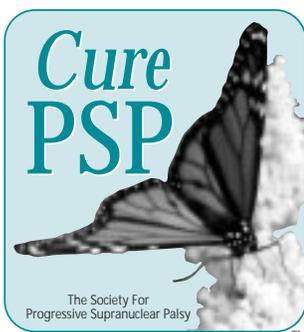


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INSIDE:

**SPECIAL PSP
MEDIA COVERAGE
HOUSTON
CHRONICLE
"SOMEONE TO
LEAN ON"**



"Whenever progressive supranuclear palsy (PSP) is widely publicized, many people enduring their suffering in silence with nowhere to turn are reached."

PSP MUST RECEIVE MORE MEDIA COVERAGE

You can help!

Once the relief of finally finding a name for this disease has passed and the reality of what lies ahead has set in, PSP families face the isolation of dealing with a relatively unknown disease that few have heard of—including many doctors. Day-to-day management of the difficulties caused by PSP can become extremely overwhelming, leaving little time for anything else. But, there is a way that PSP families can help other PSP families feel less isolated and, at the same time, educate the public about progressive supranuclear palsy and the Society for PSP.

Contact the media.

Whether you are trying to start a support group or raise awareness, media coverage is the only ticket that will give you access to vast numbers of people otherwise out of reach. Everyone watches TV, listens to the radio or reads the newspaper.

What will make the media want to cover you or your event? It's all in the marketing. Media outlets are always looking for content. Local outlets are always looking for local stories. The media will cover just about any event if there's a good hook to it. Hooks are the things that attract the media to cover a story. We have two hooks approaching: October is PSP Awareness Month and November is National Caregiver's Month. News media look for other interesting hooks, such as a odd or colorful occasion, a timely event, or certain people with special stories—and all of our PSP families have special stories.

Here are some examples of the past media coverage for progressive supranuclear palsy and the Society. On June 8, 2003, the Houston Chronicle (with a circulation of 65,000) ran a piece profiling the lives of Molly and Joe Dean and their struggles living with PSP. In the weeks



following the publication of that article, Karen Kennemer, Houston support group leader, was contacted by 19 families in the Houston area who were unaware of the Houston group or the Society for PSP (see Houston Article, page 19. Clifton Gunderson's magazine *Relationships*, Issue 10, 2003, featured an article about former

Society Board of Director's Chairperson, George Jankiewicz, and the contributions he and his firm have made in updating technology for the Society. Information about progressive supranuclear palsy, as well as the Society, was included, leading to numerous calls and contacts to the Society office. Dr. Paul Donohue, nationally syndicated health columnist, has featured PSP in his column on two occasions. The Society for PSP received nearly 500 calls on its toll-free number during each week of its publication. All callers were sent free information. And of course, the single biggest wave of coverage for PSP was when Dudley Moore went public with his diagnosis in 1999, deluging the Society office with inquiries.

But how do you go about it?

What do you do to get your story told?

There are some simple steps to follow to get your local media to tell your PSP story.

Whether for TV, radio or newspaper, it is good to approach outlets with materials for them to review. Write a short bio on the person to be profiled. This can be just a couple of paragraphs highlighting life and career. State when symptoms of PSP first appeared and how the person has progressed to the present. Gather a few photos from both before and after onset of PSP. If you intend to approach TV stations, home video of the patient before PSP will be helpful.

Continued Page 16

The Society for Progressive Supranuclear Palsy

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The Society for Progressive Supranuclear Palsy, Inc. is a nonprofit 501 (C) (3) organization.

Our Vision: We envision a world free of PSP

Our Mission: The Society for PSP is dedicated to advancing research, giving support and hope for families coping with PSP.

PSP is a fatal degenerative brain disorder that has no known cause, treatment or cure.

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Director's Doings

I wish to thank my Society friends for their heartfelt outpourings of compassion and sorrow over the passing of my husband, Albert. As I continue my life journey since my husband's death, I have encountered many challenges that have tested my strength. Family dynamics are not the same—children need support, friends rally and fade away, finances are different, and handling daily activities without a mate to share is an adjustment that I am making.

If I can only pass on to PSP families one thing from this experience, it is to "PLAN" and keep your financial affairs in order. Fortunately, we had done our estate planning 10 years ago and had the plans reviewed before Albert received his stem cell transplant. When the time came to handle legal affairs, everything was in order.

This means seeing a financial planner and a tax or estate attorney who can put your affairs in order. Also, it is important to know how to access the financial resources, public and private, to assist with your journey with PSP. Hopefully, there will be expansion of prescription services and long-term care to assist with the ever-increasing number of PSP cases.

While most people are challenged by the pain of PSP, they have the foresight in their estate planning, to remember the Society by making a planned gift. One doesn't need to be wealthy to make a gift through a will or some other planning tool. Often, funds not available during a person's life become available when a loved one passes.

The Society is in need of funds for research. Please consider a planned gift to establish a research fund in tribute to a loved one. I know that my husband, Albert, will live on through the volunteer work and the financial contributions he made to the causes he cared deeply about. So many people have benefitted from his thoughtful contributions and remember him as a generous, kind and caring person.

You can do this, too—your gifts do make a difference.

Warm wishes for a year of health and peace.



Ellen Pam Katz
Executive Director



A Special Thanks

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

President's Corner

"People are persuaded by reason, but moved by emotion; (the leader) must both persuade them and move them." Richard M. Nixon

As the Board President, you entrust me with the leadership of the organization, which requires me to lead by example through being socially, morally, fiducially responsible to the organization in helping to fulfill the organization's mission. Among the top three areas I am focused on is overseeing the financial management of the organization, to be an advocate for all impacted by PSP and to do my utmost to ensure that the cause and cure for PSP are soon discovered. As Board members, we are focused on raising money, one of the top priorities of the Society. Recently, my employer recognized me for the MetLife Volunteer Service Award. This award recognizes associates of the company who provide help and hope to those who need it most and demonstrate the company's culture for caring. I was one among 20 associates who received this grant from the MetLife Foundation. I was, of course, honored and extremely pleased to present a check in the amount of \$2500 to Ellen Katz, Executive Director, who accepted on behalf of the Society.

I recognize that we are all at different stages in our lives and that it is not always possible to contribute money even though you would like to. One suggestion I would like to make, that only requires your time, is exploring an opportunity through family and friends for similar volunteer grant programs at their place of employment. Most applications require financial information about the organization, so please don't hesitate to contact the Society's office so that they can help you obtain the appropriate information at 1-800-457-4777.

With the unveiling of the Strategic Plan in early December, many of the initiatives we have planned will require more funding. For example, there will be an emphasis on Public Relations and Advocacy. These are new priorities that are being added to the Strategic Plan and an area that has not had a lot of attention at this point. We are a growing organization and need to align ourselves for growth in the next three years. As a result, we recognize the need to have an advocate for us in Washington and collaborate with the NIH and NORD organizations. Additionally, through written communication, media, etc., our message needs to be heard. Each of us has the power to make a difference.

Sincerely,
Elizabeth Brisson
President



Funded Grants from the October 2002 Cycle

Matt Farrer, PhD (Mayo Jacksonville) will refine our understanding of the H1 haplotype, the only genetic marker of PSP to date. The hypothesis to be tested is that there is subtype of the H1 haplotype (a haplotype is a string of easily-detectable but innocent genetic variants along the same chromosome that delineate the approximate location of an elusive, disease-causing variant) this is particularly strongly associated with PSP. **Funded by the Eloise H. Troxel Memorial Research Fund.**

Etienne Hirsch, PhD (INSERM) and Hospital de la Salpetriere, Paris) will infuse rats with annonacin, a prime suspect for the toxin in sweetsop and soursop that may be causing the Guadeloupean PSP-like illness. He will study the accumulation, aggregation and phosphorylation of tau in order to develop an animal model of PSP and to understand how annonacin toxicity kills neurons. **Funded by the Eloise H. Troxel Memorial Research Fund.**

Shu-Hui Yen, PhD (Mayo Jacksonville) will study brain cells that have had a gene for abnormal tau inserted. He will study the details of tau protein in those cells, particularly with regard to activation of kinases (enzymes that attach phosphates to proteins) and the abnormal production of other non-tau proteins. If drugs that interfere with tau aggregation directly prove difficult to find, it may be much easier to find drugs that interfere with the action of other proteins necessary to the aggregation and toxic action of abnormal tau. **Funded by the Dudley Moore Research Fund.**

Ronald L. Klein, PhD (LSU School of Medicine) will study a new rat model of tauopathy, especially with regard to the participation of parkin and the rest of the ubiquitin-proteasome systems, which is the normal brain cell's mechanism for disposing of defective or worn-out proteins. **Funded by the General Research Fund.**

Alison Goate Dphil (Washington University School of Medicine, St. Louis) with coinvestigator Eduardo Tolosa, MD (Hospital Clinic, Barcelona, Spain) will attempt to reach the same goal as the Farrer project but using a different approach. They will seek a specific tau mutation in PSP by laboriously sequencing portions of the tau gene from patients with PSP and CBD and analyzing any variants they detect by comparing its frequency between patients and control individuals. **Funded by the General Research Fund.**

Funded Grants from the April 2003 Cycle

Lap Ho, PhD (Mt Sinai School of Medicine) with Hanna Ksiezak-Reding, PhD and Giulio Maria Pasinetti, MD, PhD, co-investigators, are studying candidates for biomarker proteins in cerebrospinal fluid (CSF) and brain tissue from patients with PSP. This would help make the diagnosis of PSP more accurate and sensitive. **Funded by the General Research Fund.**

Maria Grazia Spillantini, PhD (University of Cambridge, UK) is studying the tau transgenic mouse with regard to the time course of events leading from the expression of mutant tau protein to the formation of tau filaments and neuron loss. This may answer the question of whether the tau filaments themselves actually cause the neuron loss and could identify targets for drug treatment. **Funded by the Eloise H. Troxel Memorial Research Fund.**

Sarah J. Augood, PhD (Harvard Medical School) is using messenger RNA profiling to identify genes involved in the neuron loss of PSP that have not previously been suspected. This technique uses a "gene chip" that permits rapid identification of hundreds of types of messenger RNA, each representing a different gene, in a single sample of homogenized brain tissue. This could allow identification of new targets for drugs. **Funded by the General Research Fund.**

Jianhua Zhou, PhD (University of Massachusetts) is attempting to create a way of controlling whether brain cells growing in the laboratory express exon 10 of the tau gene. (The protein fragment arising from exon 10, a part of the tau gene, is always included in the tau protein in brain cells in patients with PSP, but in only half of the tau produced by healthy brain cells.) Using this model system could provide new ideas into how to normalize the abnormal expression of exon 10 in PSP and could permit testing of treatments designed to return exon 10 expression to a normal state. **Funded by the Erwin and Pearl Poizzner Memorial Research Fund.**

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Making Friends In The Windy City



With the dog days of summer in full swing, Society Executive Director, Ellen Katz, and Director of Outreach & Education, Jessica Quintilian, visited the beautiful city of Chicago, Illinois to host "An Afternoon of Caring & Sharing" at the Marriott Hotel in Oak Brook on July 13, 2003. This event marked a page in the Society's history, as we had the largest attendance ever at a Caring & Sharing! Over 120 individuals representing the states of Illinois, Indiana, Wisconsin, Ohio, Minnesota and Michigan gathered in the Windy City to learn more about PSP and meet other families. A special guest was honored when the Society presented a plaque to Lois Zoller dedicating the office of the Director of Outreach and Education in loving memory of Lois' mother, Ruth Swartzberg (see page 6 for PSP Story).



Ellen Katz presenting the plaque to Lois Zoller



Dr. Michael Rezak

Each of our three professional speakers was extremely well-received. Dr. Michael Rezak, Director of the Movement Disorders Functional Neurosurgical Program and the Movement Disorders Center at Glenbrook and Evanston Hospitals, presented "Challenges of PSP." His lecture included early signs and symptoms of PSP, criteria for diagnosis, therapeutic options, including medications, and the greatest challenges in PSP from a doctor's perspective. Dr. Rezak also stressed the importance of caring for the

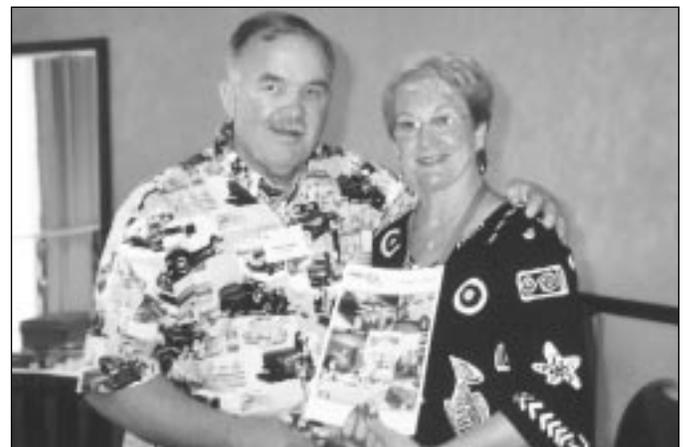
caregiver's mind, body and spirit—a point often overlooked when time is tight and resources are stretched.

The day's program included a presentation by Executive Director, Ellen Katz, who overviewed the Society, its operations, revenue, donations and research grants program. Ellen shared the Society's new vision and mission statements, "We envision a world free of PSP; The Society for PSP is dedicated to advancing research, giving support and hope for families coping with PSP."

Dr. Nancy Muma, Professor of Pharmacology at Loyola University Medical Center and Principal Investigator on two Society research grants, wrapped up the day by clearly explaining current PSP research. Dr. Muma's presentation focused on mutations in tau protein, genetic models of PSP, oxidative damage, mitochondrial impairment and mutation in parkin. Overall, families felt that the conference was very informative and helped them to better understand the disease.

Special thanks goes to all of our speakers and to Marie Carberry and Anne Bonadeo for providing excellent service throughout the day. Thanks to Douglas and Barbara Bloom

Continued Page 17



Pat and Jimmy Downs from Lawton, Michigan

Outreach

“We Have To Do Something”

Lois Zoller nostalgically remembers her mother’s mantra, “We have to do something.” Lois said, “Ruth Swartzberg cared deeply for other people and taught me and my brother the value of generously giving time and financial resources to many charitable causes.”

“My mother was born Ruth Corrine Herzfeld on the west of Chicago in 1911. She died of PSP after a grueling 8-year battle in 1999. Her life, alongside my father, Irvin Swartzberg was dedicated to her children and to her community.”



Through the success of the family business, ReaLemon, the Swartzberg family supported and were involved in many non-profit Chicago institutions including the Jewish Federation, Michael Reese Hospital, The Jewish Children’s Bureau and the Gastrointestinal Research Foundation at the University of Chicago. Through the support of Swartzberg House at the Council for Jewish Elderly (CJE), Lois’s parents created important services for the elderly.

In a recent conversation with Ellen Katz, Director of the Society, Lois Zoller remembers how she first became aware of the Society for PSP nearly 2 years after her mother was diagnosed. “The support group was too far away even though I needed it desperately. I was alone in this—no one had heard of it and I didn’t know where to turn.” She first met other Society members in 2000 when Board member, Janice Clements and support group leader Bea Irminger visited her.

“They comforted me and discussed the needs of the Society to fund research and to assist the families with information and support.” Lois and her brother, Allan Swartzberg of Sante Fe, New Mexico, initially decided to make a gift of \$50,000 in 2000 to the Society for research but Ellen Katz, Executive Director, suggested to Lois that their gift could be more effectively utilized to establish a position for a “Director of Outreach and Education.” The position was a critically needed professional position to enlarge and nurture the budding efforts performed piecemeal by part-time Society staff and volunteers. “We needed a full time position to meet the growing and compelling needs of our families throughout the country” Katz explained. Lois and Allan agreed and within 6 months, Jessica Quintilian was engaged as the Society’s first Director of Outreach and Education.

At the recent Chicago symposium attended by 120 PSP families, Lois saw the impact of her gift. With the event organized and presented by the expertise of Jessica, families met others coping with PSP, learned the latest in PSP research and care and are now forming several new support groups.

Lois expressed, “This is just what my mother would have wanted. The gift reached many people and assuaged their feelings of isolation and despair. We are very happy and satisfied that our gift has made a difference.”

In honor of Lois Zoller and Allan Swartzberg’s gift from the Swartzberg Family Philanthropic Fund, the Society has dedicated the Office of the Director of Outreach and Education in Ruth’s memory.

“Ruth’s resilience, strength, wisdom and love is reflected in the Society’s work for families. She would be very proud to be remembered that way.”

See Outreach pages 5 & 17 for more information about the gift honoring Lois Zoller.

SIXTH NATIONAL BIENNIAL PSP SYMPOSIUM VIDEOTAPE ORDER FORM

The Sixth Biennial PSP Symposium May 17-18, 2002 Baltimore, MD Video Tapes-3 pack \$75 plus \$7 shipping in US and \$10 outside the US

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Ask the Doctor

Question:

What are the common early symptoms of PSP?

Answer:

The most common first symptom, occurring, on average, in the 60s, is loss of balance while walking. This may take the form of unexplained falls or of a stiffness and awkwardness in the walk that can resemble Parkinson's disease. Sometimes the falls are described by the person experiencing them as attacks of "dizziness." This often prompts the doctor to suspect an inner ear problem or hardening of the arteries supplying the brain.

Other common early symptoms are forgetfulness and changes in personality. The latter can take the form of a loss of interest in ordinary pleasurable activities or increased irritability and cantankerousness. These mental changes are misinterpreted as depression or even as senility. Less common early symptoms are trouble with eyesight, slurring of speech, and mild shaking of the hands. Difficulty driving a car, with several accidents or near misses, is common early in the course of PSP. The exact reason for this problem is not clear.

Question:

What happens next?

Answer:

The term "progressive" was included in the name of the disease because, unfortunately, the early symptoms get worse and new symptoms develop sooner or later. After 7 to 9 years, on average, the imbalance and stiffness worsen to make walking very difficult or impossible. If trouble with eyesight was not present early on, it eventually develops in almost all cases and can sometimes be as disabling as the movement difficulty. Difficulty with speech and swallowing are additional important features of PSP that occur eventually in most patients.

Question:

What does the name "supranuclear palsy" mean?

Answer:

In general, a "palsy" is a weakness or paralysis of a part of the body. The term "supranuclear" refers to the nature of the eye problem in PSP. Although some patients with PSP describe their symptom as "blurring," the actual problem is an inability to aim the eyes properly because of weakness or paralysis (palsy) of the muscles that move the eyeballs. These muscles are controlled by nerve cells residing in clusters or "nuclei" (NUKE-lee-eye) near the base of the brain, in the brainstem. Most other brain problems that affect the eye movements



Lawrence I. Golbe, MD

originate in those nuclei, but in PSP the problem lies in parts of the brain that control those eye-movement nuclei themselves. These "higher" control areas are what the prefix "supra" in "supranuclear" refers to.

Sometimes complicated disease names are avoided by the use of the name of the physician who discovered the disease. However, for PSP, there were three such physicians and the string of names—Steele, Richardson, and Olszewski (ol-SHEF-skee)—is even less convenient than the descriptive name. It is only rarely used in the U.S., but in Great Britain it is the more commonly used term. Continental Europe and the rest of the world seem to use "PSP" and "SRO" equally frequently.

Incidentally, although Drs. Richardson and Olszewski are deceased, Dr. John C. Steele, who was a neurology resident (i.e., a trainee) when he collaborated in the original description of PSP, still does neurological research and serves as Honorary Chairman of the Society for PSP.

Question:

Is the visual problem the most important part of PSP?

Answer:

In most cases the visual problem is at least as important as the walking difficulty, though it does not appear, on average, until 3 to 5 years after the walking problem. Because the main difficulty with the eyes is in aiming them properly, reading often becomes difficult. The patient finds it hard to shift down to the beginning of the next line automatically after reaching the end of the first line. This is very different from just needing reading glasses. An eye doctor unfamiliar with PSP may be baffled by the patient's complaint of being unable to read a newspaper despite normal ability to read the individual letters on an eye chart. Some patients have their mild cataracts extracted in a vain effort to relieve such a visual problem.

Another common visual problem is an inability to maintain eye contact during conversation. This can give the mistaken impression that the patient is senile, hostile, or uninterested. The same eye movement problem can create the symptom of "tunnel vision" and can interfere with driving a car.

The most common eye movement problem in PSP is an impaired ability to move the eyes up or down. This can interfere with eating or with descending a flight of stairs, among other things. This problem is not usually as vexing for the patient and family as the inability to maintain eye contact or to coordinate eye movements while reading, but is much easier for the doctor to detect. This reduction in vertical eye movement is usually the first clue to the doctor that the diagnosis is PSP. Other conditions, particularly Parkinson's disease and normal aging, can sometimes cause difficulty moving the eyes up. However, PSP is nearly unique in also causing problems moving the eyes down.

Yet another eye problem in PSP can be abnormal eyelid movement—either too much or too little. A few patients experience forceful involuntary closing of the eyes for a few seconds or minutes at a time, called "blepharospasm." Others



Education

have difficulty opening the eyes, even though the lids seem to be relaxed, and will try to use the muscles of the forehead, or even the fingers, in an effort to open the eyelids ("apraxia of lid opening"). About 20 percent of patients with PSP eventually develop one of these problems. Others, on the contrary, have trouble closing the eyes and blink very little. While about 15 to 25 blinks per minute is normal, people with PSP blink, on average, only about 3 or 4 times per minute. This can allow the eyes to become irritated. They often react by producing extra tears, which can itself become annoying.

Question:

What about the speech problems?

Answer:

The same general area of the brain that controls eye movement also controls movements of the mouth, tongue, and throat, and these movements also weaken in PSP. Speech becomes slurred in most patients after 3 or 4 years, on average, although it is the first symptom in a few patients. In Parkinson's disease, the speech problem is characterized by soft volume and rapid succession of words. In PSP, however, the speech may have an irregular, explosive quality (called "spastic" speech) or a drunken quality ("ataxic" speech) or may have the features of speech in Parkinson's disease. Most commonly, there is a combination of at least 2 of these 3 features in the speech of PSP.

An erroneous impression of senility in PSP can be created by the combination of the speech difficulty, the slight forgetfulness, the slow (albeit accurate) mental responses, the personality change and the poor eye contact during conversation.

Question:

What about the swallowing problems?

Answer:

Swallowing tough foods or thin liquids can become difficult because of throat muscle weakness or incoordination. This tends to occur later than the walking, visual, and speech problems, but can become very troublesome if the patient tends to choke on food. Unlike the other difficulties in PSP, this one can sometimes pose a danger for the patient—the danger of food going down the wrong pipe into the breathing passages, termed "aspiration." Usually, difficulty managing thin liquids precedes difficulty with solid food. This is because in PSP, the swallowing muscles have difficulty creating a watertight seal separating the path to the stomach from the path to the lungs. The same is true for the swallowing difficulty of many neurological diseases. For non-neurologic conditions such as stricture of the esophagus, however, difficulties start with solid foods.

Repeated, minor, often unnoticed episodes of small amounts of food and drink dripping into the lungs can cause pneumonia. Often, it is not apparent to the physician or family that the PSP patient's pneumonia is in fact the result of subtle aspiration. But "aspiration pneumonia," in fact, is the most common cause of death in PSP.

Hey doc, what does that mean?

General Neurological & Medical Terms (Part I)

ACETYLCHOLINE - a chemical in the brain that acts as a neurotransmitter/chemical messenger.

ACTIVITIES OF DAILY LIVING (ADLS) - personal care activities necessary for everyday living, such as eating, bathing, grooming, dressing, and toileting; a term often used by healthcare professionals to assess the need and/or type of care a person may require.

ADAPTIVE/ASSISTIVE EQUIPMENT - special device which assists in the performance of self-care, work or play/leisure activities or physical exercise.

ADVANCE DIRECTIVES - documents (such as a Living Will) completed and signed by a person who is legally competent to explain his or her wishes for medical care should he or she become unable to make those decisions at a later time

AGITATION - a non-specific symptom of one or more physical, or psychological processes in which motor or vocal behavior (screaming, shouting, complaining, moaning, cursing, pacing, fidgeting, wandering) pose a risk or discomfort, become disruptive or unsafe, or interfere with the delivery of care in a particular environment.

AGONIST - a drug that increases neurotransmitter activity by stimulating the dopamine receptors directly.

AKINESIA - no movement.

ALZHEIMER'S DISEASE - a form of degenerative brain disease resulting in progressive mental deterioration with disorientation, memory disturbance, and confusion and leading to progressive dementia often accompanied by dysphasia and/or dyspraxia. The condition may also give rise ultimately to spastic weakness and paralysis of the limbs, epilepsy, and other variable neurological signs.

AMANTADINE - an antiparkinson medication; it may be used early in the disease or added to levodopa.

ANTIDEPRESSANT - medication used to treat depression.

ANTIOXIDANT - a chemical compound or substance that inhibits oxidation.

APHASIA - loss of the ability to express oneself and/or to understand language. Caused by damage to brain cells rather than deficits in speech or hearing organs.

APNEA - temporary stop in breathing.

ASPIRATION - when fluid or food enters the lungs through the wind pipe. Can cause a lung infection or pneumonia.

ATAXIA - loss of balance.

ATROPHY - the progressive loss of muscle mass, or wasting, caused by a reduction in the size or number of muscle cells through prolonged disease.

ATYPICAL PARKINSONISMS - disorders related to Parkinson's disease in that they are characterized by bradykinesia, sometimes rigidity tremor, and balance problems, but have other clinical features and other pathology.

AUGMENTATIVE AND ALTERNATIVE COMMUNICATION - use of forms of communication other than speaking, such as sign

Education

language, “no/yes” signals, gestures, picture board, and computerized speech systems to compensate (either temporarily or permanently) for severe expressive communication disorders.

AUTONOMIC NERVOUS SYSTEM - a part of the nervous system responsible for control of bodily functions that are not consciously directed; for example, heart rate, blood pressure, sweating, intestinal movements, temperature control.

AXON - the usually long process of a nerve fiber that generally conducts impulses away from the body of the nerve cell.

BASAL GANGLIA - the interconnected cluster of nerve cells that coordinate normal movement, made up in part by the substantia nigra, striatum, and globus pallidus.

BLEPHAROSPASM - forced closure of the eyelids.

BLINK RATE - the number of times per minute that the eyelid automatically closes – normally 10 to 30 per minute.

BRADYKINESIA - slowness of movement.

BRADYPHRENIA - slowness of thought processes.

BROMOCRIPTINE - a dopamine (the primary chemical messenger of the basal ganglia) receptor agonist.

BULBAR - of, relating to, or characteristic of the medulla oblongata.

BULBAR MUSCLES - the muscles that control the speech, chewing and swallowing.

CT OR CAT SCAN - Computerized Axial Tomography. An X-ray device linked to a computer that produces an image of a pre-determined cross-section of the brain. A special dye material may be injected into the patient's vein prior to the scan to help make any abnormal tissue more evident.

CASE MANAGEMENT - facilitating the access of a patient to appropriate medical, rehabilitation and support programs, and coordination of the delivery of services. This role may involve liaison with various professionals and agencies, advocacy on behalf of the patient, and arranging for purchase of services where no appropriate programs are available.

CATHETER - a flexible tube for withdrawing fluids from, or introducing fluids into, a cavity of the body. Frequently used to drain the urinary bladder.

CENTRAL NERVOUS SYSTEM - the brain and spinal cord.

CHRONIC - marked by long duration or frequent recurrence.

COGNITIVE FUNCTION - the ability to think, to remember, to plan, and to organize information.

CONDOM CATHETER - a soft latex, self-adhesive male external (non-invasive) catheter that is connected to a urinary leg or overnight drainage bag.

CONSTIPATION - diminished ability of intestinal muscles to move feces (stool), often resulting in very hard stool.

DEMENTIA - a progressive decline in mental functions.

DENDRITE - extensions from the neuron cell body that take information to the cell body.

DIETICIAN - an individual trained in diet and nutrition.

DME - durable medical equipment. Medical supplies that are durable, not disposable. Insurance companies use this term often. Examples of DME include walkers, wheelchairs.

DOPAMINE - a neurotransmitter found in many areas of the brain and is important for movement and other behavior.

DYSARTHRIA - difficulty in forming words or speaking them because of weakness of the muscles used in speaking or because of disruption in the neuromotor stimulus patterns required for accuracy and speed of speech.

DYSPHAGIA - a swallowing disorder that is characterized by difficulty in oral preparation for the swallow or moving material from the mouth to the stomach. This also includes problems in positioning food in the mouth.

DYSPHASIA - language disorder; the inability to speak words which one has in mind or to think of correct words; or inability to understand spoken or written words.

EEG - Electroencephalogram. A procedure that uses electrodes on the scalp to record electrical activity of the brain. Used for detection of epilepsy, coma, and brain death.

EDEMA - collection of fluid in the tissue causing swelling.

EMOTIONAL LABILITY - exhibiting rapid and drastic changes in emotional state (laughing, crying, anger) inappropriately without apparent reason.

EPIDEMIOLOGY - the study of the distribution of disease and its impact upon a population, using such measures as incidence, prevalence, or mortality.

ETIOLOGY - the study of the cause of a disease.

EXTENDED CARE FACILITY-(BASIC) - a residential facility which supplies 24-hour nursing care and supervision and assistance with activities of daily life.

EXTENDED CARE FACILITY-(SKILLED) - a residential facility for the patient who requires 24-hour nursing care (IV, special feeding tubes, intramuscular injections, skin care, oxygen) rehabilitative services such as physical therapy, occupational therapy, or speech therapy on a less intensive basis than as an inpatient in a comprehensive rehabilitation center.

EXTENDED NURSING HOME HEALTH CARE - LPN's and RN's that are scheduled for extended hours to come into your home to take care of patient who requires skilled nursing care, as directed by a physician.

FDA - U.S. Food and Drug Administration, the branch of federal government that approves new drugs.

FAMILIAL - occurring in clusters of families in which a large number of individuals are affected.

FLACCID - lacking normal muscle tone; limp.

FLEXION - a bent, curved posture.

FREE RADICALS - unstable molecules that transport oxygen.

GAIT - pattern of walking, the manner in which a person walks.

GASTROSTOMY - the introduction of a feeding tube directly into the stomach through a small opening, for persons who have difficulty chewing, or are unable to chew or swallow.

GENE - unit of inheritance, a piece of the genetic material that determines the inheritance of a particular characteristic or group of characteristics. Genes are carried by chromosomes in the cell nucleus and are arranged in a line along each chromosome.

A Wheelchair Can Be A Wonderful Liberator

WHEN IS IT TIME TO GET A WHEELCHAIR?

It is time to get a wheelchair when you are in danger of falling and being injured and you are no longer going out on routine outings. When you get a wheelchair, it does not mean that you must use it all the time; use it for distance mobility.

Many people believe that using a wheelchair takes away from one's independence. Using this type of assistive equipment can actually be quite the opposite; it can increase one's independence. Visit an OT, PT or rehab specialist to be evaluated for the proper fitting of a wheelchair and appropriate accessories. You will be measured and weighed to determine seat depth, width height, back height and wheel placement. Get your wheelchair from a medical equipment supplier that is certified with the National Rehab Tech Supplier.

CARING FOR A PERSON IN A WHEELCHAIR

It is often the case that "walking people" literally "down-talk" to people sitting in a wheelchair. Try to be more aware of your body language. Kneel or stoop down to meet the person's eye level when talking to them.

Also try to be more aware of the needs of wheelchair riders, especially if they cannot propel themselves and /or if they have language problems, sensory impairment (lack of sight, hearing and feeling), or memory problems or if they are unable to mentally understand instructions.

Check the position of the person in the wheelchair to prevent pressure sores and injuries. The person should sit in the most neutral position as possible. Ensure that both feet are placed properly on the foot plates. Make sure that the fingers cannot be caught in the wheels (place the hands into the lap or use a table top for those persons who have no control over their upper limbs).

Ask the person in the wheelchair whether he/she is comfortable.

HOW TO USE A WHEELCHAIR

Unfold wheelchair: Most wheelchairs are unfolded by pushing down and out on the side edges of the seat, keeping the fingers inwards (never put your fingers between the frame and the seat; you could injure yourself then).

Fold wheelchair: Turn the footplates upright (and if detachable model, rotate or remove footplate). Then pull the seat upward or use the grab handles. Before using wheelchair, always make sure that the chair is in a good working condition (that the brakes are OK and the tires are firm etc.). Before transferring someone into the chair, make sure that the brakes are locked and lift up or swing away the footrests to prevent the person falling over the footplates. If you have a detachable model, take out the armrest nearest to the person to have an easier transfer.

Encourage the person to sit back into the chair or assist him/her in that. Check that the person sits in the most neutral position as possible and that his/her fingers cannot be caught in the wheels. While approaching a narrow doorway also ensure that the person's elbows are inside the wheelchair to prevent them from knocking the door frame.

GOING UP AND DOWN CURBS

Place the wheelchair at a right angle facing the curb. Stand behind the wheelchair while holding onto the push handles. Step onto the tilting bar at the rear of the wheelchair and tilt the wheelchair carefully backward (towards you). Lift the front casters onto the curb and push the chair forward on its back wheels until they touch the curb. Then gently lower the chair down until the front casters touch the floor and lift the back wheels onto the curb. To go down a curb, just do the opposite—stand with the back of the wheelchair at a right angle to the curb. Step down, and again tilt the wheelchair by stepping onto the tilting bar. Wheel the chair backward down (on its back wheels), and again gently lower the chair until its front casters touch the floor.



UP



DOWN

GOING UP STAIRS

Two persons are required for safety. The chair should always face the bottom of the stairs when going up or down. When going up, place the wheelchair backwards at a right angle to the stairs. Tilt the chair by stepping onto the tilting bar. The person holding onto the push handles is the leading person. The second person holds onto the wheelchair frame (DO NOT HOLD ONTO ANY DETACHABLE PARTS). The leading person gives the command. Now, step-by-step the leading person pulls the chair up and the second person pushes the chair up and prevents any unwanted downward movements.



Education

GOING DOWN STAIRS

Place the wheelchair front at a right angle to the stairs. Now the lead person is the one going down first (the person holding onto the wheelchair frame) and the person at the push handles moves forward with a pulling action to prevent the chair from "running" down. Here again, tilt the chair and move forward and step-by-step go down.



GUIDELINES FOR TWO-ASSISTANT TRANSFER FROM BED TO CHAIR

1. Get the person ready; change clothes if required.
2. Get the wheelchair ready. Place the wheelchair nearby, remove one armrest (the side nearer the bed), and swing away both footrests.
3. Get the person to sit at the edge of the bed. Roll onto the side, lower the feet off the edge of the bed and encourage him/her to get into a seated position by pushing up with his/her hands.
4. One assistant steadies the person while the other assistant positions the wheelchair by the side of the bed and applies the brakes to lock the wheelchair.
5. Get yourselves ready:
Assistant (A) is in front of the person. Position one foot between the person's feet (which are flat on the floor with both heels touching the floor); place the other foot in the direction of movement and place both hands firmly on the person's upper back.
Assistant (B) is in between the wheelchair and the person, with one knee kneeling on the bed, the other leg in the direction of movement and the hands supporting the person's buttock.
6. Get ready for the 'move':
Alert the person that you are ready to 'move'. One assistant gives the command for a coordinated move. Assistant (A) shifts his/her body weight in a backward rocking motion to lift the person's weight off the bed while assistant (B) supports the person's buttock and shifts over to the wheelchair seat. With one coordinated, smooth movement, the person is transferred over to the wheelchair.
7. Then assistant (A) leans the person forward while assistant (B) scoops the person's buttock well into the seat.
8. Position the person upright. Place the person's feet onto the footrests in a comfortable position, straighten out the person's clothing, then unlock the wheelchair.

GUIDELINES FOR ONE-ASSISTANT TRANSFER - FROM BED TO CHAIR

1. Roll the person onto his or her side, lower the feet and get into a seated position by having him or her push up with the hands.
2. Get the person ready. Change clothes and put on the shoes if required.
3. Get the wheelchair ready. Remove the armrest of the wheelchair that is closer to the bed, swing away both footrests, position the wheelchair by the side of the bed and apply the brakes to lock the wheelchair.
4. Get yourself ready. Position one foot between the person's feet (with both heels touching the ground), place your other foot in the direction of movement and place your hands on both sides of the person's back.
5. Get ready for the move: Alert the person that you are making the move, keeping your back straight, lean back to lift the person's weight off the bed and swing over to the wheelchair in a smooth and controlled movement.
6. Lean the person forward, move his or her buttock well into the seat and sit the person upright. Put back the armrests and footrests, place the person's feet onto the footrests in a comfortable position, straighten out the person's clothing and unlock the wheelchair.

Information from TSAO Foundation
www.tsaofoundation@tsaofoundation.org

PSP EUROPE

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

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DISCLAIMER

Information, reference material concerning research being done in the field of PSP and answers to reader's questions are solely for the reader. It should not be used for treatment purposes but only for discussion with the patient's physician.

GIVE A GIFT ONLINE

www.psp.org



Education - Helpful Hints

Home Healthcare Products

Series I

BATHROOM ASSISTIVE DEVICES

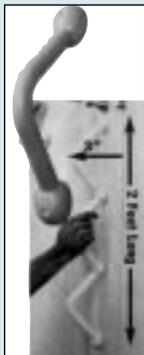
The following products can be ordered from:
 MOMS Home Healthcare Products
 1-800-232-7443 or www.momscatalog.com
 or from
 North Coast Medical
 1-800-235-7054 or www.BeAbleToDo.com

Products From Moms

SAFETY HAND GRIPS

Mount these plastic hand grips wherever you need support. Installs easily with the included screws and anchors.

- JR JH3939 \$7.99
Three-Tier Hand Grips (tiers come attached)
- JR JH392 \$9.99
Two-Tier Hand Grips (tiers come separate)



SAFETY GRIP TUB BAR

The Tub Bar's multi-grip design helps you get in and out of the tub safely.

- Fits most tubs
 - High-grade coated steel
 - Installs quickly with clamp provided
 - 14 1/2" high
- EQ 1609 \$39.89

CLEAN, SOFT MANAGEABLE HAIR WITHOUT WATER

Simply warm the Comfort Bath™ Hair Care cap in your microwave, then put cap on and massage in the gentle no-rinse shampoo and conditioner. Box contains one cap. One shampoo per cap.

HB7909 \$7.99



BATHE WITHOUT WATER

Just microwave a Comfort Bath™ cleansing pack, then wipe your skin with 8 warm soft washcloths for an easy, rinse-free bath.

- Aloe and lanolin prevent drying
- 8 washcloths per package for one full body bath

HB 7900R

Comfort Bath™ \$5.99

HB 7903

Comfort Bath™ Unscented \$5.99

HB 7904

Comfort Bath™, Box of 4 \$23.99

EASY, CONVENIENT SHAMPOO TRAY

The Shampoo Tray's durable lightweight plastic tray funnels water into the sink, so you and your bathroom stay dry.

Shoulder straps keep the tray stable. Easy to clean. Measures 12 3/4" x 17 3/4".

SA 9203-36 \$49.99



RAISE YOUR TOILET SEAT WITHOUT CHANGING THE SEAT



This hinged ring permanently installs under your toilet seat, so you get 3" of height without changing the look of your bathroom.

- Hinge allows ring to be lifted the same as standard toilet seat.
- Hinge allows easy cleaning

MDK F725710000 \$77.99

Hinged Elevated Toilet Seat, Standard

MDK F725710005 \$78.99

Hinged Elevated Toilet Seat, Elongated

INNOVATIVE, EASY-LIFT TOILET SEAT

The ingenious hydrolic supports and comfortable handgrips gently help you stand.

- Support weights between 90 and 280 lbs
 - Includes a commode pail
 - No batteries, electricity, plumbing, special installation required
 - Rust-resistant, easy-clean finish
- LE TOIL1W \$329.99



SAFETY FRAME AND RAISED SEAT ALL IN ONE

This sturdy combination frame and padded raised toilet seat supports you comfortably.

- Safest toilet frame design with non-slip finish

Adjustable Seat Height: 17"-22"

Seat Depth: 16"

Width Between Arms: 19"

Base Size: 24" x 17 1/2"

Weight Capacity: 250 lbs.

Weight: 8 lbs.

EAG 34043 \$94.99

Education - Helpful Hints



CONVENIENT ALUMINUM FOLDING COMMODE

This lightweight aluminum commode folds back to just 7¹/₂". Great for travel or limited space.

- Includes commode pail and lid
- Easy no-tools assembly

Adjustable Seat Height: 18" - 21" Base Size: 21¹/₂" x 19"
Seat Depth: 14" Weight Capacity: 250 lbs.

Width Between Arms: 18¹/₂" Weight: 16 lbs.
EAG 34027 \$164.99

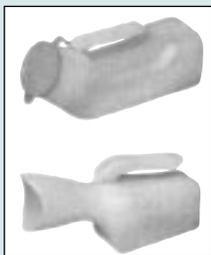
WHEN YOU NEED INSTANT RELIEF

Quick, sanitary and easy-to-use urinal increases your confidence and reduces odor. Unique design won't leak or spill in any position.

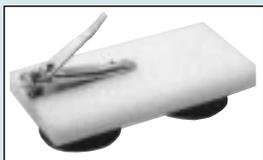
- Holds up to 25 ounces (700 cc)
- Opaque style for discreet use
- Safety cap prevents spills
- Sure grip safety handle

EQ 5076 Clear Urinal \$4.99

EQ 5068 Female Urinal \$4.99



Products From North Coast Medical, Inc.



NAIL CLIPPER BOARD

Compact enough to take anywhere. This standard size nail clipper is securely attached to a plastic base. Two suction-cup feet provide stability and prevent

slippage. Ideal for people with arthritis or limited pinching ability. Board measures 4" x 2".

NC28698 \$15.95

RUBBERMAID® PORTABLE SHOWER BENCH

Convenient one-piece bench for bathtub. Compact size makes it ideal for travel and storage.

The bench fits standard bathtubs that measure 19" to 28" wide. Bench measures 31" x 14¹/₄".

Weight capacity is 300 lbs.

NC28954 \$43.95



Easy adjust feet adjust to the exact height you need.

RUBBERMAID® BATH TRANSFER BENCH

- Enter and exit the tub safely with this adjustable transfer bench.
- Features a supportive seat back, a large easy-to-grip handle and a raised edge at the rear of the seat for added security.
- Designed for bathtub entry from either the right or left side.
- Exact Level™ system adjusts the seat height from 18¹/₂" to 23¹/₂". Supports up to 300 lbs.

NC28968 \$115.00

FOLDING SHOWER SEAT

Easy-to-store shower chair allows for versatile seat angle and height adjustments. The warm-to-the-touch backrest and seat are made of heavy-duty plastic. The overall height, width and depth dimensions are 29" to 36" high, 23" wide and 17¹/₂" deep. The seat height adjusts easily from 17¹/₂" to 23¹/₂". Weighs 14¹/₂ lbs. Clean with regular household cleaners and disinfectants. Weight capacity is 285 lbs.



GUARDIAN® LOCKING ELEVATED TOILET SEAT WITH ARMS

Larger seat with raised arms is ideal for elongated toilets. Adds 5" to the height of the a toilet seat. Foam-padded raised armrests add security. Measures 16" x 14". Made of composite resin. Weight capacity is 250 lbs.

NC2893 \$74.95



Support Groups As Of 9/16/03

PSP Support Groups will encourage and organize activities that foster communication, exchange and interactions of comfort and mutual benefit to Support Group members who are family, friends, caregivers and persons with PSP. The Society would like to thank the following Support Group Leaders and Communicators who take their time and show their concern by sponsoring support groups, phoning and visiting PSP families. For information about support groups please contact: Jessica Quintilian, Director, Outreach and Education at 1-800-457-4777.

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

Progression of PSP

These messages were posted on the Society's Web site.

Visit the PSP Forum today at www.psp.org

My mother, age 65, started with a few falls in August 2002, saying she felt weak in the knees. She rapidly started losing speech and ability to walk (her speech is badly slurred and she struggles with a walker now, can't get out of bed alone). She is also having trouble with swallowing. Most of what I've read (since her neurologist told me he thought it was PSP 3 days ago) seems to indicate such progression takes years, not months. Have others seen such rapid progression of PSP?

They tell me everyone's progression is different. I was diagnosed in April 2002, after being told for 2 years that they (the neurologists) thought I had Parkinson's disease. The wonderful physician who diagnosed me spotted signs no one else had noticed, but PSP is his specialty. My initial problems were rigidity of my fingers and balance. My walking has progressed down hill very rapidly in the last 2 months. Physical therapy helps a lot, and I am going out to look for a cane tomorrow. Your mother is 5 years older than I am, and I'm sorry she is progressing so rapidly. I have found this Web site to be both informative and comforting.

My husband is 63 and was diagnosed with PSP in Dec. of '99. He was still working in 1998 but 3 back surgeries and a foot surgery seemed to speed progression. He uses a walker but still falls—in fact he's demolished 3 walkers and is now using one provided by Hospice! He is able to drive a power wheelchair in wide open spaces but not in the house. It seems once we recognized all the symptoms of the disease that progression slowed, but I know it never actually stops. Most likely, when you think about it, you may remember signs of PSP in your Mom before 2002. By the time it is diagnosed it has usually been there awhile. My husband's symptoms go back as far as '95 but we didn't have a clue that anything like PSP was in his body! I wish the very best for you and your mother!

The best piece of advice I can give to you is that no one can tell you (even doctors) when the end is near. I know you probably would like a time span (we all would) but you can never prepare for the death of a loved one. It will not make it easier, you just have to realize that when it is time for him to go home to heaven, God will take him with open arms and your father will no longer suffer. It sounds like your dad is having difficulty swallowing; be prepared to make a decision on whether your family wants a feeding to be put in place; this sounds like the next step. My boyfriend's father was recently diagnosed and since then he seems to be progressing rapidly. I had many of the same questions but now I realize every case is so different.

This is a quote from the book *Tuesdays with Morrie*. Every since I read this it made death make sense to me. "As long as we can love each other, and remember the feeling of love we had, we can die without ever really going away. All the love you created is still there...You live on in the hearts of everyone you have touched and nurtured while you were here." Death ends life, not a relationship." I hope I helped you a little with some honest answers...take one day at a time, and put everything in God's hands; he will give you the strength.

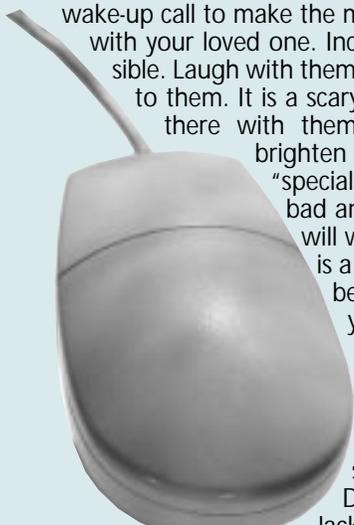
Thanks to those who responded to me. I feel so much better, not that he does not have a time span, but that I finally have support with other people who have gone through the same thing. My other family members will never understand as they are not around as often as I am - and I also clean him up a bit (shaving, brushing his teeth) by the time they come and visit. I trust that God will make things easier for him when the end comes—he is not in any pain, unless frustration can be called painful. The aides in the nursing home can only do so much and I am grateful to them, but the doctor himself knows nothing about this disease and is helpless. The best info I get is other people's experience and I would appreciate if anyone can keep it coming so that we all can benefit from your experience.

The best info I get is other people's experience and I would appreciate it if anyone can keep it coming...

There is no normal timeline with PSP. Every case is different. An average time span is somewhere between 5 to 10 years. Many people have PSP long before they are diagnosed with it. Many are misdiagnosed with other diseases. The symptoms can vary from case to case. One thing that is specific with PSP and not usually other diseases is problems with eye movement. My husband had PSP for about 5 years, and there were periods of rapid progression, and sometimes periods of leveling off and stabilizing.

Choking is common, especially on thin liquids. Falls will happen more often as PSP progresses. The last year or so, I had to puree all of my hubby's food. We made nutritious shakes with fruit, yogurt, ice cream, juices, protein powder, etc. He could drink out of a straw pretty good. When we fed him pureed foods with a spoon, he would often involuntarily clamp down on the spoon and not be able to release it. I found the vinyl coated spoons you can purchase at a medical supply store very helpful (after he chipped a couple of front teeth). He did NOT want a feeding tube. This is something you all need to discuss WHILE they are still able to talk about it. It is a very personal decision, and must be theirs.

Please remember, you are not alone. Unfortunately, there are many PWSP and families out there dealing with this awful disease, but we are all here to help each other. My husband died about 2 1/2 years ago at age 44—the prime of his life. This age is not the norm for PSP, but there some others this age also. No, you cannot really prepare for the death of a loved one. Knowing it ahead doesn't really help, except in financial or other business situations. But it should be a



wake-up call to make the most of the time you have left with your loved one. Include them in everything possible. Laugh with them, cry with them, talk with and to them. It is a scary, lonely road, but we can be there with them to lighten their load and brighten their day. One day... this "special" time will be gone, and, as bad and hard as it seems now, you will wish you had it to do again. It is a special time, and if you avoid being with your loved ones, you will be missing out.

One last thing I would like to say. Please talk to your PWSP about the brain donation program that is sponsored by Dr. Dennis Dickson at Mayo Clinic in Jacksonville, FL. It is an extremely difficult subject to talk about, but it is one GOOD thing that can come out of this disease. Much more research is needed in hopes of one day finding a cure, or at least an effective treatment to halt the progression.

My husband was diagnosed with PSP only a year ago, but he has been sick for at least 3 years. We went from doctor to doctor, with diagnoses of Alzheimer's, Parkinson's, etc. My husband will be 60 in 2 weeks, so I think he is young to have this illness. I know all of you share the same frustrations and problems that I have. My husband falls constantly. He is restless and will not stay put for very long. He also now finds it almost impossible to keep his eyes open. Anyone used or been advised to try botox for this problem? I understand most patients with PSP can't look down; my husband can't look up. Look forward to hearing from all of you.

My mom has had PSP at least 10 years. She got Hospice involved about 2 years ago — showed most if not all of the final symptoms — and is still hanging in there. She has no chronic pain; her heart, lungs, etc seem to be fine. We are all amazed. She is totally disabled. Her eyes are sometimes expressive, sometimes they look like "no one is home." She has excellent care in the area I added to my home, and her "room" is the center of the house — sort of a family room. She, too, chokes easily, especially on thin liquids. We tried the thickeners, but prefer to give her slow sips—one or two and then rest a minute. I've taken her off all her medicines except laxatives, stool softeners, and when needed, a relaxer or a sleeper, and liquid Tylenol w/codeine for pain.

PRIVACY POLICY/DISCLAIMER

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

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.



Media Coverage

Continued from Page 1

Choose which type of outlet you wish to approach:

TV, radio, or print. Call the offices of your chosen outlet and ask for the name of the medical reporter or producer. Send a cover letter to this person and state that you are available to be interviewed for a story about PSP. Let them know about PSP Awareness Month or National Caregivers' Month. Include your patient history and factual information about PSP. You can give reporters photos and video once they have committed to running a story, but do mention that they are available.



Follow up with phone calls. It may take several attempts to reach your contact, so be persistent. These folks are busy and are continually bombarded with story ideas.

After you have connected with your reporter, a time will be established to interview you and your family. If the interview is for television, a camera crew and reporter will come to your home to talk with you for up to an hour. However, a TV interview will later be edited down to a two-or-three minute piece. Radio interviews will air as longer pieces and may be conducted over the telephone.

A couple of points to remember are: 1) Make it clear that PSP is not a type of Parkinson's disease and that your reporter understands that PSP is a disease distinct and separate from Parkinson's disease; 2) Rather than refer to PSP as "rare" it is better to describe it as "little known." Reporters will be interested in increasing knowledge of a disease rather than doing a story on something rare which may not affect many in their audience.

If you have a neurologist in your area who is well versed in PSP, you can include that person in the story. Most medical journalists have relationships with local medical professionals, but you can recommend and contact in advance anyone you feel would make a valuable contribution to the story.

When your story is run, be sure to tape it or buy several copies and ask friends to do the same. Please send a copy to the Society office for the media archives.

Tips If The Media Calls

- Respond immediately to an interview request. A reporter is working under deadlines, so assume the interview is needed immediately.
- Ask ahead and find out what the reporter knows and what areas he/she will focus on during the interview.
- Prepare and write down what you want to talk about ahead of time (key points). This will keep you from getting sidetracked.
- Dress appropriately and check your grooming!
- Keep your comments short and to the point because reporters are looking for brief quotes or soundbites. Do not ramble.
- Prepare for tough questions and remember that nothing is "Off the Record."
- If you don't know an answer, say so. NEVER fake an answer.
- Sound positive and up-beat about educating people about PSP and connecting PSP families.

If you have any questions, please feel free to contact: Ceri Williams email medianet@earthlink.net telephone 818 343-3259

Support

FREE EQUIPMENT FOR PSP PATIENTS!

ACTIVE LIFE WHEELCHAIR AND WALKER

Good condition. Ideal for person about 5'4" or shorter.
Contact: Sharon Poggis at 714-879-8776 or email:
poggis@adelphia.net

LEBER WALKER WITH HAND BRAKES

(from Shirley Walker Company)
Contact: Patrice O'Toole at 301-262-2306 or email:
patrice.otoole@verizon.net

12 WHEELED WALKERS

Available from the Shirley Walker Company
Staffen model, never been used!
If interested, contact Jessica Quintilian at the Society office,
1-800-457-4777 or email: outreach@psp.org.

GRANT ANNOUNCEMENT:

The Society for PSP announces its Regular Grant Program up to \$50,000 supported by the Erwin and Pearl Poizner Memorial PSP Research Fund, The Dudley Moore PSP Research Fund, The Eloise H. Troxel Memorial PSP Research Fund and other designated funds.

Deadlines: April 1 and October 1

The Society also announces the Annual Eloise H. Troxel Memorial Fellowships, each of \$50,000 for research in PSP.
Deadline: October 1

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

Society for Progressive Supranuclear Palsy Brain Donation Program

For Diagnosis of and Research on PSP

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

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

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

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

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

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

Windy City

Continued from Page 5

for dedicating the event in memory of Sophie Shapiro and to Jack Hetrick in honor of Doris Hetrick and in memory of Albert Katz. Special time was reserved during the program for families to question the experts, and meet each other and share in fellowship. Families are so grateful to have this opportunity to talk about the disease with others who are experiencing the same challenges. Participants expressed definite interest in a Chicago area support group, and the Society would be thrilled to help organize a group in this area. If you are interested in leading or being part of this group, please contact Jessica Quintilian at the Society, 1-800-457-4777, or email to outreach@psp.org

Our trip to the Midwest encompassed much more than just this single event! On July 10th, Society donors Bob Barnett and Lois Zoller hosted a wonderful dinner thanking the Society's major donors at the Onwentsia Club in Lake Forest. This lovely evening included presentations by Dr. Muma and Ellen Katz, enabling donors to see how their gifts have advanced research and supported families. While in Chicago, Jessica and Ellen also had the fantastic opportunity to visit the Alzheimer's Association national headquarters. After spending a whole day with this friendly, extremely competent staff, we were encouraged by the potential for growth of the Society and the services we could provide to PSP families.

After organizing caring and sharing events nationally, the Society staff continues to be moved by the enthusiastic response and gratitude received from families. We realize that these regional events are extremely valuable educational opportunities that we will keep expanding to help families better manage the daily challenges of PSP.

We envision a world free of PSP.



*Standing: Nancy Muma & Julia Schackelford
Seated: Marcie Dolgin, Mararet Magnusom
& Elizabeth Bernardi*

Support - Our PSP Stories

In Memory of Jeanne Alter

Sept 6, 1931-March 15, 2003

By Diane Alter

"I feel fine." That is how my mother Jeanne answered when asked how she felt, even just before she died. My mother passed away on March 15, 2003. She was first diagnosed about six years ago with Parkinson's disease. She seemed to have all many of the symptoms of Parkinson's, but as my mother grew sicker and did not respond to the medication, it was confirmed she had PSP.

My mother never complained and she continued as long as possible to go out with family and friends, to travel and to go on with her daily routine. As her illness progressed and she became more confined and less active, my mother retained her sense of humor, her faith became stronger and the love and devotion of our family strengthened. My mother had nine children, five grandchildren and two great grandchildren. She and my father were married just shy of 50 years. My mother lived a full life and she was the light and heart of our family. She was so kind, and extremely unselfish. She never gave up hope and she fought a long and heroic fight.

Not a day goes by that I do not think of her. I miss her more than words can say. But, this is not a story of pain, suffering or dying. It is a story of a devoted wife, a loving mother, grandmother, great grandmother, friend and a wonderful lady. I try not to mourn her passing but to celebrate her life and remember her goodness, the fun we had and the love we shared. And just when I miss her most, need her most, and want her most, I find a penny—a penny from heaven and I know my mother is with me.



Left to Right: Janet, Jeanie, Mom, Betty Ann, Maureen, Diane, Kathy, MaryLou and Dad.

Earl's Story



In memory of Earl A. Smith, I am writing to share our story. My husband, Earl, had retired from 30 years with General Motors in March 1996. We had planned such a wonderful life, including going into the golden years hand-in-hand. Our children were grown and with four wonderful grandchildren, we were on the way. Earl was a vivacious, enthusiastic, fun-loving individual who relished and enjoyed each and every moment of life's joy.

He began to experience vision problems, have speech difficulties, etc. It took us 3 doctors and 3 neurologists before he was finally diagnosed with PSP. What a blow. It took me well over a year of disbelief and just plain shock to overcome the news. I remember I couldn't even bear to say the name.

We struggled through the devastation and debilitation for the next 4 years. I prayed that when the time came, we would all be together. We laughed, took trips to the Eastern Shore to my home, and strived to keep life as normal as possible.

On April 11, 2000—after whispering in his ear how very much we loved him, he took a deep breath and peacefully slipped away. You are never prepared to part with the one you love so much. It is one of the most painful aspects of life—however; it is far more painful to watch PSP does.

I do thank God for you all and this magazine. We had felt so alone and isolated. I also thank God for each moment, each second and each day we had together. It has been two years but it seems like just yesterday. I hope that a cure will be found soon so that many other people can be spared the suffering. I applaud your efforts and dedication. God bless you all.

Sincerely,
Gladys M. Smith
Maryland

GIVE A GIFT ONLINE

www.psp.org



Someone to lean on



Molly Dean helps her husband, Joe keep his balance as they walk through their home. Joe Dean suffers from progressive supranuclear palsy, or PSP, which affects his ability to walk or speak.

Rare neurological disease brings couple closer in ways they never imagined

By BARBARA KARKABI
Houston Chronicle

It has taken awhile, but Molly Dean has finally learned to walk backward. She can even laugh about it, with a glance at her husband, Joe, 64, who struggles to smile back.

“Humor has always been the basis of our relationship,” Molly says, gently patting Joe’s hand.

There are many things Joe can’t do now. It’s almost impossible for him to talk, and he can’t walk without her help. That’s how she began walking backward.

“I have him grab me on my waist, and I lift him up under the arms,” she says. “Then I tell him to move his arms to my shoulder. When we are walking, I put my hands under his elbows to keep him balanced.”

Joe can hear and understand everything.

He’s fully aware of being a prisoner in his own body and once told Molly that he felt like a computer with no monitor. Joe communicates with a combination of nods, thumbs up or

down, sounds and facial expressions, and Molly works hard at interpreting.

Friends notice their loving repartee. Molly laughs and jokes with Joe, and he responds by kissing her on the neck. At night, they go to sleep holding hands.

In August 2000, Joe was diagnosed with progressive supranuclear palsy, a neurological illness that attacks portions of the mid-brain, or movement center, which controls balance and speech. As the disease progresses, muscles may become rigid. Eventually most patients are bedridden and need 24-hour care.

First diagnosed in 1964, PSP can strike anyone over the age of 50, but is more likely to occur when

people are in their 60s.

There is no cure. Patients are often given five to seven years to live, although length of survival varies widely.

PSP is a rare disease, affecting 20,000 to 80,000 Americans, according to Dr. Paul Fishman, professor of neurology at the University of Maryland Medical Center.

Because of PSP's nonspecific early symptoms, patients are often misdiagnosed with Parkinson's disease. PSP's profile was raised when actor Dudley Moore was diagnosed with the degenerative illness in 1998. He created the Dudley Moore Research Fund for PSP several years before he died in April 2002 of aspiration pneumonia, a complication of PSP.

When Moore experienced early symptoms such as unsteadiness and slurred speech, it was rumored that he was an alcoholic. When he couldn't remember his lines for a 1996 movie, he was fired.

The Deans and other Houston families with PSP patients say they can identify with Moore's problems. The beginning stages of PSP are confusing and hard to identify, Molly Dean says.

Joe Dean, who was dean of a community college in Dallas, was able to hide his symptoms from Molly for years. Looking back, Molly believes it was denial, rather than an intent to deceive.

"It's hard to say, but I don't believe he associated what was happening with a disease. I think Joe started having symptoms about 10 years ago," Molly says. "He fell into a depression right after we got back from a mission trip to Guatemala."

Joe, a gifted musician, had taken his trumpet on the trip. Molly, 62, has an achingly clear memory of the day he played his trumpet in the middle of the valley where they had helped build several houses. Everyone came out to listen to the clear, strong tones, she recalls.

"What was the song you played, Joe?" she asks. "Was it *Amazing Grace*?"

Joe can only mumble.

"Can you hum it?" she asks.

Joe tries, but Molly shakes her head, tears in her eyes.

"This is the most frustrating thing," she says. "He knows what it is, but he can't communicate it to me. He can't write, and he can't talk."

But Joe can still look at her with love and a twinkle in his eyes. Molly takes his hand. She dries her tears. It's a sunny day, and she has family and visitors around her.

Granddaughter Rebecca, 4, who is spending the day, runs in and out of the room.

Molly's 92-year-old mother, Mary Stewart, lives with the couple now. A master gardener, she cooks and grows vegetables in the back yard.

Another friend, Karen Kennemer, has stopped in to chat.

Kennemer's sister died from the effects of PSP in February 2000. A few months later, Kennemer started the PSP Network of Houston. The group numbers about 45 families.

During their lively monthly meetings, group members exchange advice on medicine and caregiving and offer general support. Because PSP can be officially confirmed only through a brain autopsy, many group members (both caretakers and patients) are committed to that course of action. Molly, Joe and Mary (her mother) have all agreed to brain autopsies, which are done at the PSP brain bank in Florida.

Their hope is that it will help researchers find an effective treatment, the cause and a cure.

Many members who have lost spouses, siblings or parents to PSP still attend meetings to support friends and pass on medical equipment. Others never want to hear about PSP again, Kennemer said.

"Before I had the group, I felt so alone and isolated. I was just desperate," Molly Dean recalled. "Now I'm not crying all the time, and I have a support system. I can cry with them if I want, but we try to encourage each other. People who don't have PSP don't have a clue. All they can say is, 'It's going to be all right.' But it's not going to be all right."

Because it's often difficult to distinguish between Parkinson's and PSP, doctors sometimes give patients a diagnosis of "Parkinson's plus."

"I despise that term," Kennemer said. "Years ago they knew there was something more going on than just Parkinson's, so they added the 'plus.' Many doctors are not going to tell you that you might have PSP, because it's not as hopeful an outcome as Parkinson's. So they don't tell you until you finally have so many symptoms they have to say it's PSP."

While the progression of the disease varies, its first symptoms usually include loss of balance, unexplained falls, unusual gait, depression or apathy, changes in handwriting, difficulty driving and double or blurry vision.

As it worsens, symptoms include more pronounced vision problems, a wide-eyed staring look, speech and swallowing difficulties and problems processing information. For most the mind remains relatively clear, Kennemer said.

Joe Dean was diagnosed at various times with gait disorder, Parkinson's plus and Alzheimer's disease. In her search for answers, Molly briefly suspected Alzheimer's.

Looking back, she believes Joe was depressed after their Guatemala trip because his difficulties at work were mounting.

"He was a dean over seven divisions at the community college in Dallas, but he wasn't able to perform his functions," Molly says. "He was able to mask it for a long time, and he did not communicate anything to me. He was downsized four times, but I thought he just had different jobs."

By the time Molly figured out that something was wrong, Joe's pay had been cut in half, and they were thousands of dollars in debt. Joe had handled the finances. Molly had raised their three boys and taught costume design at Booker T. Washington High School for the Performing and Visual Arts.

In 1995, Molly took over the family's finances, a blow to Joe.

"I was very angry at Joe for letting things get so bad and refusing to let me know what was going on," Molly says. "Each time I asked, he would say, 'When I get it together, we can go over it.' It was probably a relief when I found out his dreadful secret."

They agreed to move to Houston, where her parents and son Kelly lived. Kelly, 40, is the father of their three grandchildren. David, 38, is a university professor in New Zealand, and Andrew, 33, lives in Dallas.

"They went through a period of denial and couldn't understand why I was crying all the time," Molly says. "Then Joe went through a really rough time, and they saw him going down. They feel more like me now; this is who their daddy is. They don't like it, but this is who he is."

She found a job in the University of Houston theater department in 1996 and commuted between Houston and Dallas for a year until Joe could take early retirement at age 58.

Although Joe was holding his own, "there were some strange things. He

would do this kind of 'freezing,' " Molly says. "I would turn around and he would be just standing there, and I would say, 'Joe, what are you doing?' Finally I would get him to say, 'Watching Molly work.' "

By the time they moved to Houston, his problems were obvious. He found several jobs, but none lasted long. When their closest friends visited for Christmas, they were alarmed at Joe's lack of facial expression and insisted that Molly take him to the doctor.

A magnetic resonance imaging test showed nothing. In 1998 they were given the Parkinson's plus diagnosis and told to "look it up on the Internet," Molly says.

A breakthrough of sorts happened when Molly's father, George Stewart, was to have surgery for a blood clot and was asked to participate in a study on falling.

"I remember my mother saying her husband didn't fall, but her son-in-law did," Molly says. "That was where we met Elizabeth Protas, a physical therapist and movement specialist, who took one look at Joe and said, 'Has anyone ever mentioned PSP to you?' It was that fast.

Both Molly and Joe were relieved to get the diagnosis – and a name to put on their suffering.

"The not knowing and not understanding was so much worse," Molly says.

Protas referred them to Dr. Joseph Jankovic at the Baylor College of Medicine Parkinson's Disease Center and Movement Disorders Clinic. Jankovic made the diagnosis in 2000 and eventually attended the support group. Molly had never talked to another family dealing with PSP.

"I had spent such a long time crying and feeling so alone and desperate," she says. "It is much better knowing and much better when I get down, because about that time I will get an e-mail from Karen asking how things are going. I find comfort in helping other people, too."

Molly retired in January, leaving her more time with Joe. They still enjoy a social life — going to church, visiting neighbors, having family over — though it's far from a typical retirement.

"People ask if I miss work, and I tell them I don't have time," Molly says. "It's like one long, hard weekend. But I don't miss the pressure of doing both."



Molly and Joe Dean have been dealing with Joe's symptoms of PSP for 10 years. "I don't know that I would trade with anyone else. I don't think it's tremendously tragic; it is just what life has given us," Molly Dean says.

Getting Joe ready in the morning is one of her biggest challenges. He can pull himself out of bed with the help of bars her sons set up. But Molly has to help him dress. She places him in a doorway and makes sure he is hanging on to two bars.

"I sit down and put on his shoes and socks and pull up his pants," she says. "When I go to get up, he reaches down to help me, just like he always used to, and it breaks my heart."

Molly is a philosophical person, Kennemer says, not given to blaming others for her problems. But it is hard not to get angry when you watch your life partner slipping slowly away.

Most days are peaceful at Joe and Molly's house, though Joe still falls often — Molly calls it the "shiny object syndrome." He sees things on the floor and wants to pick them up. Molly doesn't get angry anymore because she knows it's the disease, not Joe.

"You lose your partner (of 41 years) as you knew him and whatever part they took in the marriage, and you gain a responsibility," she says. "But it's a gradual thing, so there is time to adjust. I don't know that I would trade with anyone else. I don't think it's tremendously tragic, it is just what life has given us."

After a recent PSP group discussion of

hospice versus palliative care, Joe let it be known what he wanted.

It took awhile, but he finally got his message across to his wife.

She tears up, recalling: "I said, 'You want palliative care and Molly?'"

Joe nodded.

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Photos: © Houston Chronicle

RESOURCES

The next meeting of the PSP Network of Houston is scheduled for 1 p.m. June 21 at Learning Center B, Professional Building II of Memorial Hermann Southwest Hospital. For information on time and location, call 281-358-2282. To find out more about PSP, call the Society for PSP at 800-457-4777 or check their Website at <http://www.PSP.org> The Meredith C. Teel Regional Symposium for Persons Diagnosed with PSP, their families and caregivers, will be held on Oct. 11, at the Sheraton North Houston. Call the PSP Network of Houston for more information.

Friendraising and Fundraising for PSP!

You can be a special event planner volunteering to increase awareness of progressive supranuclear palsy.

You can also raise funds to support the Society's programs and services. Call the Society office today and learn more. 1-800-457-4777

Look at the wonderful events planned for this fall! Thank you, special event planners!

THE JIMMY DOWNS CURE PSP HAWG & HOT ROD BENEFIT

Help us support The Society for PSP and cure progressive supranuclear palsy!

Sunday, September 7, 2003

Downs Manufacturing

715 N. Main Street, Lawton, Michigan

11:00 a.m. until ?

\$20 minimum donation buys two meal tickets (Food provided by D'Coy Duck), plus your vehicle will be entered in the show. Music provided courtesy of Endless Summer Silent auctions and raffles for amazing items! Additional meal tickets are available for \$10 minimum donation.

Please make checks payable to The Society for PSP. For information, contact Pat Downs at 269-624-4081

Raised - \$17,000 Congratulations

JEANS DAY

September 19, 2003

San Diego, California

Employees at the Latham & Watkins law firm will be wearing jeans to work on this date and supporting The Society for PSP with donations. Coordinator: Nadine Hylander

WHEN IT'S NOT PARKINSON'S DISEASE CONFERENCE

October 3, 2003

10 a.m. - 2 p.m.

Philadelphia, Pennsylvania

Heather Cianci at 215-829-7275 or

email hjcianci@yahoo.com

PSP AWARENESS DAY REST STOP

October 11, 2003

Burlington, Vermont

"Leafers" make sure to stop here on your way to view the fall foliage! PSP information and refreshments for travelers. Janice Clements at 802-893-1263,

email: janclem@moomail.net or

Gale Cass at 802-434-4181,

email: gcass0522@aol.com

Raised - \$800 Congratulations

Also Coming in October...

AT THE HOP DINNER AND DANCE PSP AWARENESS BENEFIT

October 25 • 5:00pm-11:00pm

Deep Creek Landing, Newport News, VA

Contact: Tracie Sansavera at 757 766-8383

email igothands@cox.net

Nancy Brittingham 757 838-0777

email NancyB501@cs.com

PSP WALKATHON

October 14

Contact: Sheri Collie • email scylecollie@yahoo.com

NEW YORK CITY PSP BENEFIT

October 1

Contact: James Bernard • email kimo69@earthlink.net

MINNESOTA PSP SUPPORT GROUP SILENT FUNDRAISER

Charlotte Tripet at 763-546-1694, email:

chartrip@yahoo.com

Raised - \$5,000 Congratulations

Mark your calendars for this future golf tournament!

THE DONNA JEAN FOR PSP

Saturday, June 5, 2004

Hartland Glen Golf Course

Hartland, Michigan

12:00 Shotgun start

4 man best ball scramble. \$125.00 per golfer-all proceeds benefit The Society for PSP.

Continental breakfast, lunch at the turn and steak

dinner with a prize/50-50 raffle

and silent auction. All are

welcome!!! Currently seeking gifts and sponsorship donations.

Signage for sponsorship is available for \$250.00 For

more information, please contact:

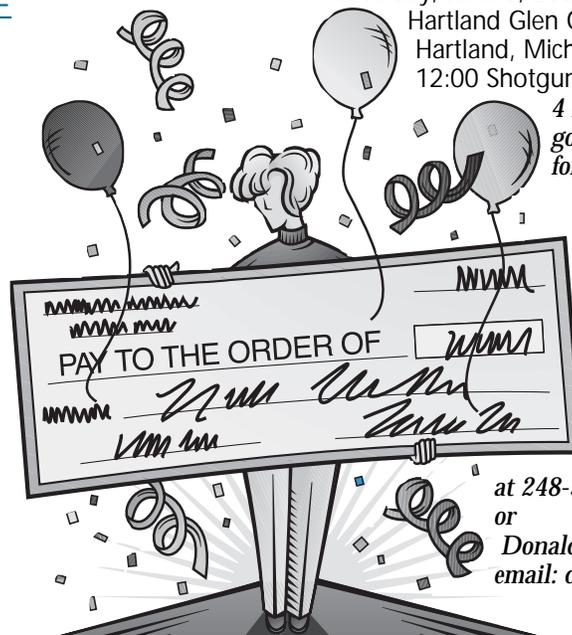
Andrew McAlpine

at 248-545-3993, email: andykaren@juno.net

or

Donald McAlpine at 734-367-8056,

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Report Of Gifts - May 1 to August 31, 2003

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.

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In Loving Memory of Our Wonderful Parents,

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Ruth Lawless In Memory of Ross Lawless

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William Ron Sandwith

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American Home Shield In Memory of Roland Kaput

Mary Amory In Memory of David Amory

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Paul & Stacy Horvath In Honor Of

Stephen Horvath

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Johnson & Shute, P.S. In Memory of

William Ron Sandwith

Julia Keith In Memory of Robert Boatright

Joel & Eleanor E. Levy In Memory of Isadore Lourie

Betty B. Lourie In Memory of Isadore Lourie

Robert T. Martin

Susan McBride

Coleman McGowan In Memory of

Elizabeth McGowan

R. Sheldon & Patricia L. Milligan In Memory of

Don Wells Sr

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Eddien Nelson

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John & Judith Remondi In Memory of

Joan M. Cullen

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William Ron Sandwith

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The South Financial Group In Memory of

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Sol Tuchman

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PATRONS \$100 AND OVER

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Carol & Steve Andilorro In Memory of

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Report Of Gifts

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Judith Herrman
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Stephanie T. Averbach In Memory of
Irwin J. Averbach
Merwin & Ruth Bailey
Sara L. Ball In Memory of Donald H. Ball
Kenneth & Patsy Barnes In Honor Of Patsy Barnes
Stephen & Charlene Barron In Memory of
Marvin Totsch
Laurie & Rick Barsam In Memory of
Elizabeth McGowan
Harry M. & Carol M. Baum In Memory of
Isadore Lourie
Nancy Baxter In Memory of Jane Sorensen
Richard D. Beal In Memory of Leora M. Beal
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Lea Gillispie-Collinson
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Ronnie & Sharon Bell In Honor Of Willie L Jenks
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Theodore A Bennett
William Betts
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John E. Jack Mann
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George & Laurie Fox In Memory of
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Paula French In Honor Of Ralph Poe
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Candace L. & Charles S. Gilderman
In Memory of William Ron Sandwith
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Carolyn Clack
Karen Goldberg In Memory of
Loujean Southard Karon
Mel Goldberg
Steve & Janice Goldberg In Memory of
Arthur Goldberg
Marian Golic In Memory of Mervin Golic
Inez H. Good In Memory of Henry S. Good
Kim Gordon In Honor Of Charles H. Reeves
Arlene Graham In Memory of John E. Graham
Rebecca Graham
Randall E. & Jana Waring Greer
Silvia Gregory In Memory of James E. Gregory
Mary P. Guarino
Giuseppina Guiles In Memory of George E. Guiles
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Warren K. Hamburg In Memory of Lola Hamburg
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Wanda Kusnierz
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Lillian A. Hitchcock
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Robin Kanen In Memory of Olga Tully
Vernice Kaphingst In Memory of Robert Kaphingst

Report Of Gifts

PATRONS \$100 AND OVER

Continued

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William W. Kingston In Memory of
Anastasio diBenedetto
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Frank & Cheryl Koons In Memory of
Veronica Geosits
Krauss-Maffei Corporation In Memory of
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William & Joyce Kravec In Honor Of Joyce Kravec
Peggy Krichbaum
Kathy & Dillian Lafferty In Honor Of
Kathryn B. Keener
Ian D. & Lois A. Laing In Honor Of Lois A. Laing
Gray Laney In Memory of Pamela Laney
Pamela Lange In Memory of Thelma Lange
Hazel Langhans In Memory of Herman Langhans
Gerald F. & Anita M. Lathan In Memory of
Patricia Lewis
Lena M. Latragna In Memory of Joseph Latragna
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In Memory of William Ron Sandwith
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Rick Lewis In Memory of John E. Jack Mann
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Patricia Lughezzani In Memory of Don McMican
Leonard Lukowski In Memory of Betty Lukowski
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John E. Jack Mann
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John E. Jack Mann
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Elizabeth Gilbert
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Bill Martini
Gene Mason In Memory of Mabel Mason
William & Joan Mathews
Tom & Gloria Mattero In Honor Of Alda Mocogni
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Carolyn N. McCauley In Memory of
Betty Lacy Latham Clifford
Jane R. McCormick In Memory of
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Barbara & Paul McNulty
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William Ron Sandwith
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John E. Jack Mann
Gary Milgard In Memory of William Ron Sandwith
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Isadore Lourie
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Evelyn Stevens
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Anastasio diBenedetto
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Miriam Rehr In Memory of Aaron J. Rehr
Joan Reifler
Ken & Lisa Reisen In Memory of Gerald Zimmerman
Don & Marie Rennie In Memory of
Dorothy Ann Kimball
Alan & Anne Reyner In Memory of Isadore Lourie
Deirdre H. Richards In Honor Of Burt Harkins
Josephine D'Amato Richardson In Memory of
Anna Consorte D'Amato
Elisabeth Rieger In Memory of Josef Rieger
Meg H. Robbins In Memory of
Henry B. Holmes & Jessianna H. Johnson
Richard Robbins In Memory of Roland Kaput
Harold & Olza Roberts In Honor Of Olza Roberts
William Dixon Robertson III. In Memory of
Isadore Lourie
Jan Como Rodriguez In Memory of Ilio G. Como
John Roeger & Laura Lughezzani In Memory of
Don McMican
John R. & Carol C. Roof In Memory of
Isadore Lourie
Lou & Mary Rosato In Memory of Rita Tropeano
Gene Rose In Memory of Delores Rose
Mildred R. Rosin
Mariana B. Rowe In Memory of Don Wells Sr.
Robert V. & Edith F. Royall In Memory of
Isadore Lourie
Dr. Richard L. Rubens In Memory of Diane Davey
Janice & Mac Russell
Anna Saladino In Memory of Nan Scelzi
Imelda Salnoske In Memory of Carlton Salnoske
Kirk M. Sandifer In Memory of John E. Jack Mann
Mark & Tamela Sandwith In Memory of
William Ron Sandwith
Patricia Iturriaga Sandwith
Thomas E. & Wendy E. Scheg In Memory of
William Ron Sandwith
Toni & Randy Schepher In Honor Of
Howard M. Dodge
Helen Chin Schlichte In Memory of
George A. Schlichte
Kelly & Joe Schmidt In Memory of Lyle Buettner
John E. Schoenecke In Memory of
June Clarice Schoenecke
Edward & Joni Schroeder In Honor Of
Sally Schroeder
Othmar & Sally Schroeder In Honor Of
Sally Schroeder
Cynthia Schwab In Memory of Judith Herrman
Scott & Reid General Contractors In Memory of
Robert Boatright
Jeanie & Dave Seal In Memory of Donald F. Murphy
Sevan Sales, Inc. In Memory of
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Charles A. & Carol A. Simonson In Memory of
James A. Toll, Sr.
Bret Sisney In Memory of Robert Evans
Donna & Chuck Sisney In Honor Of
Robert Evans
Robert Slominski In Honor Of Mary Slominski
Barbara P Smith In Memory of
John Hohler & Madeline Pindar
Berl A Smith In Memory of Berl S. Smith
Charles Robert Smith In Memory of Peggy Smith

Report Of Gifts

PATRONS \$100 AND OVER

Continued

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Robert F. Smith
Gerald Souder In Memory of Catherine E. Souder
Melvin & Rita S. Spira In Memory of Isadore Lourie
Arlene & Jeffrey Spitzer In Memory of Arthur Goldberg
Clyde A. Spooner In Honor Of Leslie E. Spooner
Spratt In Memory of Anastasio diBenedetto
St. Thomas Lutheran Church Bridge Club In Honor Of Gunnar Hausmann
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Kevin & Laurie Stiver In Memory of Theodore Cocca
Carter & Doris Stokes
Lane & Nancy Stokes In Memory of Martha C Christian
David & Donna Stone In Memory of James A. Toll, Sr.
Ty Storlie In Memory of John E. Jack Mann
John & Charlene Storms In Memory of Cleo A. Teel
John Strada In Memory of Marcia N. Strada
Gary A. & Susan M. Strand In Memory of Paul Bickerstaff
George Ken & Sheila Stringer
Sunshine House In Memory of Isadore Lourie

Superior Engineered Products Corp. In Memory of William Ron Sandwith
Robert P Tardiff In Memory of Laurier Tardiff
Pete & Karen Tarricone In Memory of Kathleen May-Maglio
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Beverly Tezak In Memory of Anne Blackstock Allen
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Leonard & Jean Tomat In Memory of Aldo Tomat
Henry Torre In Honor Of Mary Torre
Georgeen Transue In Memory of Alan Transue
Mary Trotta In Memory of Jerome Trotta
Frank & Mary Trulaske In Memory of Evelyn Stevens
Thomas J. Tucker In Honor Of Betty Jo Tucker
Unique Marketing of Florida In Memory of Diane Davey
United Way Anonymous
Robert Vadnais
Stuart & Susan Vendeland, DDS In Memory of William Ron Sandwith
Veritas In Honor Of John & Anne Stubbs
The Verry Family In Memory of James A. Toll, Sr.
Cheryl Vierthaler
Vista Window Company LLC In Memory of William Ron Sandwith

Joseph & Barbara Volpicelli In Memory of Evelyn J. Faretra
Ken & Kelo Waldorf In Memory of Betty Lacy Latham Clifford
Jack Ward In Memory of John E. Jack Mann
Joe & Margaret Watkins In Memory of Isadore Lourie
David L. & Iris S. Webster In Memory of William Ron Sandwith
Linda B. Webster In Memory of Robert E. Webster, Jr.
Paul Jay Weinberg In Memory of Dolores Bartas Weinberg, Wheeler, Hudgins, Gunn & Dial, LLC In Memory of Isadore Lourie
Lawrence S. & Francine R. Weiner In Memory of Isadore Lourie
Frank Jr. & Judy Wells
The Wilson Family In Memory of Roland Kaput
Wilson Law Firm In Memory of Isadore Lourie
Anne S. Wilson
James & Susan Wilson In Memory of Douglas Harkleroad
Mark & Sheila E. Wilson In Memory of Clarence P. Hicks, Jr.
Doneta & Ben Wire In Honor Of Edward Underriner
William P. Yetter In Memory of Jeanne B. Yetter
Carolyn Young
Laura M. Zaidman In Memory of Isadore Lourie

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 Green 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: • Ellen Katz, Executive Director
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 Medical Professional's Journal Review/*The PSP Advocate*
- #14 Brain Bank Information Packet
- #15 Physician Referral Cards
- #16 Giving Envelopes
- #17 The Society for PSP/National Institutes of Health PSP Brainstorming Conference/Dr. John Steele meeting with the Maryland Support Group \$25, plus \$3 shipping in US and \$5 outside the US.
- #18 Beautiful Acknowledgment Card to someone special for any occasion and will personalize your message. By donation only.
- #19 Planned Giving Information
- #20 Information About PSP translated in Spanish
- #21 I Have Been Diagnosed with PSP
- #22 Challenges in the Management of PSP
- #23 Support Group List

Mail to: _____

Fax to : _____ Email to: _____

FOR PHYSICIANS ONLY:

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

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The Decade of Hope

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