Ionia
989-855-2987

MINNESOTA

JOAN MALECHA

JOANNIE McARTHUR
Elko
952-461-2089 • gpm461@aol.com

CHARLOTTE TRIPET

Golden Valley
763-546-1694 • chartrip@yahoo.com

SANDRA VARPNESS

Golden Valley
952-993-2253
varpns@parknicollet.com

MISSOURI

PAT LYNN*

Jackson
573-243-3964

AMY MANDLMAN

St. Louis
314-432-5461 • mand54611@aol.com

ALICE KITCHEN

Kansas City
816-753-4424 • akitchen44@aol.com

NEBRASKA

DON HAMMEL

Omaha
402-331-6479 • donhammel@cox.net

NEVADA

CAROL UPTON*

Las Vegas
702-731-8329 • parkinsonslv@cs.com

NEW JERSEY

CAROL SOLOMON*

Marlton
856-985-1180 • info@chsgeriatric.com

DIANE ALTER

Long Branch
732-936-3330 • scoups@aol.com

NEW MEXICO

KAREN KENNEMER

Kingwood
281-358-2282 • kmk1224@aol.com

NEW YORK

HARRIET FEINER

Floral Park
718-224-4654 • hfeiner@nyc.rr.com

MARCY TODD*

Port Washington
516-883-7455

JAMES BERNARD

(fundraising/awareness group)
New York City
212-351-4329 • kimo69@earthlink.net

MARY CONNOLLY*

Canandaigua
585-394-5306

NORTH CAROLINA

MARGARET AKERS-HARDAGE

Charlotte
704-846-6606
mhardage@carolina.rr.com

OHIO

MEGAN BROOKS

Massillon
330-833-1958 • joabbro@aol.com

PAT BEEKMAN

Berea
440-234-0007
PSPmombekman@aol.com

REBECCA AND DAVE DANGLADE

West Jefferson
614-879-6624
Davbec95@msn.com

JENNIFER SKEEN*

Cleveland/North Royalton
440-582-1319
PUMPKINVILLE@YAHOO.COM

PENNSYLVANIA

RUTH NULPH, R.N.

Butler
724-287-8600 • lnulph35@aol.com

HEATHER CIANCI

Philadelphia
215-829-7275 • hjciani@yahoo.com

TEXAS

KAREN KENNEMER

Kingwood
281-358-2282 • kmk1224@aol.com

MUREL & TERRY PEAKE

Dallas
214-348-2633
terrypeake@sbcglobal.com

VERMONT

JANICE CLEMENTS

Milton
802-893-1263
janclem@moomail.net

VIRGINIA

HOWARD COOLEY

Clifton
703-830-4819 • hgc1235@aol.com

KATHY SANDS*

Vienna
703-242-9322 • kathy.m.sands@saic.com

WASHINGTON

FRAN McMAHON*

Rochester
360-273-9496 • franmcdoll@aol.com

JIM BARRON

Pullman
509-332-6053

barronjc@escapees.com

MARY ANNE MEMMINGER

Spokane
509-921-6645 • manwa@bigplanet.com

ROBERTTA HUNT*

Walla Walla
509-529-1364 • robertta@hscis.net

WEST VIRGINIA

JENNIFER SKEEN*

440-582-1319
PUMPKINVILLE@YAHOO.COM

WISCONSIN

BARBARA SHARKEY

Rhineland
715-362-1777
bsharkey@frontiernet.net

LAURIE CONRAD

Madison
608-442-7444 • conradswi@yahoo.com

AUSTRALIA

JEAN BENTLIN*

Gympie
+61 07 5482 5819
pspsupport@ozwide.net.au

CATERINA MARIGLIANI

BARBARA WINKLER

Victoria
+61 3 9265 1494
c.marigliani@southernhealth.org.au

CANADA

JANICE STOBER

Markham
905-472-7082
stober@movementdisorders.ca

SANDIE JONES

Toronto
416-227-9700
Sandie.jones@parkinson.ca

MARIA DASILVA

Ottawa
613-722-9238 • mdasilva@ohri.ca

MARY CHIBUK

Alberta
780-482-8993
marychibuk@parkinsonalberta.ca

JONATHAN ANDERSON

Montreal
514-277-0621 • jonathan@bigcity.net

*PHONE/EMAIL GROUP

Let us post your support group news and announcements in the PSP Advocate.

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

This is my first time posting to this forum, although I've read it off and on over the last few months. My mother was diagnosed with PSP in March, although like many people, she has had symptoms for at least 2, maybe 3 years. Currently, she is still mobile with aid of a walker (although falls occasionally) and is eating okay. She is living in an independent living retirement home and we're hoping that she can stay there as long as possible. She is fiercely independent and is pretty much in a state of denial about PSP at this point. Here's my dilemma. She desperately wants to go on a plane trip to see her newest great-grandchildren that she has never met. My husband and I agreed to accompany her since there was no way I was going to put her on a plane by herself! She has always enjoyed traveling, and it breaks my heart that this will surely be her last trip (and why I couldn't say no). We finally persuaded her that she would need a wheelchair in the airport. We also persuaded her to cut down the trip from 10 days to only 4 days, which will be pretty exhausting to see everyone in such a short time, but better than being away from home for so long. So are we crazy for having agreed to this? Any suggestions for making the trip go smoother?

RESPONSES FROM THE PSP FORUM:

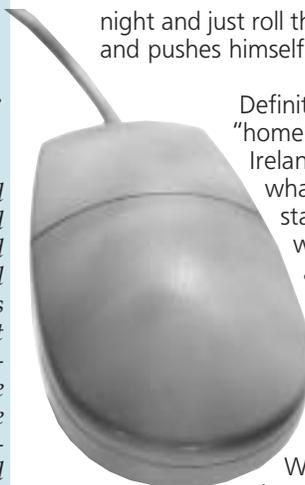
We have only traveled in the early stages to our daughter's house which was about three hours away. I can say to you and encourage you to take her as much as you can. The airports do have wheelchairs (most of them) that you can use and they might consider an outside seat if you request. We went on a trip when Charles was just beginning this disease and I used the wheelchairs they provided. I would suggest Depends or another product like them if the trip is a long one and the use of a rest room is needed. You will not regret doing this for her and there does come a time when it is just about impossible to take the PWSP (person with PSP) on a trip.

There is going to come a time, unfortunately, when your mother's traveling will be curtailed. If she can do it now, do it. Once she has more limitations, you can still have local trips to museums and restaurants. We didn't let my father's condition totally restrict us or him. Even though there are physical limitations, keep the mental stimulation, people interaction and positive influences coming.

My husband has had PSP about 4 years on a walker around the house, but needs a wheelchair to go anywhere further. We just took another plane trip (approx. 3 hrs. long). We packed the walker and the wheelchair (which the airlines takes at the entrance to the plane and returns to you when you get off). I made sure all the hotels were wheelchair accessible. He has bad balance and can't see when he walks, however, he likes the change of pace and is happy because he has me all to himself. The plane trips are getting more difficult, but road trips are still good. I feel that as long as I can move him and he is able to move around the change is good for him.

When we travel in the car (just bought a truck actually so he can see high up and it seems to be easier pulling himself in and out) I limit driving to 5-6 hours and find a hotel with a pool for his legs or he takes a good nap. We also go to the beach at

night and just roll the wheelchair on the boardwalk. He is brave and pushes himself for us, too. We plan to keep on going.



Definitely go for it! I sent my parents back "home" (Dad, PWSP, to England and Mom to Ireland) twice before it became impossible. From what I gather, my Dad was at about the same stage as your Mom on his last trip. I have one word of advice - PLAN - then plan some more and in case you have not planned enough, plan a bit more. Contact the airlines ahead of time to arrange wheel chairs, priority boarding, seating, etc. The ones I used could not have done more for Mom and Dad (even to upgrading them both times).

We purchased a van and drove to Maine. Biggest problem encountered in traveling as his condition worsens is that not many "companion" restrooms exist. There needs to be more of them so that caregivers can accompany their folks and see that they are ok. We are considering attending a family reunion in SC/GA in September and the restroom deal enroute driving or flying is my biggest concern at this time. He says he will be ok.

I took an early retirement from my job because my husband with PSP could no longer be left alone. He has needed help with daily functions for the last 2 1/2 years. He is in a nursing home since April, and is wheelchair bound. Although I am very sad, I know I did everything I could to keep him with me as long as I could. He is a big man, 6 ft 220 lbs. I am 5 ft 2 in. 115 lbs. When he started falling a lot in March, I finally had to put him in the nursing home. They are just wonderful to him and it is only 1 mile from our home. I volunteer there 3 days a week. It gives me a chance to check on him and get him involved in the activities, as he is so dependent on me. The reason I am telling you all this is that I traveled with my husband and my 86 year old dad one year ago. I took them in our Sienna Van from Pompano Beach, Florida up to Cape Cod for 6 weeks. We stayed at a beach house right on the ocean in Sandwich. My one daughter helped arrange this for us. Then we stayed with my other daughter and her family for 1 week. We were surrounded by family and friends. It was wonderful for George and I got some much needed rest and enjoyment spending time with my grandchildren. George was in a wheelchair at that time, but I brought along all the necessary items. You need to think about raised toilet seats, medications, emergency numbers, doctors, and also taking as many personal items that will make him feel at home. I was able to do that because of the van. I also took him on a couple of plane trips to Boston and Mississippi, and though it was tough, I know how much it meant to him. We left in May and returned the end of July. I was exhausted when we returned home, but I am so glad I did it while he was still able to speak a little and see pretty well. I even took him out of the nursing home in June and drove him up to Orlando to meet up with his brother and sister-in-law who drove all the way from Oklahoma to spend 4 days with us. I also had to bring a bed rail along on this trip. He has a terrible fear of falling out of bed. I know that was his last trip, but I am glad I did it. Even though it may seem so unfair this is happening, try to make the best of every minute you can together. I go one day at a time.

Support - Our PSP Stories

Nothing Better To Do

Continued from Page 1

personality and physical capabilities were eroding. I suppose there was some element of denial on my part, too. Unlike the example above, most of the early signs were subtle.

There was a tendency to defer more everyday decisions to me. I would come home from work to find that something relatively routine needed my attention. I wondered why she just hadn't gone ahead and taken care of it. But I didn't really focus on it until a cousin remarked that she was surprised how much my mother had "slowed down."

Soon more dramatic and disturbing changes began to occur.

Only My Dignity

First she would say something like "I fell down while distributing magazines at the hospital today." Then it became more frequent, sometimes more than once a day.

"Only my dignity" was her standard response when asked if she hurt herself.

When I observed her fall, it wasn't a stumble or trip. The loss of balance almost always was a sudden fall slightly backward, but mostly straight down. It was as if she involuntarily sat down on the floor. As my sister once described it, "She was standing in the kitchen talking to me and suddenly just fell down."

We were concerned but not alarmed. Perhaps, on some level, we wanted to believe that the falling and other signs of physical deterioration were just part of a normal aging process. And if she would exercise a little extra caution, limit her activities a bit or get a new prescription for her glasses, then the problems would be manageable.

That was not to be. One day she came home from an appointment with her doctor and asked me if I had ever heard of progressive supranuclear palsy.

Progressive Supranuclear Palsy

I had never heard of it, but I knew exactly who to call. At that time my ex-wife was working at the National Institutes of Health. The following are excerpts from the information she sent.

"Progressive supranuclear palsy (PSP) is a rare brain disorder that causes serious and permanent problems with gait and balance...The most obvious sign of the disease is an inability to aim the eyes properly...The disorder's long name indicates that the disease begins slowly and continues to get worse (progressive)...The most frequent first symptom of PSP is a loss of balance...As the disease progresses, most patients will begin to develop problems controlling eye movement...In fact, eye problems usually offer the first definitive clue that PSP is the proper diagnosis...Problems with speech and swallowing are much more common and severe...In some patients, the slowness, stiffness and balance problems may respond to antiparkinsonian agents, but the effect is temporary...The speech, vision and swallowing difficulties usually do not respond to any drug treatment...Another group of drugs that has been of some modest success in PSP are antidepressant medications. The anti-PSP benefit of these drugs seem not to be related to their ability to relieve depression...PSP gets progressively worse...There is currently no effective treatment for PSP."

I was stunned by what I read and by what it meant. Most of the disease's symptoms were or were to become apparent with my mother. There was the "loss of balance while

walking." There was the "impaired ability to move the eyes up or down...blink very little." Speech became slurred. Swallowing foods became difficult. And "although mental confusion is more apparent than real, most patients do eventually develop a mild or moderate degree of mental impairment." Check on that too, but it was really rather mild. Also, she was one of the "small fraction of patients" that developed what is known as "echolalia," which is "manifested by involuntarily repeating what is said."

The Reality

I was shocked, stunned, depressed and unwilling to face what lay ahead. Somewhere in all that information I had read that patients lived an average of six to eight years after the initial diagnosis. I latched onto that and took it as assurance that she would be around for a long time.

I think she did, too. In our talks, one or the other of us observed that another six or eight years meant she would live longer than both her parents. Initially, I think that became a goal for her.

But on a practical level, numerous changes were set in motion. Around the house safety features like handrails and grab bars went up along the hallways and bathrooms. We installed an automated calling device which could be activated by an emergency button she would wear pinned to her clothes. We started off with a small bell for her to ring when she needed assistance. The bell was soon exchanged for a whistle she wore on a chain around her neck. That whistle became her constant companion and permanent accessory. More on the whistle later.

The biggest change arose from the realization that my mother would have to have someone with her during the day. We began a search for someone part-time, telling ourselves that would be all we would need for quite a while. Our early thinking was that we would get someone to stay for part of the day, help her with lunch and just be there for assistance. We were wrong about that. Within a few months, full-time help became necessary. Fortunately, on our second try, we found someone who became an excellent helper.

How The American Healthcare System Works

As near as I can determine, if you have something wrong with you and there is a chance you can get better, then Medicare will help. But if you are sick and you are not going to get better, then, sorry, you are on your own.

Actually, what I think happens when confronted with the latter situation is that the system has to break down the patient's illness into discreet conditions for which coverage is allowed. For example, shortly after she was initially diagnosed with PSP, my mother was given a limited number of hours of physical therapy over a certain time period. Then after the prescribed amount of physical therapy was completed, it stopped without regard to any underlying change in her condition.

Of course, doctor appointments, hospital visits, tests and other necessary procedures were covered to some degree. The paperwork generated by all this seemed rather bizarre at times. We would receive statements listing in minute detail each individual medical activity performed and listing what seemed like astronomically high charges for that activity. It was as if a line item might read "Nurse took her temperature and asked 'And how are we feeling today?'...\$400.00." Medicare would then include a statement something like "On your behalf, we have negotiated lower charges." The charge of \$400 for taking her temperature would then be reduced to

Support - Our PSP Stories

\$100 and identified as "Medicare approved." Medicare would then show \$80 as the amount "We paid your provider." And finally, the residual \$20 was the amount "You may be responsible for" or "Your total responsibility."

Milestones

Milestones may not be the right word. But changes began, slowly at first, and then accelerated. Some seemingly normal activity that she had performed most of her life would be given up. She accepted this progressive deterioration with grace and, at least to me, never complained.

Driving was the first to go. She stopped driving at night and later stopped altogether. She had been an avid reader, mostly of fiction. That, too, was given up. A short aside: When my father was alive, she would drive him to a weekly civic club meeting. She would wait nearby for him in a small community library. She told me she read every book in the fiction section.

One day I arrived home from work and asked if there was any mail. She said she didn't feel safe walking out to the mailbox.

For a while she could walk unaided, but with the risk of falling. Then she could walk, but not without assistance. Then we got a wheelchair.

The personal things like getting dressed, taking a bath, etc., came to require assistance from me or our helper.

For many years, she had a standing appointment with her hairdresser every Saturday morning. First, I began driving her there and dropping her off at the door. Then I had to help her walk into the beauty parlor. Then it was wheeling her in. Finally, we arranged to have the hairdresser come over to the house.

There were some minor constraints on my work and social life. I had a habit of occasionally going in to work on the weekends. That stopped, except in emergencies. There were everyday things like grocery shopping and other errands. I would take her with me, if possible. Otherwise, I tried to be as efficient as possible in order to minimize the time she would be alone at home. My social life suffered a bit.

The need to be near at hand had its up side, too. I had a ready-made excuse for taking frequent breaks from yard work on hot summer days.

After church on Sunday, we always went out to eat. We rotated among several restaurants. However, when it became difficult for her to feed herself, she felt uncomfortable going out to eat. So, we switched to carry-out places for our Sunday meal.

The Little Engine That Could ... Arrives Early

While she could still walk unaided, but with declining skill, her steps took the form of almost slow-motion, straight-line, no tolerance for deviation off the track. Whether she was headed for the car, her chair or the dining room table, she seemed to fix the destination firmly in her sight and mind and move relentlessly toward it. Her expression and body language seemed to shout pure determination.

When we were younger, I don't remember my mother being particularly concerned with punctuality. But as her mobility diminished, not being late became paramount. Actually, it meant being early. An 11:00 appointment with her doctor, only a 10 minute drive away, meant being dressed and in the car by 10:15. Sunday school classes starting at 9:30 meant being in her seat by 9:00.

It may just have been that, as her outside activities came to require more effort, she felt the need for more time to physically and mentally prepare. While she could still walk, I often would find her sitting in the car, buckled up and waiting, while I was still looking for the car keys.

A Day In The Life

I get up as close to 5:30 as possible, depending upon how many times I hit the snooze button on my alarm clock. After showering and dressing, I go out to pick up the newspaper. Next I prepare her bowl of cereal, start her coffee brewing and set out her morning pills.

Then I get my mother out of bed, put her bathrobe on her and help her into the bathroom. After that, we go to the kitchen for breakfast. If she has trouble with the spoon, I'll feed her a few bites.

Back in the kitchen, I'll give her a couple more spoonfuls if she hasn't made much progress. Then I go out back to feed the dogs. After that, I eat my breakfast, help her finish and make sure she takes her pills.

When we are both finished, I help her into her chair in the living room. I put the coffee mug in her hands and pin the emergency call button on her bathrobe. Last, I either kiss her on the forehead or brush my hand through her hair and say "Behave yourself." She tells me "Drive carefully." I'm off to work. Our helper arrives about 30 minutes after I leave. She bathes, dresses and looks after my mother during the day.

I usually return home between 6:00 and 7:00. First, I chat with her and our helper for a few minutes. After that, I feed the dogs and then eat my own supper. If I have time, I do the dishes before she is ready to go to bed, which is sometime around 8:30.

I go back into the living room where she is watching television with her eyes closed. I kid her about sleeping in front of the television. She tells me she wasn't sleeping. I say "Oh yeah? What's happening." She responds by giving me an accurate one sentence summary of the show.

I help her into the bathroom and stand just out of her line of sight in the hallway until she tells me she is through. Then I help her off the toilet and over to the sink to wash her hands.

She likes to have her face washed before she goes to sleep. Sometime during this process she says "Water." I respond "There's water right here." She comes back with "Water to drink." I come back with "Where do you think you are, in the middle of the desert?"

In a variation of the water routine, sometimes I remember to ask her if she wants a drink before we leave the living room. Sometimes she says yes. Sometimes she says no, then waits until she is in bed and blows her whistle. When I come back into her bedroom, she smiles and says "I changed my mind."

After the bathroom, we go to her bedroom and I sit her on the side of the bed while I get her a glass of water. After her drink, I lift her feet and legs onto the bed. At this point we decide which side she wants to sleep on, covers on, covers off, etc. I'm through until 10:00 unless she blows her whistle.

Around 10:00, I give her the last pill of the day. Then I help her to the portable toilet close to the bed and step out in the hallway until she is finished. Then it back to bed for her and, shortly thereafter, bed for me, too. My day is over until the whistle blows.

The Whistle

The whistle she wore on a chain around her neck was her constant companion, taken off only when showering or going out in public. Sometimes she would even sleep with it between her lips. As her mobility and speech became more difficult, the whistle was one thing she could still control. I'm sure it made her feel more secure. Generally, the whistle would blow if she wanted something and I wasn't in the same room or if she just wanted to talk or find out what I was doing. Only once did she abuse it.

Typically, she would blow the whistle a couple of times a night; to go to the bathroom, get more or less cover on the bed or get turned



Support - Our PSP Stories

over on her other side. But on one particular night the whistle began to blow shortly after 10:00 and continued at 15-20 minute intervals. It was the regular requests for more cover, less cover, turn over on the other side, go to the bathroom, etc. But it was every 15-20 minutes.

Basically, she just couldn't sleep and was restless and bored. Finally, at 2:00 I told her that she had to let me get some sleep and she couldn't blow her whistle again for two hours.

The next thing I knew, I was awakened from a sound sleep by the sound of the whistle. I stormed into her room to find her smiling innocently and trying hard not to giggle. The clock next to her bed read 4:07. At least she gave me an extra seven minutes.

The Beach Towel

Many years earlier, my college girlfriend gave me a beach towel. The girlfriend didn't last. After graduation, she went to teach school in Colorado and I joined the Peace Corps. We corresponded for a while, but soon lost touch. I never saw her again.

When I left for the Peace Corps, the towel along with other accumulated college valuables went home to Texas. There, over the years, it was actually used as a beach towel on the many times my sister and her family visited my parents.

As PSP began to rob my mother of her mobility, she would spend much of the day sitting in her chair. For some reason, regardless of the season, she would have trouble keeping warm during the day and keeping cool at night. One of my regular comments to her was "How come you get cold when the sun rises and warm when the sun sets?"

Anyway, that old beach towel was just the right size and weight to cover and keep her warm during the day. So wherever the old girlfriend is, thanks for the towel. Hope you've had a good life.

The Chin Is Also An Appendage

Here is the issue. You need to get your mother dressed. She can't do it herself. You want to maintain some semblance of modesty and personal privacy. You only have two hands.

Begin with her sitting on the edge of the bed in her nightgown. Start with the underpants. Slip them over her feet and up to about knee level. Lift her up to a standing position. Wrap her arms around your neck. Lean forward, lock your chin over her shoulder. Holding her tight with your chin, reach down and pull up the underpants. You need to do the chin-lock-and-pull-up part quickly. Otherwise, she may fall back on the bed and you will have to start all over again.

Next, sit her back on the bed. Move around behind her and kneel on the bed. Don't let her fall forward. Pull the nightgown over her head and put on her bra from the back. If she is going to be wearing a dress, that's easy. The dress goes on over her head. If she is going to be wearing a blouse; that's easy, too. With slacks or a skirt, you have to repeat the chin procedure.

While all this is going on, try to keep up a flow of casual conversation in order to divert attention from what you are doing. Make small talk about the weather, what's for lunch, or whatever. If you have to discuss the fact that you are dressing your mother, keep it matter of fact and technical.

Polite Denial

I vaguely remember reading a newspaper column on etiquette where the writer used the term "polite denial" to describe how one should act in certain awkward situations. That is, if the situation requires invading someone else's privacy or modesty, then the individual should simply ignore or politely deny the action is taking place.

I think I got pretty good at doing that as my mother began to need more and more help with getting dressed or undressed and going to the bathroom. When she was in the bathroom, I would stand in the hallway just out of her line of sight, but close enough to help if needed. When helping her get dressed, I would try to act as if everything was normal and I wasn't really doing what I was doing.

Speak Up! I've Got A Bandage Over My Ear

I was shaving when I heard the crashing sound in my mother's room. In the early morning darkness, I found her on the floor next to the bed mumbling something like "I fell down." When I asked her if she was hurt, she replied "I don't know."

Whenever she admitted to being in pain or even hinted at the possibility, it was a sure sign something was wrong. I turned on the light and saw a large gash on her ear lobe and blood everywhere.

Fortunately, my sister was visiting us. So the two of us decided on a "tag team" approach. I would finish getting ready while she got our mother dressed. I would drive her to the emergency room while my sister got dressed. She would meet us at the hospital and take over so I could go to work. And that is the way it went.

When I got home that evening, my mother was wearing a huge bandage over her ear and an expression on her face that seemed to say "Guess what kind of day I had."

Other Disasters—Big, Small And You're Not Going to Believe What Happened Today

One Sunday morning she fell while getting ready for church. At the time, she said her hand hurt a bit and then complained about a couple of times later in the day. That should have been a clue, but I brushed it off. The next afternoon I came home to find her wearing a brace on her wrist. She had broken a small bone in her hand. Our helper told me in no uncertain terms that the next time my mother complained about something, I had better pay attention.

I was just about to walk out the door on my way to work when I heard a strange sound. I found my mother on the bathroom floor. The toilet was tilted at about a 45 degree angle and water was gushing everywhere. She had difficulty getting up from a sitting position. So she applied a lesson from her physical therapy. The lesson was, if you have trouble getting up, try rocking back and forth, or in this case from side to side, until you develop enough momentum to get up. Apparently the technique worked, although applying it to the toilet had eventually loosened its anchor bolts. We finally stopped laughing long enough for me to turn off the water and dry her off. And that's when we got the handicap toilet.

Two other stories I heard about later. One involves another lesson from the physical therapist. The other has to do with water. The physical therapist taught my mother that if she fell down, getting up immediately did not have to be the first priority. One could try to get comfortable on the floor until help arrived or one could crawl over to some piece of furniture and use that as support to stand up. The emergency call button my mother wore alerted a service which would first try to call her back. If the service did not get an answer, it would call one of the "responders" listed to request they go over and check on her. Only after that would the service call for emergency assistance. So, one day a family friend got a call from the service. Upon arriving at our house, she found my mother sitting on the living room floor. My mother had fallen, but was unhurt. After a couple of attempts, the friend was unable to get her up. So the two of them sat together on the floor, chatted and drank coffee until our helper arrived for work.

The other water story took place at the same friend's house. For some reason, I've forgotten what, our water was temporarily shut off and my mother needed a bath. So our helper drove her over to the friend's house. Apparently, getting my mother into the tub and bathing her was no problem. The problem was getting her out of the slippery tub, particularly when all three women were laughing hysterically. Eventually they came up with a solution. One woman held my mother's feet firmly on the bottom of the tub to keep her from slipping. The other wrapped a bath towel around her back and under her armpits and pulled her upright.

Support - Our PSP Stories

Sunday School And Church

My mother belonged to the same Sunday school class for about 50 years. When my parents first joined, it was called the Couples Class and as the name implies, it consisted of young married couples. After several decades, as the members aged and membership dwindled, the name was changed to the Chapel Class because they met in the small chapel close to the main sanctuary.

Our routine after she stopped driving was that I would take her to Sunday school and then return an hour later to attend the regular church service with her.

At Sunday school, she sat in the fifth pew from the front on the left side, one space in from the aisle. I never asked, but I assumed the space closest to the aisle was where my father sat.

The class had a collection box where members could put an offering. This was separate from the church offering, which I'll get to later. Anyway, she would ask me to get some money from her purse and put it in the collection box. Since she was always the first one there, my standing joke with her was to say "Why do you want to do it in now? Nobody's here to see you put the money in." She would laugh and tell me to just do it and mind my own business.

Seating at the regular church service was more flexible, although we usually sat in the same general area. Shortly after sitting down I would write a check for her weekly offering. She tithed. At the beginning of each year she estimated her annual income, calculated ten percent of that amount and divided it by fifty-two weeks. And that was the amount I wrote. On occasion, she would come into some additional funds. Ten percent of that would be given, too. The other duty I took care of before the service started was to fill out for her a prayer request form asking the congregation to remember one or more of her ailing friends.

To an extent, her physical decline could be tracked by the changes in her church service activities. First, we would walk up the steps to the sanctuary. Then we took the elevator. Then we would use the wheelchair and the elevator. First, we would stand and sing from separate hymnals. Then we would stand and sing from a shared hymnal. Then we would stay seated during the hymns. First, we would walk together down to the church altar to receive communion. Then I would steady her as she walked and help her kneel and stand. Then we would remain in our seats and communion would be brought to us.

The Rest Of Sunday

After church we went out to eat. As already mentioned, we followed a rotation of sorts among several restaurants. The routine was after we got in the car I would ask "Where do you want to go to eat?" She would respond "I don't care, as long as I don't have to cook."

We followed that pattern until she reached the point where she had difficulty handling eating utensils and felt somewhat embarrassed to eat in public. After that, we would drive to one of several places that offered carry-out food.

After the Sunday meal, it was nap time. The evening meal was almost always peanut butter and jelly sandwiches. Again, the exchange was often "What do you want to eat?" and "I don't care, as long as I don't have to cook." Although sometimes she would roll her eyes and say "What do you think I want for supper?"

Moments

Many of my favorite moments with my mother have been mentioned already. Most, but not all, involved some sort of humorous exchange between the two of us. Here are some more.

During one of my sister's visits, the local news media reported that a comet would be visible in the night-time sky. At the recommended time we trooped outside to see it. As we looked up at it, my sister noted that it would be many years before the comet made another visible pass. So, she said to our mother, "Take a good look at it now, because the next time it passes by, you'll be looking down from

heaven at it." My mother started chuckling and before she could get it out, I said it for her, "Don't be too sure about the 'looking down' part."

I came home from work one day to find a package from my ex-wife sitting on the kitchen table. It was probably for a birthday or Christmas. She almost always sent chocolates of some sort. I opened the package and put the box of candy in the refrigerator. Later, as we were finishing supper, my mother said "I think you got something in the mail today." I looked at her. She looked back at me. I asked, "Are you saying you want some candy?" She replied, "Yeah."

We flew to Arkansas to attend one of her cousin's funerals. As I drove out of the Little Rock airport, I took a wrong exit. It didn't take long to get turned around and headed in the right direction. As I was doing that, I asked her how she was doing. She looked over at me and said "I'd be doing better if you knew where you're going."

As her reactions slowed and her ability to speak became more difficult, her responses tended to become more delayed and monosyllabic. It became a routine joke that after she said "Yes," "No" or "Maybe," I would say "I've asked you three questions over the past two minutes. Which one are you answering?"

For a number of years, I played Santa Claus at a Christmas party an old friend would have for her large extended family. Dressed as Santa, I would burst in the front door with a bag full of presents for all the kids. The kids would sit on my knee and I would try to get them to say or do something funny before giving them their present. The last year I performed at the party, the woman I was dating did something unexpected. After I finished with all the kids, she guided my mother over and sat her down on my knee. Then with shouts of encouragement from the crowd and cameras snapping and flashbulbs popping, my mother kissed Santa on the nose.



Only once in those declining years did I observe her lose grasp of the present. One Sunday afternoon we went to visit one of her childhood friends in the hospital. It was a pleasant visit with lots of reminiscing and story telling. But I think the visit tired her and left her somewhat disoriented. Later that evening she asked where my father and sister were. I don't think on my feet very well and only managed to mumble some unsatisfactory response. A short while later, she again asked where my father was. I got choked up and said something to the effect that she and I were the only ones at home now. She was quiet for a moment, looked very sad and told me she understood.

My 55th birthday. She told me I was her hero.

TERESA ENGSTROM

Teresa Maxine McKenzie was born September 24, 1918 in Oklahoma. Her family moved to Texas when she was six years old.

She married Howard William Engstrom on January 7, 1940. They had two children, two grandchildren and, as this is written, three great grandchildren.

After many years of working full time to help raise and educate her children, she went back to school. She graduated with honors and became an elementary school teacher.

In October 1998, she got to see and hold her first great grandchild.

Teresa Engstrom died November 12, 1998.

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.

Report Of Gifts - June 6 - August 31, 2004

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

DIAMOND MONARCHS (\$50,000+)

Edward Faulkner In Memory of Herbert J. McCave

GOLDEN MONARCHS (\$10,000+)

Continental Products, Inc.

SILVER MONARCHS (\$5,000+)

Richard & Jody Goodman In Memory of Arthur Goldberg

Bernard & June Kasten In Memory of Herbert J. McCave

Frederick Koallick

James W. Taneyhill In Memory of Maryanna Dregier
Jay Troxel

CRYSTAL MONARCHS (\$1,000-2,499)

Edward H. Andrews Foundation

Ball Corporation In Honor of June Davis

Safwan Barakat, MD In Memory of Benjamin B. LeCompte, Jr.

Mustfa Biviji In Memory of Margaret Peggy Ryan

Alison Curran In Memory of Alice Strobbe

Ken & Susi Darwin In Memory of Arthur Goldberg

Alice O'Connor In Honor of Dr. B.H. Brown

Eleanor R. Stewart

Stuart & Suzanne Wainberg In Memory of Arthur Goldberg

Marie A. Walling & Family In Memory of Marie G. Walters

Modern Woodmen of America

GOLD PATRONS (\$500-999)

Warren Farrington, Jr. In Memory of Elizabeth Farrington

Cathryn M. Fisher In Honor of James Fisher

Richard & Reatha Godwin

Donald & Marie Gross In Honor of Marie Gross

Health Services Department of CalOptima

In Memory of Gary Munsell

Jack & Doris Hedrick

Winifred Joyce Hinze In Memory of Robert W Hinze

Mary Anne Memminger In Memory of Charles Memminger

Connie Mitchell In Honor of Fred J. Suellentrop

Mildred Molz In Memory of Jack K. Molz

Bruce & Alice Rosen In Honor of Sandra Stern

Anne S. Wilson In Memory of Marie C. Sparks

Weber Wood Medinger Corp. In Memory of Dominic Hunt

SILVER PATRONS (\$250-499)

Irene Adamiak In Memory of Harold A. Adamiak

Suzanne Anderson In Memory of JoAnn Anderson

Craig & Patricia Apregan

Evan & Linda Binder In Memory of Arthur Goldberg

Sue Blake In Memory of Arthur Goldberg

Britton-Gallagher & Associates, Inc. In Memory of Phyllis A. Posey

Antoinette Chieppa In Memory of Amelia Biondi

Becky & Dave Dangler In Memory of Betty Simmons

Ralph & Nancy Densmore In Honor of Ralph Densmore

Division of Genetics and Metabolism, and Genetic Counseling, University of Minnesota

In Memory of Ruth Hirsch

Donna Gardiner In Memory of Arthur Goldberg

Peter Hausmann In Memory of Gunnar Hausmann

Morris Hirsch In Memory of Ruth Hirsch

Illinois Tool Works Foundation

Klemtner Advertising In Memory of Herbert J. McCave

Helen Lewis In Memory of Hughie Lewis

James Lundy

Gregory & Nancy Mendel In Memory of Arthur Goldberg

Northern Illinois Medical Center/Centegra

In Memory of Benjamin B. LeCompte, Jr.

Steven Nussbaum In Memory of Arthur Goldberg

Hugh O'Brien

William J. & Phyllis M. Oetgen In Memory of Maryanna Dregier

Joan Reifler

Allan & Sharon Rimland In Memory of Arthur Goldberg

James & Grace Rivera In Memory of Robert D. Schmidt

Scarborough Funeral Centre In Honor of Norman & Barbara Wylie

Dr. Richard & Jill Scharf In Memory of Arthur Goldberg

Charlie & Lisa Seideman In Memory of Arthur Goldberg

Craig Stock In Memory of Herbert J. McCave

Robert P. Tardiff

United Way of Buffalo & Erie County

Kathleen White In Memory of Maryanna Dregier

Yale Zaideman In Honor of Sandra Stern

Marie K. Zimmerman In Memory of John G. Zimmerman

PATRONS (\$100 AND OVER)

Todd & Debbi Abrams In Memory of Arthur Goldberg

Rob & Andrea Alexander In Memory of Arthur Goldberg

Charles H. Anderson In Memory of Joan Anderson

Glenn & Angela Anderson In Memory of Eleanor McCarthy

Joanne E. Armstrong & Richard A. Janney

In Memory of B. Irvin Armstrong

Robert Arndt In Memory of Barbara Valyou

Aquarium Water Company - Supply Operations

Department In Memory of Mary T. Kaminski

Azrael, Gann & Franz, LLP In Memory of Maryanna Dregier

James B. Baker In Memory of Joseph B. Brooks

Bruce H. & Jackie A. Ball In Memory of Phyllis A. Posey

Hugh & Barbara Barnes

Alvin Benedict In Memory of Robert D. Schmidt

Shirley M. Benson In Memory of Herbert J. McCave

Jacob Benzer In Memory of Locke Purnell, Jr.

Larry Bernard & Diane Dutra In Memory of John Neto

Mimi Bernstein In Memory of Harris C. Greene

Josephine Blaszczyński In Memory of Nellie Nurski

David Blough In Memory of Bessie Blough

Noel & Pamela Bonvouloir In Memory of Raoul Bonvouloir

Barbara Brewster In Memory of Norvell (Russ) Johnson, Sr.

Bristol-Myers Squibb Pharmaceutical Research

Institute In Memory of Jack Meanwell

Frank & Pam Brocco In Memory of Richard Malugani

John and Kathrine Bryant In Memory of Gladys Martin

Howard Bolton

Buzz Oats Companies In Memory of Dalcie M. Child

Martha Casella In Honor of Sandra Stern

Eric & Carol Chandler In Memory of Gladys Martin

Carole Clancy In Memory of Jean Bonds

Janice Clements

Scott Conking In Memory of Herbert J. McCave

Nick & Angela Coso In Memory of Mary Kukich

Harold & June Creamer In Memory of Margaret E. Parker

Lori Cueva-Garcia In Memory of Dr. Luis Cueva, Sr.

Steven & Kathy Curran In Honor of Sandra Stern

Carol Jean Curtis In Memory of Robert D. Schmidt

Ken & Susi Darwin In Memory of Arthur Goldberg

Delmont & June Davis In Honor of June Davis

Charles Deacon In Memory of Joyce Deacon

Marc & Susan DeChellis In Honor of Helen Bloom

Michelle Dolan In Memory of Ruth Hirsch

Michael Donohoe In Memory of Gary Munsell

Carolyn & Greg Dorfman In Memory of Arthur Goldberg

Leo A. Dregier, II In Memory of Maryanna Dregier

Roberta & Robin Evans

Brenda Farmer In Memory of Edward Farmer

Harry Farrell In Memory of Joanne Grant

Richard Faulkner In Memory of Herbert J. McCave

Konrad & Pamela Filutowski In Memory of Joseph A. Cerni

Martin & Susan Fischer In Honor of Sandra Stern

Dawn Fitzpatrick In Memory of Lillian Locasto

Richard & Marie Foge

Foley & Lardner LLP In Memory of Gary Munsell

Joan E. Foster In Memory of William H. Foster, Jr.

William E. & Suzanne G. Foster In Memory of Robert Gregson

Barbara Fox In Memory of Harold W. Fox

Tony Fox In Honor of Sandra Stern

Josh Friedman In Memory of Rayzla Sala Miedzigorski

Leo Furcht & The Department of Laboratory

Medicine and Pathology In Memory of Ruth Hirsch

Denny Gagne In Memory of Mildred Gagne

Gary & Barbara Gettenberg In Memory of Robert Swenson

Babe & Terry Galketsis In Memory of Robert D. Schmidt

Margaret E. Gillenwater In Memory of William E. Gillenwater Jr

Lynne & Elliot Glantz In Memory of Mary Mendel

Kenneth & Vicky Goldberg In Memory of Arthur Goldberg

Ralph & Audrey Goldberg In Memory of Arthur Goldberg

Steve & Amy Goldman In Memory of Arthur Goldberg

Marian Golic In Memory of Mervin Golic

Good Shepherd Hospital Medical Staff

In Memory of Benjamin B. LeCompte, Jr.

Gary & Kay Goss In Memory of Richard Malugani

Eugene Grabinski In Honor of Rita Grabinski

Linda Hamer In Memory of Norman Hamer

Don & Ruth Hammel In Memory of Norma Evans

Annalee Hanson In Memory of Thelma Thomas

James F. Heegan In Memory of Florence Heegan

James C. & Elaine D. Hendershot In Honor of James C. Hendershot

Doryce Hills-Wells In Memory of Donald A. Wells, Sr.

Nina Hinchee In Memory of Don M. Hinchee

Daniel Hoey

Stephen & Theresa Horvath

Carolyn Houston In Memory of Dalcie M. Child

Derrick H. Lenz & Erin Hubner In Honor of Rose Weingarten

Mary Hunt In Memory of Dominic Hunt

Debbie & Allan Janoff In Memory of Arthur Goldberg

William & Margaret Jervis In Memory of Raoul Bonvouloir

Joann Johnston In Memory of Richard D. Johnston, Sr.

Robert Jones

B. Jeremy Kaufman In Honor of Sandra Stern

Donald W. Kelton In Memory of Nancy Todd Kelton

Richard Kirisitz In Memory of Dennis Wesolek

Mona Kirk

Kroger Store Card

Ferdinand & Sherine Kuckhoff In Memory of Robert Gregson

Enid & Solomon Kuperman In Memory of Ruth Hirsch

Alan & Deborah Lieberman In Memory of Ruth Stein

Report Of Gifts

PATRONS (\$100 AND OVER)

continued

Carol Ann Leibner In Honor of Sandra Stern
Maria Lescano & Joanne Lewis In Memory of Charles E. Flanigan
Maddy Licata In Honor of Jack Anderson
Jack & Louise Light In Memory of Gloria M. Cummings
Melvin & Barbara Markey In Memory of Stanley Berkowitz
William & Jeannine Marotto In Memory of Raoul Bonvouloir
Kenneth R. Marshall In Memory of Kathryn B. Marshall
John & Maria Mato In Memory of Jose Da Cunha
Kathie Mautner In Memory of Karl F. Mautner
Captain & Mrs. Michael McHugh, USN, (ret) In Memory of Dennis Wesolek
Nicholas A. & Patricia C. Meanwell In Memory of Jack Meanwell
Beth & Jeffrey Mendel In Memory of Ruth Hirsch
Gregory & Nancy Mendel In Memory of Robert & Mary Mendel
Janet Mingle In Memory of Donald C. Mingle
Regan & Lodi McClellan In Memory of Dr. James E. McClellan
Rose Anne McClellan
John McKinnon In Honor of Sandra Stern
Kenneth A. & Augusta McKusick
Brett Milgrim In Memory of Sidney & Jacqueline Milgrim
Thomas & Ekaterina Mincheff In Honor of Dr. Luke Baxley
Sharon Moore In Honor of Edna Kremer
Karen Morris
Kim E. Morris In Memory of Arthur Goldberg
John Moynihan In Memory of Harold A. Adamiak
Scott Martin & Cecelia Murphy In Memory of Gladys Martin

Richard & Melissa Nicol In Memory of Vera M. Nicol
Philip D. Oiler In Memory of Bonnie M. Oiler
Joseph & Nancy O'Sullivan
Anthony Petrarca & Linda J. Gorman In Memory of Elaine Loflin Pignataro
Arthur E. Pfalzgraff In Memory of Bernice Pfalzgraff
Pfizer Foundation In Memory of Margaret E. Parker
Nick & Robin Politan In Memory of Arthur Goldberg
Angela Price In Memory of Joyce Deacon
The Prudential Foundation Matching Gifts In Memory of Angelo Battista
Harvey Raschke
Susan Reisdorf In Memory of Irene A. Fuhrman
Tomme & Wendy Render In Honor of Ed Peitz
Marge Loyd Renner In Honor of Harry Lloyd
Thomas & Dianne Riley In Memory of Ruth Hirsch
William Riopelle In Memory of Virginia Waddell
Jill Shomer In Memory of Charles E. Flanigan
Marie F. Shuman In Memory of Anthony Falsone
Dale & Mary Souder In Memory of Catherine E. Souder
Margaret Tidball In Memory of Maurice G Tidball
Serena Tidwell In Memory of Steven Dorchak, Jr.
Debbie Turnbull In Memory of Ruth Rappaport
Harold Roberts In Memory of Olza Flynt Roberts
The Ryan & Kennedy Family In Memory of Herbert J. McCave
Frederic B. Sargent In Memory of Richard J. Swiderski
Sue Savage In Memory of Joyce Witte Wolken
Daniel & Mary Ellen Schwartz In Honor of Sandra Stern
John P. & Linda F. Sharp In Memory of Herbert J. McCave
David Sheahan
Terry Sieker & Linda Clemetson-Sieker In Memory of Henning Clemetson
Southern Neveda Water Authority Data Resources Division, Staff In Memory of Robert D. Schmidt

Clyde A. Spooner In Memory of Leslie H. Spooner
Regina Statz In Memory of Felix W. Statz
Daniel Steele In Honor of Sandra Stern
Howie & Ellen Stein In Memory of Arthur Goldberg
Lane & Nancy P. Stokes In Memory of Martha C. Christian
Jullea Stolsky In Honor of Milton Jan Schwantz
Andrew & Barbara Streifel In Memory of Ruth Hirsch
Lillian Swenson In Memory of Robert Swenson
Kathy Thomas In Memory of Mary Ellen Bryan
Daniel Tuchman In Memory of Sol Tuchman
Patrick Tully
Georgena Underhill In Memory of Robert Smidth
Unit 1 - 5 St. Josephs Hosp. In Memory of Raoul Bonvouloir
United Way of Central Maryland
United Way of New York City
Alfred Valyou In Memory of Barbara Valyou
Denise VanZago In Memory of Emile Jabra Marshi
Paul & Mary Virtue
David Wade In Memory of Margie Thompson Wade
Daniel K. Waterman In Memory of Harry R. Miller, Jr.
Edwin, Rachel & Cindi Watts In Honor of Edwin Watts
Larry Weiner & Dr. Nancia Marika Shawver In Memory of Ruth Hirsch
Lauren & Stephen Weiss In Memory of Arthur Goldberg
Frank Jr. & Judy Wells
Wisdom Lane Middle School In Memory of John Lipani, Sr.
Phyllis & Dennis Wesolek In Memory of Dennis Wesolek
Bruce & Karen Wiener In Memory of Arthur Goldberg

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
1 (800) 457-4777 or 1 (410) 486-3330
FAX: 1 (410) 486-4283 • email: SPSP@psp.org

Or • Ann Wilson, Regional Investment Manager,
Provident Bank of Maryland, Pikesville Office,
3635 Old Court Road, Baltimore, MD 21208
410-277-7815 or 410-274-1244
FAX: 410-602-0932.

A transfer can be easily made electronically.
DTC Number 0443 • Account Number 5LV052345
Account for the Society for Supranuclear Palsy, Inc.
It is the policy of the Society that stocks are sold as soon as they are received in our account.

The Society for PSP, Woodholme Medical Building, Suite 515, 1838 Greene Tree Road, Baltimore, MD 21208
1 (800) 457-4777 • 1 (410) 486-3330 • In Canada (866) 457-4777

PLEASE MAKE ALL CHECKS/GIFTS TO "THE SOCIETY FOR PSP."

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 Planned Giving Information
- #18 Information About PSP translated in Spanish
- #19 I Have Been Diagnosed with PSP
- #20 Challenges in the Management of PSP
- #21 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.
- My new address is: _____

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

Name _____
Address _____
City _____ State _____ Zip _____ Country _____
Fax _____ Email _____

Person w/PSP Family Physician Other _____
.....

Enclosed, please find my gift to help support The Society for PSP and those impacted by PSP.

\$25 \$50 \$100 \$250 \$500 \$500-\$1000

Name _____

Address _____

Phone/Fax/email _____

Check/Charge to: Visa Mastercard American Express

Card number _____ Expiration Date _____ Signature _____

Thank you for your TAX-DEDUCTIBLE gift. A copy of financial statement available upon request.

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:

- | | | |
|---|---|---|
| <input type="checkbox"/> Budget/Fiscal | <input type="checkbox"/> Fundraising: | <input type="checkbox"/> Board of Directors |
| <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) _____ |

THE SOCIETY FOR
PSP
Progressive Supranuclear Palsy

Woodholme
Medical Building
Suite 515
1838 Greene Tree Rd.
Baltimore, MD 21208

2000-2010
The Decade of Hope

Address Service Requested

NON-PROFIT ORG.
U.S. POSTAGE
PAID
HAMPTON, VA
PERMIT NO. 799