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INSIDE:

**PSP RESEARCH
ABSTRACTS II**

**ADAPT-ABILITY
WITH PSP:
AN OCCUPATIONAL
THERAPIST'S
PERSPECTIVE**

HOPE AND HELP IN AN EVER-CHANGING WORLD

Become a Support Group Leader and Make a Difference!

You've heard it all over our nation: resources today are fewer than in past years. Lately, that has meant less money for companies, organizations and individuals nationwide. But resources include much more than just dollars. They include PEOPLE – especially when you are living with a disease like PSP.

PSP by nature is an isolating disease. People who are diagnosed with it are fortunate if their physician is familiar with progressive supranuclear palsy (We are working to change that too, but that's another article!). After the shock of receiving a diagnosis of PSP, families usually want to know, "Who can I talk to that will understand?" I sometimes feel like my title should read "connector" since one of the main goals of the outreach & education program is to connect families with others who know what they are going through as they travel the journey of PSP. Did you know that part of the Society's strategic plan includes establishing a process to educate and support patients with PSP and their carepartners? Support groups play an enormous role in helping families find local resources, support and, most importantly, "real-life" experience. Support group leaders and fellow group members are walking, or have walked, in your shoes. They know firsthand the challenges you are struggling with and can share with you what has (or has not) worked for them. Don't travel this road alone!

"Each person brings a little something to the group that when added together brings hope and help."

-Heather Cianci, Pennsylvania

WHY DO WE NEED LEADERS?

To date, the Society has 59 support groups listed on our roster. We have leaders in 32 states, Canada and Australia. That is great



Support and Friendship

news! But more are needed. New people are being diagnosed with PSP all the time. After each *PSP Advocate* is published, Charlotte Tripet, Minnesota contact on the Society's support group list, gets calls from readers looking for someone to talk to about their experience with caregiving for someone who has PSP. Think back to how you felt when your loved one

first received the diagnosis of PSP. Wouldn't you have given anything just to meet someone else who had heard of PSP? Perhaps you are reading this newsletter for the first time after hearing that you have PSP. Maybe you have lost a dear family member to PSP and wish that you could find a way to help others cope with this disease. "We comfort each other, relive each other's losses and laugh about the funny things that happened along the way," says Alice Kitchen, co-facilitator of the Kansas City group. "We hope our new members get the sense that they are not alone."

Our support groups are in a constant state of flux for many reasons. Most group members are also caregivers, and some find it difficult, if not impossible, to take charge of a group while balancing the challenges of caring for a loved one who is in the later stages of PSP. Some have trouble even making it to a group meeting. The most difficult reality is that PSP has no known cure yet. Many individuals understandably pull away from support groups after losing a loved one. Support group leaders are wonderful volunteers, but even caring, dedicated

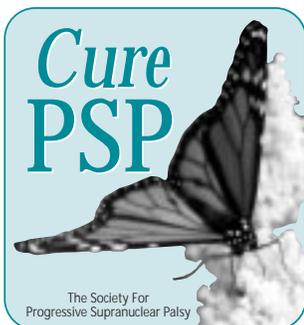
"It brings me comfort and peace knowing that I am helping others.

I have walked in their shoes.

PSP caused us to meet, but hearts made us friends."

-Patti Ryan, Massachusetts

Continued Page 16



The Society for Progressive Supranuclear Palsy

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

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

Dear Friends,

On May 12, my husband of 32 years passed away from leukemia. Albert was the wind beneath my journey with the Society for PSP. He listened with caring and concern for the multifaceted issues I was involved with on a daily basis - on board issues, fundraising, special events, finance and human resources issues. He was a master manager, a highly skilled businessman, a lover of people, a philanthropist and a genuine friend. He advised me, consoled me and guided me on many issues affecting the Society.

He understood the need to travel and be away from him, to spend weekends on Board meetings and to spend many evenings on conference calls and committee meetings. He traveled with me as much as possible, attending symposium and special events. He attended every Board dinner and enjoyed the repartee with all members of the Board. He tried to find our single female board members husbands, advised the board on pharmacy issues and just enjoyed their company. He was a volunteer carting around Society paraphernalia anywhere I went, selling tee shirts and doing what ever was asked of him. He called upon his friends to donate items to the Society for door prizes and artwork hanging in the Society's headquarters. He was always here to support me.

He was above all, most proud of my work with the Society and stood beside me as a stalwart, an advocate for PSP and a true friend to me and the Society. We shall all miss his warmth, his kindness and his friendship.

Although you cannot always see the bird singing, if you listen with your heart, you can always hear his song. Goodbye, Albert.

Ellen



Albert Katz's Illness

Albert was perfectly healthy in mid-December. He even ran 90 minutes on the treadmill on December 17, 2002. On the evening of December 20, he woke up with shaking chills, fever, a headache and nausea. Albert's physician diagnosed "the flu" and began Albert on antibiotics. Two courses of antibiotics did not help and he was losing weight. A blood test in mid-January revealed low platelets and Al was referred to a hematologist. When the doctor

July 28, 1935-May 12, 2003

said, I think you have leukemia, Albert replied, I think you are crazy.

Increasing fatigue, inability to work, anemia and lower platelet counts caused Albert to be immediately admitted to the Greenebaum Cancer Center at the University of Maryland.

The diagnosis was acute lymphocytic leukemia or "ALL." Mostly seen in children, ALL is very treatable if under the age of 18, where the cure rate is 75%. In adults, the prognosis for a cure is dependent on genetic factors, especially missing and defective genes. In Albert's case, his genetic factors were made up of many altered genetic arrangements, resulting in an aggressive virulent case of ALL. Albert would

not go into remission after 3 heroic attempts of aggressive chemotherapy, radiation and 2 stem cell transplants with cells matched exactly from his brother, Larry.

The doctors, nurses and staff, using state-of-the art treatments, worked valiantly to save his life. The Greenebaum Cancer Center is a fabulous facility.

Albert never gave up hope that he would be cured. He faced the disease, the debilitating side effects of chemo and radiation, and infections with bravery and determination. The doctors and staff were inspired by his courage and grace.

He succumbed to an infection on Monday, May 12, 2003 at 6 pm with his family, friends, clergy and abundant hospital staff surrounding him with prayers, songs and much love.

Goodbye our dear, Albert. You will always be missed but you will always be remembered in so many hearts and by the people whose lives you touched.

President's Corner

"You make a living by what you get. You make a life by what you give." Winston Churchill

In late February, the Strategic Plan Steering Committee had its first meeting in Baltimore to begin talking about the direction of the Society for 2004-2007. I was pleased with the progress we made in only one day. Six key areas were identified and where we focused our attention. They are:

- Research
- Volunteers/Leadership Programs
- Outreach and Education
- Development
- Advocacy
- Public Relations



We have a very distinguished committee made up of a combination of 17 members from the Board of Directors, Medical Advisory Board, Researchers, Volunteers, Executive Directors for other non-profit organizations and the staff from the office. Currently the committee members are working on identifying the top priorities for each of these six areas and are creating strategies for implementation which will be presented to the Board of Directors later this year. I will continue to share with you the progress of this committee and welcome your thoughts or any interest you may have in participating in any one of these areas.

Inside this newsletter, you'll find practical tips and information focusing on our support groups. I am thankful to these individuals for your tremendously positive focus on strengthening the organization and spreading the word about PSP at a local level. There are many ways that each of us can help make our voices heard, whether through financial contributions, volunteering time or putting together an event. Now more than ever, we desperately need a strong collaboration from the PSP community to help the Society meet important objectives - namely, finding the cause and cure of PSP and helping to educate persons, families and caregivers dealing with PSP. Without funding it will be difficult for us to continue these programs that have helped so many throughout their struggle with PSP. Please contact the office at 800-457-4777 to find out more on how you can help, or make a gift online at www.psp.org.

Sincerely,
Elizabeth Brisson, President

Education, Connection, Hope...

An afternoon conference on PSP offers information, support and friendship to PSP families

One day last fall, Russ Swerdlow, MD, Assistant Professor of Neurology at the Center for the Study of Neurodegenerative Diseases, University of Virginia Health System, was contacted by the Society and asked if he would be willing to participate in a spring conference on PSP to be held in Charlottesville, VA. Not only was his response an immediate "yes," but with it came a referral to Susan Dietrich, the American Parkinson's Disease Coordinator at the UVA Health System and Janice Morris, Director of Continuing Education programs. The plans began.



Russ Swerdlow, MD

This collaboration revealed a gold mine of experts who actively work with persons diagnosed with PSP and their families in different disciplines of the medical field. As each speaker was invited, he or she responded with another immediate "yes" and enthusiastically asked about other ways to help. PSP families in Virginia and surrounding areas are fortunate to have this expert PSP team available to work with them.

On March 29, 2003, Nancy Brittingham, *The PSP Advocate* Editor and Special Programs Coordinator, welcomed guests to the Zehmer Hall Conference Center at the University of Virginia. Among these guests were seven persons diagnosed with progressive supranuclear palsy, PSP families, social workers, registered nurses and even a general neurologist – all seeking to increase their knowledge on how to better manage the symptoms of PSP. While each speaker kindly took time to answer questions from the audience, PSP families were not the only participants who increased their awareness of PSP management. The speakers themselves took many notes while listening to each

other's presentations. Virginia and Maryland families even had the opportunity to meet PSP families from West Virginia and South Carolina! Above all, this connection among families inspires hope and comfort as individuals unite as friends sharing in the journey of PSP.

The afternoon's program began as Joel M. Trugman, MD, Associate Professor of Neurology, UVA, discussed "The Basics of PSP." Some of the topics presented by Dr. Trugman included:



Joel M. Trugman, MD

Parkinson's disease versus atypical Parkinson's

PARKINSON'S DISEASE:

- Asymmetric
- Tremor
- Good response to L-dopa
- Balance impairments occur late

ATYPICAL PARKINSONISM:

- Symmetric/bilateral
- No tremor
- No response to L-dopa
- Balance impairment occurs early

Differential diagnosis: Diseases that must be excluded when diagnosing PSP

- Parkinson's disease
- Atypical parkinsonisms: multiple system atrophy and corticobasal degeneration
- Degenerative dementias: Alzheimer's disease and frontotemporal dementia
- Stroke

Pathology of PSP

- Neurons and astrocytes (supporting cells in the brain) accumulate tau protein, a type of microtubule associated protein.
- Neurons die and there is visible shrinkage of the parts of the brain that are affected.

Management of symptoms in PSP

- Gait instability – weighted walker
- Swallowing – change food consistency
- Slurred speech – speech therapy
- Depression – antidepressants and counseling

Visual disturbances in PSP and treatment options

- Decreased blink rate - artificial tears
- Blepharospasm - Botox
- Inability to open eyes - talking books
- Double vision - prisms
- Inability to look down

Future therapy in PSP

- PSP is clinically similar to Parkinson's disease and pathologically similar to Alzheimer's disease
- These are all diseases with abnormal protein aggregation in the brain
- There is reason to believe that treatments developed for Parkinson's or Alzheimer's disease will be beneficial for PSP since there are most likely common mechanisms of pathogenesis.

When faced with a rare disease like PSP, families often thirst for understanding and accurate knowledge of any kind. Perhaps most directly applicable are the strategies shared by medical experts for making the activities of daily living more manageable. "Physical Therapy and PSP" was discussed by John Zenker, MS, PT, Neuroscience Services, UVA Health System. Mr. Zenker shared tips for getting in and out of bed, getting up from a chair and getting in and out of a car. He discussed walking tips, wheelchair cushions, helping the caregiver and protection from falls.

Special Events



John Zenker, MS, PT

Listed below are a few excerpts from this very informative presentation. He cites thanks to the resource material developed by Heather Cianci, PT, GCS, The Dan Aaron Parkinson's Rehabilitation Center, Pennsylvania Neurological Institute, Philadelphia, PA.

Role of Physical Therapy

- Unfortunately, physical therapy cannot affect the changes in the brain brought on by PSP.
- Physical therapy can provide help with compensatory techniques to improve mobility.
- Physical therapy can help prevent secondary changes brought on by PSP.

Exercise

- Look for activities patient and helper can perform together – do things you enjoy!
- Staying active is often the best exercise.
- Exercise has positive effects on your sense of well-being.
- Stretching exercises keep joints & muscles limber, which makes mobility easier.
- Stretch the neck, trunk, shoulders, ankles and hamstrings.
- Types of exercise:
 - Conditioning/Aerobic (Biking, Swimming, Dancing, Walking)
 - Strengthening (Muscle groups: triceps, quads, gluts, back, ankles (dorsiflexors))

When to See a Physical Therapist

- When you notice a change in abilities or a problem with falls – when the old ways of doing things aren't working or are frustrating
- When you are thinking of purchasing equipment such as a walker or wheelchair
- When you need a home program personalized for your needs

Lisa Warbuton, MS, CCC-SLP, Speech-Language Pathologist, University of Virginia Health System discussed "Swallowing Issues in PSP." She discussed different tests used to evaluate swallowing, the components of the swallow reflex and the dysphagia warning signs. Below, are some definitions and "helpful hints."



Lisa Warbuton, MS, CCC-SLP

Terminology

- Dysphagia: any difficulty swallowing
- Aspiration: food / liquid / saliva / foreign material entering airway

- Silent aspiration: aspiration without behavioral indication
- Dysarthria: unclear speech due to weakness
- Dysphonia: impaired vocal integrity

Possible prescribed swallowing compensation

- Cue to "dry" swallow and clear mouth between bites
- Alternating solids and liquids
- Change meal schedule to more frequent, smaller meals
- Cues to put spoon / cup down between bites / sips
- Therapeutic utensils / "sippy" cups
- Use phone book or tray to elevate plate to keep in line of vision

General Swallowing Guidelines

- Sit upright / keep neutral head posture
- Minimize distractions
- Take small bites / sips
- No talking while eating
- Take one bite / sip at a time
- Rinse mouth (and dentures) after meals
- Remain upright for 20 minutes after meals

Occupational Therapist Tony Gentry, OTR/L from the Partnership for People with Disabilities, Virginia Commonwealth University, gave a presentation entitled "Adapt-Ability with PSP" which included hints for daily living to make life with PSP a little more manageable. Some of the topics covered included PSP and its impact on everyday routines, getting in and out of bed, getting in and out of the bathtub, retrieving things, getting up from the toilet and car transferring. Tom cited many working strategies, and as he spoke, PSP families commented on his insightful adaptations. You can view Tom's complete presentation in his article on pages 11-13.



Tony Gentry, OTR/L

When to See an Occupational Therapist

- When you need help to perform any everyday activity
- When you want help with home adaptations
- When you have functional vision or cognition changes that affect your lifestyle

Home Adaptations

- Nonglare lighting
- Eye level markers for steps
- Tilted mirror at sink
- Improve contrasts
- Use visual aids
- Reduce visual clutter
- Increase contrast
- Focus on bathroom, kitchen, shop safety
- Think through adaptations for community outings
- Pace yourself

Special Events



The Charlottesville Group

Community Outings

- Gray-tinted wraparound glasses
- Cane to mark surface changes
- Allow more time
- Seek quieter places at less busy times

Reading & Writing

- Magnifying glass
- Magnification of computer screen
- Tools to raise materials to eye level
- Hemi-taped glasses for diplopia (There are various models. The least expensive costs about \$1000).

Our hope is in the advancement of PSP research. Russell H. Swerdlow, MD, as described earlier, is also one of the Society's research grant recipients. Dr. Swerdlow presented his PSP research at the 2002 PSP International Research Symposium held in November in Miami, FL. (PART II of the Symposium abstracts are included in this publication.) Dr. Swerdlow covered several topics including tau research, mitochondrial genes, oxidative stress and the source of free radicals.

Tau and Tangles: A Clue?

The Tau Gene

- The tau gene is on chromosome 17
- People with PSP generally don't have tau gene mutations
 - When present (less than one in 100), are they important?
- Comes in 2 different flavors (polymorphisms)
 - H1
 - H2
- Everyone has 2 copies
 - H1/H1, H1/H2, H2/H2
- For persons with PSP:
 - H1/H1 type is found more frequently than in controls
 - H2/H2 type is found less frequently than in controls
- Can tau gene type influence PSP risk?

Oxidative Stress

- There is oxidative stress in the brains of persons with PSP
 - Activates an enzyme (CDK5) that affects how tau is processed
- Antioxidant molecules (glutathione) are depleted in PSP substantia nigra
- Could agents that help mitochondria and scavenge free radicals help? (creatine?)

Summary

- Future research on tau
 - Looking at the tau gene
 - Looking at how tau is processed
- Future research on mitochondria
 - Looking at oxidative stress
 - Looking at how oxidative stress kills cells
- The search for treatments that will alter the underlying disease process
 - Drugs that influence how tau is handled by cells
 - Drugs that influence mitochondria-related events
 - Antioxidants
 - Cell death pathways
 - Repair/Replace strategies
 - Stem cells

This event lacked one thing—more time to talk and share with other PSP families. The medical experts graciously answered all the audience's questions, but families had so much more to discuss with each other. That is why we hope that a PSP



*Now why didn't I think of that?
Seen in the parking lot at the
Charlottesville Conference*

network/support group will grow from this meeting. Because connection with other people who understand what you are going through is so important, the Society is forming a new support group that would alternate meetings between Richmond and Charlottesville, VA. If you are interested in being part of this group, please contact Jessica Quintilian, Director of Outreach & Education, at 1-800-457-4777 or via email, outreach@psp.org.

In addition to thanking our guests, speakers and volunteer coordinators, the Society would also like to recognize and thank Provident Bank for sponsoring this event and making this conference possible. The Society for PSP is grateful for the support and generosity of Provident Bank, whose continued efforts have helped the Society offer regional conferences, educational seminars and caring and sharing events. We hope to continue to expand this vital portion of our outreach program.



Nancy Brittingham (The PSP Advocate Editor) with husband Bob, daughters Jane-Lauren and Kristen and sister, Mary, greeting guests in Charlottesville.

Upcoming Events

OCTOBER IS PSP AWARENESS MONTH

Start planning your event today! Last October there were eleven events that increased PSP awareness and raised over \$14,000 to support the Society's patient and family services.

Plan a walk-a-thon, spaghetti dinner, Jeans Day, golf or bowling tournament or dinner auction. Contact the Society office to learn how the Society staff and Special Events Committee can help you plan your event



The PSP Harvest Festival and Hayride held in New York October 20, 2002 raised over \$1,500 to help support the Society's services.

Join the "Special Event Volunteer" Committee

We are already planning October Awareness Month Activities as well as other fun activities for this year. Come be a part of this team. Look what our super event planners did this past October. Call Jessica Quintilian at the Society office or email her at outreach@psp.org.

Join the cause!!



AN AFTERNOON OF CARING & SHARING IN CHICAGO

Chicago Marriott Oak Brook, Oak Brook, IL
July 13, 2003 • 1:00-4:00 p.m.

For more information, please contact Jessica Quintilian, Director of Outreach & Education at 1-800-457-4777 or email: outreach@psp.org.



THE MINNESOTA REGIONAL CONFERENCE FOR PERSONS DIAGNOSED WITH PSP, CAREGIVERS, FAMILIES AND ALLIED HEALTH PROFESSIONALS

Minneapolis Marriott Southwest
Minnetonka, MN

September 20, 2003 • 12:30-5:00 p.m.

For more information, please contact Jessica Quintilian, Director of Outreach & Education at 1-800-457-4777 or email: outreach@psp.org.



THE MEREDITH C. TEEL, REGIONAL SYMPOSIUM FOR PERSONS DIAGNOSED WITH PSP, CAREGIVERS, FAMILIES AND ALLIED HEALTH PROFESSIONALS

Sheraton North Houston, Houston, TX
October 11, 2003 • 9:00 a.m.-3:30 p.m.

If you have questions about this event, please contact Karen Kennemer at 281-358-2282, email: KMK1224@aol.com or Jessica Quintilian, Director of Outreach & Education, 1-800-457-4777.

THE 107TH ANNUAL MEETING OF THE AMERICAN ACADEMY OF OPHTHALMOLOGY

The Society for PSP which will be represented with an informational exhibit at The 107th Annual Meeting of the American Academy of Ophthalmology will take place at the Anaheim Convention Center in Anaheim, CA. November 15-18, 2003. The ophthalmologist is often the first medical professional visited as a PSP family begins its search with a loved one. The Society will attend this meeting to educate ophthalmologists, nurses, ophthalmic technicians, and other allied health personnel who are engaged in the diagnosis and treatment of eye diseases, about progressive supranuclear palsy, the Society, and its services.

SOCIETY FOR NEUROSCIENCE 33RD ANNUAL MEETING NEW ORLEANS • NOVEMBER 8 - 12, 2003

The Society for Neuroscience Annual Meeting is the premiere venue for neuroscientists to meet and exchange the latest discoveries about the brain, spinal cord and nervous system. Neuroscience includes the study of brain development, sensation and perception, learning and memory, movement, sleep, stress, aging and neurological and psychiatric disorders. It also includes the molecules, cells and genes responsible for nervous system functioning. The Society will attend this meeting with an informational booth to provide information about the Society's research grant program and stimulate interest in PSP research.

Abstracts of The Society for PSP's Funded Research Part II

with editorial revisions by Lawrence Golbe, MD

MITOCHONDRIA IN PROGRESSIVE SUPRANUCLEAR PALSY



Russ Swerdlow, MD
University of VA Health Services
Center, Charlottesville, VA

Progressive supranuclear palsy (PSP) is a late-onset neurodegenerative disorder that tends not to show Mendelian inheritance. Other late-onset, non-Mendelian neurodegenerative disorders exhibit mitochondrial dysfunction that at least partly derives from mitochondrial DNA (mtDNA). To

see if mtDNA-derived mitochondrial dysfunction also occurs in PSP, we transferred mtDNA from affected individuals to neuroblastoma cells previously depleted of endogenous mtDNA. The resulting cytoplasmic hybrid (cybrid) cell lines were expanded in culture and electron transport chain activities determined. Complex I activity in the PSP lines (n=15) was 12.4% less than that of age-matched control cybrid lines (n=17) (p<0.005). Complex I is a multimeric enzyme that contains both nuclear and mtDNA-encoded subunits. Since nuclear DNA was clonal among all cell lines, this difference in complex I activity indicates mtDNA aberration occurs in PSP. As the transferred mtDNA was derived from platelets, it further suggests this mtDNA aberration does not arise as a consequence of neurodegeneration. Cybrids were also assayed for indices of oxidative stress, and relative to controls antioxidant enzyme activities were increased in the PSP lines. We conclude mitochondrial DNA aberration occurs in PSP independently of neurodegeneration, causes bioenergetic dysfunction (complex I defect), and results in potentially toxic oxidative stress.

Lay Abstract

It is uncommon for progressive supranuclear palsy (PSP) to run in families. This is the case for related diseases like Parkinson's disease (PD), suggesting that unusual genes may contribute to these disorders. In PD, there is known to be dysfunction of cellular structures called mitochondria, which have their own unique set of genes (called mitochondrial DNA) and these mitochondrial genes appear to be abnormal. To see if PSP patients also have malfunctioning mitochondria and abnormal mitochondrial genes, we moved mitochondrial genes from PSP patients into cells that we could grow in the laboratory. When we did this, we found that expressing the mitochondrial genes of the PSP patients caused abnormalities of a protein in the mitochondria called complex I. Another consequence of expressing the mitochondrial genes from the PSP patients in the laboratory cells was that the cells began to produce excessive free radicals, which are believed to be harmful. Our experiments suggest that mitochondrial genes may be abnormal in persons with PSP, and that this could lead to abnormal mitochondrial functioning and oxidative stress.

MUTATIONAL ANALYSIS OF THE TAU GENE IN PSP



Joseph J. Higgins, MD
Center for Human Genetics &
Child Neurology,
Mid-Hudson Family Health
Institute, New Paltz, New York,
NY

Frontotemporal lobar dementia (FTD), progressive supranuclear palsy (PSP), and corticobasal degeneration (CBD) are sometimes classified as the "tauopathies"

because of their distinctive tau protein (MAPT) migration patterns on Western blots and their immunostaining characteristics. The presence of neuronal and glial, intracellular inclusions containing aberrant precipitates of MAPT, led to the hypothesis that mutations in the tau gene itself were responsible for the neuropathology of these disorders. This hypothesis was unproven until mutations in the coding and splice-site sequences of the tau gene were identified in families with dominantly inherited FTD with parkinsonism linked to chromosome 17 (FTDP-17). These mutations can impair MAPT function, modify the alternative splicing of tau exons, and promote the intracellular aggregation of MAPT. Although there is considerable neuropathological overlap between FTD, PSP, and CBD, a significant number of cases do not have MAPT pathology or tau mutations, and some families with tau gene mutations lack MAPT pathology. In non-familial, sporadic forms of these disorders, mutations in the tau gene are infrequent. At this symposium, we will summarize our studies of the tau gene in patients with PSP and describe its complex relationship to the fundamental genetic processes of transcription, translation, and post-translational modification.

Lay Abstract

Progressive supranuclear palsy (PSP) belongs to a group of disorders known as the "tauopathies." A common feature of these disorders is the presence of an abnormal form of the tau protein in the brain. This finding led to the hypothesis that mutations in the tau gene itself were responsible for these disorders. Recently, mutations in the tau gene were identified in one of the "tauopathies". Although there is considerable neuropathological overlap between the tauopathies, a significant number of cases do not have tau pathology or tau mutations. At this symposium, we will discuss the genetic reasons for this discrepancy and summarize our studies of the tau gene in patients with PSP.

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



Research

TOWARD IDENTIFICATION OF A PSP GENE

Parvoneh Navas, MD
University of Washington
Seattle, WA



A human PAC (201 kb) and a mouse BAC (161 kb) containing the entire MAPT and Mtapt genes, respectively, were identified and sequenced. Comparative DNA sequence analysis revealed over 100 conserved non-repeat potential cis-acting regulatory sequences in or close to MAPT.

These islands, with greater than 67% nucleotide identity, range in size from 20 to greater than 1700 nucleotides. Over 90 single nucleotide polymorphisms were identified in MAPT. The 5' and 3' flanking genes for MAPT are the corticotrophin releasing factor receptor (CRFR) gene and KIAA1267, a gene of unknown function expressed in brain. MAPT was also screened for mutations in 96 PSP subjects. A point mutation (R5L) was identified in a single PSP subject that was not in the other PSP subjects or in 112 controls. Functionally, this mutation alters the ability of tau to promote microtubule (MT) assembly. Analysis of soluble tau from different brain regions indicates that the mutation does not affect the ratio of tau isoforms synthesized. Aggregated insoluble tau from subcortical regions, was predominantly 4-repeat tau with no or one amino terminal insert (ON4R and 1N4R). Insoluble tau from cortical regions also contained 1N3R tau.

Lay Abstract

The tau gene, which produces six variations of a neuronal protein in the human brain, is in some way involved in the onset or progression of Progressive Supranuclear Palsy. This was initially discovered when certain DNA "fingerprints" in the tau gene were found in greater numbers of individuals with PSP than in unaffected persons. Variations ("fingerprints") in the tau gene that regulate protein production might cause or contribute to PSP. A grant from the Society for PSP allowed us to compare the human tau gene to the tau gene of a more distantly related mammal. By comparing these sequences we identified greater than 100 conserved DNA regions that are potentially important regulatory elements that may influence the onset or progression of PSP. We examined the tau gene and these identified conserved regions in both control individuals and individuals with PSP and discovered more than 70 new "fingerprints." We also identified a single, novel mutation in the tau gene in one PSP subject. This mutation was not found in other PSP subjects or in 112 controls and is therefore a rare cause of PSP. This novel tau mutation will be inserted into nervous system cells growing in the laboratory in order to examine how this abnormal tau protein causes the changes that occur in PSP.

GLIAL TAU AGGREGATION IN PSP AND CULTURED CELLS

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AECM
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Progressive supranuclear palsy (PSP) is one of the neurodegenerative disorders characterized by tau dysfunction. Both glial and neuronal tau pathology have been highlighted in PSP. The pathological features have been described as abnormal intracellular tau inclusions in specific anatomical areas involving astrocytes, oligodendrocytes and neurons. The goal of our studies was to replicate pathological tau aggregation in brains of PSP patients using neuronal and glial cultures. Initially, we used astroglial cultures established from human fetal brain. Cultured cells were treated with okadaic acid to induce hyperphosphorylation and aggregation of tau. Tau aggregates were extracted with sarcosyl as described for PSP and Alzheimer's disease brain tissue. We found that okadaic acid treatment induced tau aggregates which resembled tau filaments isolated from glial-specific lesions in PSP brains. The similarity between cell culture-derived and authentic tau filaments was established at biochemical and ultrastructural levels. Our recent studies suggest that hyperphosphorylation and aggregation of tau may be linked to the upregulation of Akt kinase, a factor involved in cell survival pathways. Additional studies are needed to determine whether tau protein is a substrate for Akt kinase. If proven, these studies implicate the Akt survival pathway as a molecular mechanism for tau aggregation in cellular models of glial degeneration and in PSP.

Lay Abstract

Our research will determine why abnormalities in tau protein structure may cause PSP. For a number of years we have been studying tau protein abnormalities, which are partially shared by Alzheimer's disease, corticobasal degeneration and PSP. Abnormal tau protein aggregates in the brain are common to all these disorders. It is believed that aggregation of tau is an immediate cause of brain malfunctioning. The abnormal tau in PSP has an excessive amount of phosphate attached to it. We experimented with brain cells growing in the laboratory to determine the role of phosphorylation in the dysfunction of tau. We found that tau treated with okadaic acid was very similar to the tau from the brain of patients with PSP. We also found that excessive activity of the enzyme Akt kinase (kinases are enzymes that attach phosphate to proteins) is involved in the abnormal phosphorylation of tau. These clues may prove important in finding treatment or prevention of PSP based on correction of abnormal tau phosphorylation or the prevention of the subsequent effects on tau aggregation.

Research

INCREASED ACTIVITY AND EXPRESSION OF TRANSGLUTAMINASE IN PSP

Nancy A. Muma, Ph.D.
Loyola University Medical Center,
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Nancy A. Muma

Transglutaminases catalyze the covalent cross-linking of substrate proteins to form insoluble protein complexes that are resistant to degradation. Our previous studies demonstrated that transglutaminase-induced cross-linking of tau proteins occurs in progressive supranuclear palsy (PSP) and Alzheimer's disease. We now measure transglutaminase enzyme activity and expression of three transglutaminase isoforms expressed in human brain. Overall, transglutaminase activity was significantly increased in the globus pallidus and pons in PSP but not the occipital cortex (a region spared from pathology). Tissues with more transglutaminase-activity had more neurofibrillary tangles. Protein and mRNA levels of transglutaminase 1 were increased in globus pallidus in PSP. Transglutaminase 1 mRNA and the long isoform of transglutaminase 2 mRNA were significantly higher in PSP in the dentate of cerebellum. The mRNA levels of the short isoform of transglutaminase 2, however were significantly greater in PSP cases as compared to control cases. An increase in the short transglutaminase 2 isoform is important because in this isoform, the GTP-binding domain has been spliced out, thus there could be no negative regulation by GTP. Together, these findings suggest that transglutaminase 1 and 2 enzymes may be involved in the formation and/or stabilization of neurofibrillary tangles in selectively vulnerable brain regions in PSP.

Lay Abstract

Progressive supranuclear palsy (PSP) is characterized by the presence of aggregates of abnormal proteins in the brain. In PSP, the tau protein accumulates in brain cells in abnormal aggregates called neurofibrillary tangles. The mechanisms causing tau protein to form neurofibrillary tangles are not known. Our long-term research goals are to determine the mechanisms causing tau protein to form neurofibrillary tangles instead of performing tau's normal function. By knowing the mechanisms underlying the formation of neurofibrillary tangles, we can target drugs to prevent neurofibrillary tangle formation and preserve normal brain cells in PSP. Although the mechanisms causing the formation of neurofibrillary tangles from tau protein are not known, work in our laboratory and others are revealing some mechanisms that are likely to be involved. We demonstrated that in PSP, tau protein is abnormally cross-linked by an enzyme, transglutaminase. We found that the activity of transglutaminase is higher in PSP than in controls.

This is important because transglutaminase can cross-link proteins to form very stable protein polymers by linking together two or more proteins such as tau protein. Transglutaminase is a family of proteins in which at least three are expressed in

the human brain. We have found that two of these three transglutaminase proteins are elevated in PSP in brain regions that degenerate. These experiments lay the foundation for testing the ability of a transglutaminase-inhibiting drug to diminish the cross-linking of tau protein and potentially prevent the formation of neurofibrillary tangles.

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@umdj.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!

GIVE A GIFT ONLINE

www.psp.org



Ask the Doctor

Question:

How does the presence of a tracheotomy affect the risk of aspiration?

Answer:

Managed properly, this also reduces the risk of aspiration by allowing suctioning of secretions from the trachea. This is not necessary for most patients with PSP, though.



Lawrence I. Golbe, MD

Question:

What hope is there for those with PSP? I am newly diagnosed and I just keep hearing of caregivers and people who have died. What is the timetable like? How many years do I have? When will I be in a wheelchair? When will I face swallowing problems and feeding tube? I am very scared.

Answer:

The average lifespan after the first symptoms of PSP appear is 7 to 9 years, but this varies greatly with the age and general medical condition of the person and with the severity of the more dangerous complications such as swallowing difficulty and falls.

Question:

Does the previous physical condition of a patient who is diagnosed with PSP play any role in the timing and progression of PSP?

Answer:

Yes (see above)

Question:

Is there potential danger with the daily use of oxygen?

Answer:

PSP itself does not require oxygen, but during an episode of pneumonia caused by aspiration caused by PSP, oxygen supplementation may be necessary. There is no evidence that oxygen use accelerates the course of PSP.

Question:

I have not heard the mention of pain associated with PSP. My husband has been diagnosed with PSP, has stiffness in his legs and is in a lot of pain. Is that typical?

Answer:

Pain in PSP is very unusual, but if the limbs are dystonic (held in a fixed position, typically with a twisting component), they can sometimes become painful, especially if someone tried to overcome the fixed position forcibly.

Adapt-Ability with PSP: An Occupational Therapist's Perspective

By Tony Gentry, MA OTR/L BCN
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As anyone with PSP knows, the disease is relentless and sneaky. Over time, it whittles away at your ability to carry out the daily activities that matter to you. Vision may begin to change, posture may stiffen, your legs may seem to have minds of their own. The easiest things, such as speaking and swallowing, may become difficult. With each change in your abilities, you may feel as though you are gradually losing the skill to live a safe and fulfilling life. Many people retreat from the things they love most, afraid to fall, afraid to fail. The disease tries to rob you of mobility, social relationships and work skills. In this way, it attacks your very sense of identity and purpose in the world.

You can fight back. You can learn new ways to do things. You can make the environment around you safer and more functional. You can use the many tools available to help you stay active and independent for as long as possible. Occupational therapists can help you along this path in a variety of ways, teaching you and your loved ones (1) compensatory strategies for managing everyday tasks in new ways, (2) home adaptations to make your environment safe and more functional, and (3) how to make wise choices from the wide assortment of assistive devices available on the market today.

OTs can assist you in managing physical, functional, visual and cognitive changes related to PSP. We are trained to work from a person-centered perspective, focused on building a supportive social and environmental context to help you fight the disease. Your OT may address functional vision, physical skills, home safety, community independence, and cognition, always working collaboratively with you and your family to build the best mix of supports to help you. Though every person with PSP has a different situation and requires an individualized approach, let's look at some of the most common problems you may face and some of the recommendations your OT may suggest.

FUNCTIONAL VISION

Vision is our most far-reaching sensory ability. Any visual dysfunction can prove crippling, and in PSP, several visual skills are under attack. Characteristic visual changes associated with PSP include difficulty in downgaze, blurred or double vision (diplopia), reduced blink rate (leading to painful, dry eyes), photosensitivity (especially in bright sunlight), interrupted

Education

smooth tracking and steady gaze, and a reduced ability for the eyes to converge while watching objects move closer. Family members often say that their loved ones with PSP seem to stare off in space. This is probably an unconscious compensatory strategy intended to ease eye strain.

If you have begun to experience visual difficulties, by all means see a neuro-ophthalmologist. These eye doctors specialize in managing visual changes wrought by neurological processes. But don't stop there. Seek out a neuro-optometrist, too. These eye care professionals can fit you with glasses that combat double vision and provide other treatments to address photosensitivity and tracking difficulties. Neuro-optometrists (sometimes called behavioral optometrists), like neuro-ophthalmologists, specialize in working with individuals who have neurologically-based visual problems.

You will want to discuss your visual problems with your occupational therapist, too. He/she may recommend home improvements, task adaptations and assistive devices to help you optimize your visual skills. For instance, it's important to make sure that your lighting at home is bright, but without glare, especially in the areas where you like to read, cook, groom, work on crafts or hobbies, etc. Spend a weekend clearing out clutter from floor areas, cabinets and work surfaces so your overtaxed eyes can find things more easily and avoid pathway obstacles. Wherever possible, improve visual contrasts in the home. For instance, you may want to replace wall switch face plates and door knobs to make better visual targets. Florid wallpaper can play havoc with already-challenged eyesight. Flat colors and clearly marked surfaces work better.

If you have downgaze difficulty, you may find that a down-tilted mirror at the bathroom sink can help you see items below your visual field. Some people even install down-tilted mirrors above their kitchen stoves. A number of other tools can help, too. You can purchase mirrored prism glasses that work in the same way as down-tilted mirrors, allowing you to hold a book in your lap and read as you always have. Bookstands are available that hold reading materials at eye level. If text seems blurred, magnifying glasses may help. If you use a computer, you can easily increase print size and contrast on the screen using software that comes already installed on home computers. Many Internet web pages offer a "print only" version that is more easily read than a graphics-laden page.



If you suffer from double vision, your occupational therapist may show you how to tape a pair of glasses to compensate. To do this, you apply a finger's width of white tape to the nasal half of one lens of your glasses, blocking the vision from one eye when staring straight ahead. Since it's most important to have sharp vision when staring straight ahead (as when reading), this inexpensive strategy can help reduce double vision, at least until your eye doctor offers a more permanent solution.

Visual difficulties can make community outings a chore. Gray-tinted wraparound glasses are good choices for reducing

photosensitivity in bright daylight. You may want to use a cane as well, to help demark surface changes as you walk. Always allow extra time for any activity in the community. Seek quieter outings at less busy times, so as not to rush or overtax your visual abilities. Finally, your occupational therapist may help you learn a systematic head-bobbing strategy that can help you scan your visual environment as you walk.

HOME ADAPTATIONS FOR FALL SAFETY

If you have fallen or if your legs feel weak, you definitely want to talk to your occupational therapist about ways to make everyday tasks safe. If you don't have a tub bench or shower seat yet, you should seriously think about getting one. These sturdy, waterproof furniture items are available at medical equipment houses and larger pharmacies, and the Salvation Army often offers them used at a sharp discount. They allow you to get in and out of the tub safely, sitting down first, then swinging your legs in. You shower sitting down, so there is no risk of falling. You may want to add a shower mat, a clamp-on grab rail and maybe a shower hose as well. Your occupational therapist can recommend exactly the right combination for your needs and bathroom. For those of you who prefer baths to showers, some newer bath chairs actually raise and lower you safely into the tub. Various models are available, but none are cheap (the least expensive currently runs about \$1,000).

Getting on and off the toilet, or indeed, any chair in the house, can be a cumbersome task. Three-in-one commodes are covered by Medicare and most insurance plans. These items can fit over your toilet, serve as a bedside commode or even as a shower chair. They have armrests, and you can raise or lower their height to fit yours. One version even comes with a spring system that slowly lifts the seat to help you to your feet! The same principle works on spring-based boost-up chair pads, available at medical supply houses. You can use these pads with any chair in your house.



Many people with PSP have trouble getting in and out of cars. A good strategy is to back up to the car seat, sit down and then bring your legs into the car. When getting out, bring your legs out first, then lean forward to come to a stand. If you have trouble pivoting on the car seat, Frisbee-shaped pivot-disks are available to sit on. Or you may choose to place a plastic garbage bag on the seat to help you slide more easily getting in and out.

ELECTRONIC ASSISTIVE DEVICES

All sorts of new portable devices are available to help you manage everyday tasks and communicate with caregivers. Personal pagers and walkie-talkies can serve as emergency call bells for when your caregiver is out of earshot. Miniature computerized reminder systems now come built into wristwatches and handheld devices. Newer pillboxes have timer alarms, and some even dispense medication or send

Education



messages over the Internet to a caregiver or medical provider. There are many varieties of adapted telephones today, some with extra large keys, photo identification screens or one-touch dialing. For as little as \$100, you can purchase plug-in devices that smarten up your home, making control of lights and other appliances automatic or managed by a TV remote control. With these items, you can maintain your independence, relying less on caregivers to help you through your day. Your OT

can help you pick the right combination of electronic assistive devices for your situation. In cases where assistive technology is not covered by insurance, you may be able to acquire a low-cost assistive technology loan. Many states have set up low-cost loan programs, and have web sites designed to guide you in the process.

PSP is a relentless disease, but there are many ways that you can fight back to maintain your functional abilities in the face of this sneaky opponent. We have discussed some of the many options available for managing everyday tasks; talk to your occupational therapist about the best ways to address your own special issues.

RESOURCES:

American Occupational Therapy Association

www.aota.org – Informative website with links to neuro-rehabilitation OT's in your area. As with any of the medical professionals you meet, make sure that the OT you choose understands PSP. When choosing an OT, ask how many years of practice in neurological care he/she has had. Ask how many patients with PSP he/she has worked with. (Some OT's have attained national board certification as neurological rehabilitation experts. They may add the initials "BCN" to the names on their business cards.)

Neuro-optometric Rehabilitation Association

www.nora.org – Educational site with good information on diplopia, dry eye, tracking difficulties. Links to neuro-optometrists in your area.

Centers for Independent Living – These locally-managed, state-funded centers, run by individuals with disabilities, are great resources for help with home modification, community mobility and assistive technology. There's probably one near you.

Independent Living Products www.ilp-online.com

Online medical supply store that also carries visual assistive devices.

Maxi Aids maxiaids.com

Medical supply store that specializes in visual assistive devices.

Sammons Preston www.sammonspreston.com

Good general medical supply/assistive device store.

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www.psp.org



Why You "Knead" MASSAGE THERAPY

By Amy Mandlman

Speech Language Pathologist and
Licensed Massage Therapist
Society Board of Directors

Massage therapy is more recognized and accepted among medical physicians than ever before. One reason is that research shows its effectiveness in maintaining health and decreasing the affects of chronic illness. In this issue of *The PSP Advocate*, I discuss massage therapy, another one of the complimentary therapies in my series of articles on alternative medicine.

The Egyptians, Greeks, Indians, and Asians all used massage centuries ago. It was a normal practice in their daily lives. Today, massage therapists work in all environments including hospitals, hospices, intensive care units, spas, health clubs and more.

The basis of therapeutic massage is relaxing touch by one person to another to promote a person's emotional and physical health and well-being. Manipulation techniques include rubbing, stroking, kneading, or compression (pressure that increases or decreases or moves across the body). Massage relaxes and soothes the body. It can stimulate or comfort the body, relieving stress and anxiety by increasing blood flow to the body. Massage can also alleviate symptoms of depression. Did you notice that in describing massage, I am also describing the benefits that can be derived from massage?

There are two schools of massage therapy. The first, based on the Oriental view of the body, is called Shiatsu and Reflexology. The second one is founded on anatomy and physiology and is variously called Swedish massage, Neuromuscular Therapy (NMT) and deep tissue massage. In this article, I will focus on Swedish massage. I'll write on other modalities in future issues.

Swedish massage is characterized by the five strokes: effleurage (long smooth strokes), petrissage (kneading the skin as if kneading bread), friction, vibration, and tapotement (gentle slapping/cupping of hands over skin; also known as percussion movements).



Amy Mandlman, third from left, with the California Support Group, April 2002

Education

In a Swedish massage session, the clinician asks you to complete a questionnaire containing all of your medical history and has you list areas of your body that are giving you difficulty. If you're expecting relaxation only, you will still be asked to complete a form. The therapist must understand your body before starting your massage.

You'll want to be completely focused on the massage once you get started. The massage practitioner will briefly describe what will happen in the massage room. You will usually be able to choose the soothing music you would like to listen to, but sometimes the music is already chosen. Then, when the practitioner steps out of the room, you will disrobe to your comfort level and lay on the massage table either face up or face down as instructed.

When the practitioner enters the room, the massage begins. If at any time the pressure becomes too much or is not enough, tell your therapist. If the room temperature, music, or aromas in the room are not appropriate or relaxing, again, tell your therapist. Remember, this is all about you being able to relax! Allow your mind to think of something pleasant. Try not to think of everything you have to do or your next appointment, or have thoughts that may anger or upset you. Allow your body to relax and accept the touch. Loosen your muscles by making your limbs and body heavy and limp.

Your therapist may lift your arm or leg; this is normal-do not help! I often joke with my clients when they try to assist me by saying, "I will have to pay you when we are finished if you keep helping me!" The practitioner has a routine he or she follows to massage your whole body. The practitioner will drape your body appropriately, exposing only those areas to be massaged. If there is an area being massaged that you like, have your therapist spend more time there. Conversely, if there is an area you are not enjoying, be sure to have the therapist move on.

When the massage is over, the therapist will leave the room. Take five or ten minutes to absorb what happened to you. Memorize those feelings you have emotionally and physically. Then, in the future, whenever you have a stressful time, see if you can bring back the same relaxing feelings you had after your massage. Drink a lot of water. Try not to schedule anything urgent immediately after the massage to extend your feeling of well-being as long as possible.

You can schedule a Swedish massage session for 30 minutes to two hours. Costs range from \$50 to \$90 or, on average, \$1 per minute. In some cases, insurance may pay the cost of the massages, so check with your doctor to see if he/she will recommend it.

Virtually every system in the body can be helped by massage. A good book that describes how massage helps many of the systems of the body is The Guide to Massage by Clare Maxwell-Hudson.

Below are some of the systems:

- **SKELETAL SYSTEM:** Bone is affected indirectly by massage because improved circulation brings them oxygen and nutrients, reducing joint stiffness and pain. As the muscles become more flexible, joint movement increases.
- **MUSCULAR SYSTEM:** Some massage movements relax

and stretch muscles, reducing muscular cramping and tension. Increased flexibility is noted due to decreased muscle tone.

- **NERVOUS SYSTEM:** Relaxation massage can provide relief from nervous irritability and stress-related conditions. When using massage to stimulate, massage may relieve lethargy and fatigue.
- **CIRCULATION SYSTEM:** Massage gets the blood flowing, which helps people with poor circulation, like PSP patients who may be more immobile.
- **LYMPHATIC SYSTEM:** This involves extremely gentle strokes or taps along the lymph pathways to clear the body of a buildup of waste products. The gentleness of the massage can relieve stress, which can boost the immune system.
- **RESPIRATORY SYSTEM:** As you become more relaxed in massage, respiration may become slower and deeper since you are using your diaphragm for breathing. As a result, you expend less energy.
- **DIGESTIVE SYSTEM:** Massage aids relaxation and therefore can help increase the movement of food and waste products through the digestive system, helping to balance the digestive system.
- **URINARY SYSTEM:** Waste products that have been released during massage find their way via the blood to the kidneys where they may be filtered out and eliminated.

Anyone with a chronic illness may benefit from massage once or twice a week – whatever frequency he or she can afford – supplementing between sessions with a personal trainer or family member who helps to exercise and stretch the muscles or use massage techniques.

To learn if massage is appropriate for you, talk to your physician or massage therapist. To find a massage practitioner in your area, go to www.amtamassage.org or call The American Massage Therapy Association at 1-847-864-0123.

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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Telephone 0044 (0) 1327 860299
E-Mail psp.eur@virgin.net
Website <http://www.pspeur.org>

DISCLAIMER

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

Support Groups As Of June 1, 2003

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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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.

NEW PSP SUPPORT GROUPS FORMING!

If you are interested in attending, or would like more information, please contact these individuals directly:

**GULF BREEZE/
PENSACOLA, FL**
MICHAEL & SUE McINTIRE
850-916-7178
m_mcintire44@msn.com

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hfeiner@nyc.rr.com

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DOTTIE GEORGENS
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941-748-4028

LONG BRANCH, NJ
DIANE ALTER
732-936-3330
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BECOMING A SUPPORT GROUP LEADER

Continued from Page 1

leaders can grow weary of leading as time passes. They may take a break from leading as work or family demands increase, or they may move on to volunteer for other organizations where they are sorely needed. In today's mobile society, many people move to new cities and states frequently throughout the course of their lifetimes. Over the years, groups fade as the members move on to these different stages in their lives. Some of these members go on to form new groups and become support group leaders themselves. Often, a group is formed because a caregiver needs support, and there is no group in his or her city, county or entire state. Because groups are always changing, the cycle of leadership changes, and new leaders are usually needed every few years.



Baltimore Support Group

WHERE DO WE NEED LEADERS?

Everywhere! I would encourage anyone who is thinking of becoming a support group leader to contact the Society. However, there are several states where we have no leader at all, and other states that have only one leader. The following states have no PSP support group: Oregon, Idaho, Montana, Wyoming, Utah, Oklahoma, North Dakota, South Dakota, Iowa, Mississippi, Alabama, Tennessee, Kentucky, Indiana, Delaware, Rhode Island, New Hampshire, Alaska and Hawaii.

Many states have only one leader serving our PSP families. Check our support group list in this issue (pg. 15) and find your state. If only one contact person is listed, we need you!

I'VE NEVER LED A GROUP BEFORE. CAN I STILL BE A LEADER?

Yes! You do not have to be a health professional to start a PSP support group. Indeed, many groups are started by caregivers and family members. It only takes one caring individual who sees the need for a group and is willing and able to act on it. However, one leader cannot, and should not, do it all. True, it is usually up to one or two enthusiastic people to invest the time, energy and commitment to get things rolling. But once a group has begun, its success is ultimately up to its members. In other words, it takes more than one person to

keep a group going! Successful groups are usually started by a few people who want to make a difference. Consider who might be able to "co-lead" a group with you. Your spouse or another family member? A friend or co-worker? There are plenty of helpful guidelines for starting and running a group, and the Society is here to help you. We send out packets of information on starting support groups to anyone who is interested. We can also advertise your new group in this newsletter, refer PSP families to your group, help you find a meeting location and assist you with other start-up needs. A support group is not a therapy group, nor is it a substitute for medical treatment. It is a place where people can be themselves and talk freely and openly about life with PSP among a new circle of friends—a place to get information and practical experience from others who have walked in your shoes.

"Our group is so spread out that most of my contact is by phone or email, but it is always heartwarming to hear from the families. I consider it a gift from God to have the contact and friendship of the PSP families in Louisiana."

-Brenda Gremillion, Louisiana

I LIVE IN A RURAL AREA. WITH SO FEW PEOPLE, WON'T IT BE HARD FINDING ENOUGH PEOPLE TO MEET AS A GROUP?

That's OK. There are different models of support groups. While most groups try to meet face-to-face every month, other groups get together only bi-monthly or several times per year. Many PSP groups are too separated by distance to gather together every month and meet by telephone or communicate through email instead. If you live in an area that has a smaller population, forming a support group is still an option. You will need to decide as a group which format will best suit the group members.

I KNOW THAT LEADING A GROUP WILL ENABLE ME TO HELP OTHERS. HOW WILL IT HELP ME?

Leading a support group will change your life. Says Jean Bentlin of Australia, "Our support group has given me a lesson in endurance. I've connected with some very special people and have received much happiness from being able to help, even in a small way." Says another PSP support group leader, "Leading has made me more sensitive to people who are struggling and has helped me learn how to give them a measure of hope. It has also helped me to attain confidence in my leadership skills." Leaders find that helping others brings them comfort and peace, particularly after they have lost a

"I discovered a profound sense of satisfaction from sharing and helping PSP caregivers walk the road where I had previously stepped."

-Bob Krasnicki, Florida

Support



Torrance/Orange County, CA support group

loved one. They become better listeners, better communicators, better friends. They develop new skills through education and advocacy, enabling them to become partners with their medical professionals when making important decisions about their well-being.

“Individuals who join our group are seeking help and an avenue to share and learn. As a group facilitator, I think I have learned more from these individuals! People tell me that they can make it another six months because of how I (and our group) have helped them.”

-Amy Mandlman, Missouri

THIS ALL SOUNDS GREAT, BUT WHERE DO I START?

1 Call or write to us and ask for a packet on starting a support group. The packet includes an excellent support group leader's manual published by the National Parkinson Foundation, guidelines for starting a PSP support group, a list of current leaders who can help you get started, a list of people in your area who are willing to share their PSP experiences, and lists of caregiver websites, books and other resources.

2 Once you have looked through the packet materials and decided that you'd like to lead a group, contact Jessica Quintilian, Director of Outreach & Education. The Society will publish your name on our support group leaders list and start referring interested people to your group.

3 Publicize! After you have decided on a meeting date, time and location, it's time to get the word out. Most local newspapers accept public service announcements, as do many radio stations. You can also post notices on bulletin boards at local supermarkets, libraries, churches, senior centers and senior residential communities. One of the best places to advertise may be your doctor's office(s).

It can take time to get a group started, particularly for a little known disease like PSP where families may be scattered across the country. Remember, one person cannot do it all—ask for help. With autumn just around the corner, the Society will be kicking off PSP Awareness Month in October. What better time to get a group together and perhaps plan a PSP awareness event? Be a part of our support group growth and expansion. Why do you need a support group? Because support groups need you!

Jessica Quintilian
Director, Outreach & Education

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Support - Our PSP Stories

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

Dear Nancy,

I wanted to write and update you on what has happened since you published the article about my mother in the last edition of *The PSP Advocate* in the Our PSP Stories feature section.

I work for Apria Healthcare, a national home health company. My manager sent a copy of my article to the editor of "Insider News," Apria's internal magazine. The editor decided to publish it in the February edition. Over 10,000 Apria employees received a copy of this edition. I also sent out about 75 copies of "The PSP Advocate" to members of my family as well as friends when you first published my article. Two friends of my parents who received the article also publish a weekly column in "The Times" in Munster, IN. This is the premiere newspaper in Northwestern Indiana with a daily publication of 87,078 and a Sunday publication of 94,250. They decided to excerpt my article about my mom as well as information found in other sections of that edition of "The PSP Advocate." The publication dates in "The Times" were 04/03, 04/10, and 04/17/03. I thought you would be interested to know that the word is being spread about PSP through my mother's story. It is my hope that these efforts will help someone who is in a situation like the one my family was once in. I hope you and your family are doing well. Remember, Nancy, you do very important work!
Sincerely, Bobbie's daughter, Linda

Bobbie's Story (excerpts from the publications)



Linda and Bobbie Rasmussen

"Bobbie Rasmussen was a strong-willed, fun-loving friend with an unforgettable hearty laugh.

Her zest for life — whether it was traveling, gardening, decorating her home, cooking, golfing, partying or rooting for the Cubs — was enviable. And, she was devoted and loyal to her friends and family and to her faith.

She was in her 70s when Jim, her husband and retired Post-Tribune editor and publisher, realized something was amiss . . . her unsteadiness and spells of dizziness. What followed was an odyssey that her daughter, Linda, wrote about in a recent issue of *The PSP Advocate*, a newsletter of The Society for Progressive Supranuclear Palsy.

At some time in our lives, most of us will be caregivers — for family members or friends, for various lengths of time in different places, and for any number of reasons and illnesses. There are so many differentials, and, yet, as caregivers we share so much.

The subject matter of this column generates the similarities and diversities we all experience, especially with caregiving. Friends and strangers will approach us with personal stories, factual information and questions that keep us going in this endeavor.

Most recently we got a copy of *The PSP Advocate*, a quarterly newsletter of The Society For Progressive Supranuclear Palsy because a friend had contributed an article about her mother's decline and need for care due to the fatal degenerative brain disorder. It was first identified as a distinct neurological disorder in 1963, but has no known cause, treatment or cure.

Among the articles in this issue was one on support entitled, "Caring for the Caregiver." It addresses the issue of mixed emotions that arise during the time of caregiving, and stresses the need to maintain one's health and develop ways to cope with the situation.

We thought the "Caregiver's Self-Rating Scale" was interesting and want to pass it along to our readers. It's a start to understanding what we experience during these times and how we might begin to deal with what's going on.

Our feelings play an important role in how we manage ourselves when thrust into the position of caregivers for our ailing loved ones."

She Always Wore A Smile

Dear Ellen Katz, Executive Director, Society for PSP

On behalf of Aileen Determan, we would like to present the memorial gifts we received. Aileen was diagnosed with PSP in August of 2000 in Omaha, Nebraska. We had just moved her from South Dakota to be closer to two of her children. She was originally diagnosed with Alzheimer's disease. After moving to Omaha, she was officially diagnosed with PSP. To the family, it was somewhat of a relief to know that she would not lose her memory of us or the time we had with her. Then came the concern and confusion on what exactly was PSP and what did her new diagnosis mean to her and us. We were scrambling to gain knowledge. We stumbled across your web page and the information that is provided. We began gathering information to assist us the care of Aileen.

We know first-hand that the medical community and the general public are not aware of PSP or where to turn for assistance. We cannot tell you how much it meant to us to find you and all the information that the Society sent to us. We wanted to know so much. Your Society put us in contact with local "communicators" and that is where we learned about the PSP list serve. We got to know individuals from around the world struggling with this disease and the issues with caregiving.

Aileen Determan died on December 4, 2002 at Hospice

Support - Our PSP Stories

House in Omaha, Nebraska. She was gracious throughout her care and allowed numerous people to attend to her. She opened herself up to others during her decline. She was gracious throughout her dying process.

She declined rapidly from the time of her diagnosis in 2000. At that time, Aileen was able to walk by herself and be fairly independent. She started to have falls towards the end of that year. She continued, though, to adjust and enjoy her time here in Omaha. We took her to flower shows, the zoo, luaus, firework displays, and many other social events.

She always wore a smile wherever she went. She helped attend to other individuals at the assisted living facility where she was staying. She always had so much time for her grandchildren and so pleased to have them near. She loved it when her young grandson would start his big countdown like a space shuttle and "launch" her out of her lift chair. Her grandchildren could always get her to smile even at the very end of her life.

Aileen formed many new friendships with her caregivers and volunteers. She move to Hospice House in December of 2001. She was using a wheelchair at that time and needing more assistance with meals and daily needs. Our family visited daily, enjoying our time with her. She would look at you with her eyes and you knew she understood. She had lost most of her communication skills and mainly would say "Yes" – a reflection of her graciousness with her disease.

She also wanted to learn more about PSP and we had her on your mailing list for *The PSP Advocate*. *The PSP Advocate* was invaluable at Aileen's assisted living facility and at the Hospice House. Besides the information that we garnished from it, we were able to pass it on to her caregivers. Everyone who read *The PSP Advocate* was impressed and found the information invaluable.

The photo enclosed is the one I took on Nov. 15, 2002- Aileen's 75th birthday with her family from Omaha. Aileen lived another 19 days. We were able to all celebrate Thanksgiving with Aileen and the entire family. We have been so blessed to have Aileen with us and miss her dearly. We reflect on her smiles and the time that we got to spend with her.

We appreciate the PSP Society so much. We will always support you and your staff. Thank you so much for being there with information and support when we needed it the most.

Thanks,
Rod and Connie Determan and the Determan Family



Aileen's 75th birthday.

Dear Nancy

Two years ago my wife lost her father to PSP. It has been hard on her because there were so close. I recently found this on her desk and thought you and your readers would like to read it. Thank you for all you do for the families affected by PSP.

Bryan B.

Daddy's Hands

"Daddy's hands weren't always gentle but I'd come to understand, there was always love in Daddy's hands." That's from a country song by Holly Dunn that fit my Daddy perfectly. He was the kindest, most giving, gentlest man I have ever known. That changed when PSP came to set in and make all our lives turn upside down. From the beginning we heard the same story, "There is something wrong but we don't know what it is."

Daddy started like many others with mood changes. Then he started falling, always backwards, but also was able to get right back up on his own. I guess he didn't think anyone saw this. For a while, his progression was slow, so I guess this gave us some time to think that it was really nothing. But the mood changes were starting to get more severe to where he would throw things and just fly off the handle at the little things – so unlike my Daddy. Momma was always with him and noticing all the changes, and at the time, he was still working. We thought it was the stress of his job, so we finally talked him into retiring. That didn't seem to help, and so we went to doctor after doctor, all saying the same thing. My sister, Pam had formerly worked at Mayo Clinic and got in touch with them and got Daddy an appointment with the neurologist there. After a week or two there, with every test available, all they could come up with was frontal lobe degeneration. So, we worked with that for several years but there was still more to come.

Finally, a doctor with the Veterans Hospital in Shreveport diagnosed him with PSP. We looked at each other and said, "What's that?" As he sat there very patiently explaining every detail for what I know seemed like hours on end, answering every question, my mom and I saw everything fall into place. This was December 3, 2000. However, we had already had the task of putting him into a nursing home because my mom could no longer pick him up and take care of him the way he needed. He had fallen several times and we were all afraid that he would get seriously hurt.

They were married 49 years that December 17. We gave them a surprise anniversary party. My sister even got to fly in from Virginia. I am so thankful that I was able to make that happen. My parents were able to see friends and visit with people they had not seen in years, and of course, during Daddy's illness, they didn't go out or socialize hardly at all. So that weekend we had some very valuable family time. You see, my Daddy died on February 16, 2001. They never celebrated that golden anniversary but we had many golden memories.

I miss my Daddy. As a matter of fact, we had the song "Daddy's Hands" played at his funeral. It has such a sweet message in it, because I can see my Daddy in every word. He was my confidante, my advisor, my friend, but most of all, he was my Daddy.

Report Of Gifts - January 16 thru May 1, 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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Report Of Gifts

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Doris & Orville Glaesmann
Faye Glazer In Memory of Marvin Glazer
Helen Goldberg In Memory of Arthur Goldberg
Sidney Goldberg In Honor of Arthur Goldberg
Rhonda Rayworth Grady In Memory of Carol Rayworth
Lee F. Greer In Memory of Fern Beebe Mayhue
William H. & Margaret Jewett Greer In Memory of Thomas Burrowes
Walter & Christina I. Griffith In Memory of Fern Beebe Mayhue
Rebecca Grimes In Memory of Clara Bridgett
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Chuck & Sandra W Haase
William E. Hamilton In Memory of Pasquale Galasso
Andrew D. & Phyllis J. Hayes In Memory of Rita Bongiorno
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Lisa & Richard Hill In Honor of Ruby Cooley
Sally Hirai In Memory of Mary Ann Sei Kobuke
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Matt & Diane Johnston In Memory of Norman B Reisman
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Jean & John Kahr In Memory of C. Edward Morris
Virginia M. Kay In Memory of Eldred Kay
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Patricia A. Kelly In Memory of Josephine Kelly
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George Kralik, D.D.S. In Memory of Bela Csordas
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Elena & Benito Krawczyk In Memory of Addison Jenrette
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Toby Kruh In Memory of Raye Heksel
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Michael Ludwig In Memory of Arthur Goldberg
Betty Lynch In Memory of Fern Beebe Mayhue
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Paul & Mary Malushizky
William & Joan Mangan
C.A. Mangham In Memory of Alan Transue
Robert & Ellen Marks In Honor of Stephen Reich
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Johanna Marten In Memory of Fern Beebe Mayhue
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Wayne R. McCray In Memory of Doris Mullin
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In Memory of Anne Blackstock Allen
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Ellen J. Olean In Memory of E. James Olean
Michael O'Neill In Memory of Mildred H. Marken
Nathaniel L. & Mildred R. Orme In Memory of Thomas Burrowes
Catherine M. O'Toole In Memory of John J O'Toole
Louis & Helen Paoloni In Memory of Alice V. Madden
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Allen W. & Laura T. Puckett In Memory of V. Lee White
Harvey Raschke
Lee Reichman In Memory of Arthur Goldberg
Phyllis & Lee Reichman In Memory of Arthur Goldberg
Karen Reid In Memory of Richard Croom
Mimi & Loren Reiser In Memory of Arthur Goldberg
Kelley Elston Remy In Memory of William K Harrison
Resnick Investment Advisors In Memory of Corine Skolnick
Elisabeth Rieger In Memory of Josef Rieger
Renee Roberts In Memory of Fern Beebe Mayhue
Wendy Robertson, MD
Margaret Roder In Memory of Sheila Gough
Margaret Roder In Memory of Isabel Warner
Peter & Gloria Rohr In Memory of Jane Merrick
Ronald D. & Connie S. Romain In Memory of Margaret Romain
Florence Romanello In Memory of Vincent Romanello
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Peter F. Sayia In Memory of Allen Zerfoss
Lynne D. Schmidt In Memory of Bernice Schmidt
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Schoenwald & Marcum Family In Memory of Norman B. Reisman
Victoria R Schreck In Memory of Albert Schreck
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Dan Zeck In Memory of Doris Mullin

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.

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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 • Jennifer Walter, Regional Investment Manager, Provident Bank of Maryland, Pikesville Office,
3635 Old Court Road, Baltimore, MD 21208
410-277-2633 or 410-274-1244
FAX: 410-602-0932.

A transfer can be easily made electronically.
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It is the policy of the Society that stocks are sold as soon as they are received in our account.

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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: _____

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

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

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

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

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Home Address: _____

Home Telephone Number: _____ Fax: _____

E-Mail Address: _____

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Business Telephone Number: _____ Fax: _____

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