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INSIDE:

**THE TRIBUTE TO
JAY C. TROXEL**

**THE LATEST IN
PSP RESEARCH
PART I**

The PSP
ADVOCATE

The Society for PSP is honored to present
this tribute to

Jay C. Troxel

in recognition of his extraordinary generosity,
which has transformed this organization.

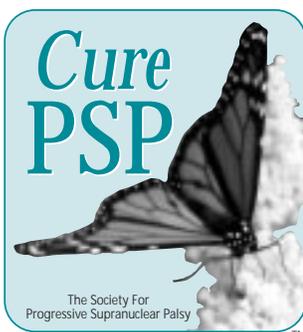
Because of his visionary and inspiring contributions in the name of his beloved wife, Eloise H. Troxel, he has touched everyone affected by PSP.

With his gifts, he has empowered the Society for PSP to establish a Brain Bank, to advance PSP research with grant and fellowship awards around the world, to publish *The PSP Advocate*, and to fully furnish and equip the Society's national headquarters.

The Board of Directors, Medical Advisory Board, PSP researchers, many of whom have been funded by the Eloise H. Troxel Memorial Research Fund, and Society for PSP staff, extend their deepest appreciation to Jay C. Troxel for his gracious personal qualities and his splendid gifts that have created hope for the future.

The Society for Progressive Supranuclear Palsy
November 9, 2002

Eden Roc Hotel, Miami Beach, Florida



Liz Brisson presenting Jay with a crystal butterfly, the Society's symbol of hope.



Joanne Armstrong presenting Jay with a plaque acknowledging his contributions.

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 501-3(C) organization that exists to promote and fund research into finding the cause and cure for PSP. PSP is a fatal degenerative brain disorder that has no known cause, treatment or cure. The Society provides information, education, support and advocacy to persons diagnosed with PSP, their families, and caregivers. The Society educates physicians and allied health professionals on PSP and how to improve patient care.

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

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(In memory of Henry and Jane Ogiba)

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(In memory of Lois Croft Davis)

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Director's Doings



Dear Friends,

I am amazed and inspired by the energy and synergy created by involved and committed volunteers dedicated to helping the Society help others. The brief span of six weeks—October awareness Month and the November

research meeting in Miami—were shining indicators of energy in motion. The volunteers who organized PSP Awareness activities around the country, raising funds and recognition of PSP, did an extraordinary job! Just look for yourself at the variety and creativity of these events along with the fun and excitement these generate! The Society is now organizing a Special Events Committee to bolster such efforts.

The November research meeting in Miami brought the Board and researchers together and gave us the opportunity to meet our Florida families and to exhibit at the Movement Disorders Society meeting. Pulling all of these events together simultaneously required expert coordination of staff and volunteers! Our staff did a superb job of supporting the multifaceted activities in Florida.

Warm regards,

Ellen Pam Katz
Executive Director

In Our Thoughts



Please join the Society's Board of Directors, Medical Advisory Board, staff and volunteers in extending our thoughts and prayers for the speedy recovery and complete healing for Albert Katz, husband of Executive Director, Ellen Katz.

DONORS WANTED:

Enthusiastic volunteers needed to contact potentially high impact donors. Volunteers will serve on a special donor committee and will receive names of several prospects to solicit gifts of \$1000 and more. This requires a high commitment and a passionate desire to raise funds to find the cause and cure for PSP. Training and support is available from the office. 1-800-457-4777 spsp@psp.org

Chairperson's Corner

Liz Brisson
Chairperson, Society for PSP

Welcome to this issue of *The PSP Advocate*, which is focused on what we've accomplished in research and where we are going. I had the pleasure of meeting many of the research grantees at the November Research Symposium in Miami as well as meeting and honoring the Medical Advisory Board.

I also had a very personal thrill at this research meeting. Let me explain. My husband, Roger, initiated the "Climb for a Cause" in 1997 where he raised \$80,000 for the Margaret Parker Research Fund. He climbed one of the world's highest mountains in Argentina and planted a flag on its summit to establish the fund. I had the pleasure in November of meeting the researchers that were recipients of four grants funded by the proceeds of that daring mountain climb. I also introduced them to Dale Ferris, Margaret's daughter, who is also a Board member. We had the opportunity to thank them face-to-face and heart-to-heart for their work in Margaret's name.

Another significant event during the Symposium was a gala tribute to Jay Troxel, an emotionally packed evening with Jay's daughter and son-in-law looking on. I am in awe of this man who gives generously to the Society and helped jump-start the research efforts. Without him, we would not have gotten to where we are today in this area.

As President, I reflect upon the challenges of 2002. The Society has grown significantly over the past five years. This has been possible through the efforts of the Executive Director, Ellen Katz, as well as the dedication of the staff, Board members, volunteers and donors along with the leadership of my predecessors. But I'm reminded that my true calling to the organization has always been through the inspiration of my aunt who lost her fight to PSP nearly four years ago. I am encouraged with what I've learned at the research symposium. I hope you will find comfort in their progress as well as you go through this issue.

As President, in 2003 I will be focused on putting into place the Strategic Plan for 2004 and beyond. Additionally, there will be more emphasis on research efforts and looking at ways to maximize our financial resources to ensure that research programs keep expanding.

Now more than ever, our voices must ring out! As we all welcome in a New Year, we bring new hope for finding the cause and cure of PSP. I want to thank you for your support for this cause as a supporter, donor, volunteer or Board member. It is an honor for me to serve as your President.



A Tribute To Jay C. Troxel



Jay Troxel speaking at the tribute

On Saturday, Nov. 9, 2002, The Society for PSP presented a moving tribute to Jay C. Troxel in recognition of his extraordinary generosity that has transformed this organization. Because of Jay's visionary and inspiring gifts, he has touched the lives of everyone affected by PSP. Through his gifts in memory of his beloved wife, Eloise, the Society

has established a PSP Brain Bank to promote research, advanced PSP research throughout the world through substantial grant and fellowship awards, published *The PSP Advocate* and fully furnished and equipped the Society's national headquarters in Baltimore, MD.

Liz Brisson, Board President, conveyed the Society's deepest appreciation to Jay by presenting him with a magnificent Daum butterfly, the Society's symbol of hope. Joanne Armstrong, Society founder, told the story of how *The PSP Advocate* has emerged from an 8 page publication to 32 pages flowing with invaluable information for families thanks to Jay. She presented him with a plaque inscribed with the message on this Advocate's cover. For a dash of humor, Brain Bank Director, Dr. Dennis Dickson assisted Jay with putting on his new "lab coat" emblazoned on the pocket, "Jay Troxel, Guardian Angel."



Dr. Dennis Dickson assists Jay with his new lab coat.

Ellen Katz, Society Executive Director, shared with the guests the story of Jay and Eloise's exquisite and devoted relationship, through their elementary school years, to college and to 57 years of marriage. She quoted those meaningful words from "Chorus Line" that describe why Jay made his gifts, "Can't regret, won't forget, what I did for love." Nancy



L-R: Albert and Ellen Katz, Jay C. Troxel, Jay's daughter, Karen, and her husband, Wayne Daly.

Brittingham described Jay as a transformational philanthropist who has dramatically nurtured and revived other non-profits in the Lakeland, Florida community including the Lighthouse Ministries, The Talbot House, and VISTE, all of whom have new buildings and programs named in memory of Eloise.

In his acceptance of these honors, Jay said, "I am still astonished when someone like the mayor or other official or even the "big shots" recognize my name. Why should they single me out?"

I consider myself to be a senior citizen living in a retirement community with a strong desire to give back to others. I believe in Percy Ross's line—He who gives while he lives, knows where it goes."

Guests included his daughter Karen and her husband, Wayne Daly. Karen expressed her feelings about her parents and the impact of her father's philanthropy. "My parents were ordinary people who came from plain people...farmers, teachers, who lived quiet and ordinary lives. Through God-given smarts, talent and plain hard, hard work, they made a successful business, invested wisely and at the end, living with the tragedy of PSP, only to rise again, like the symbol of PSP, the butterfly and make something wonderful for many out of the grief of a few."



Nancy Brittingham with Jay at the tribute.

With the Board of Directors, members of the Medical Advisory Board and PSP researchers, volunteers, and PSP staff in attendance, everyone was in awe of Jay Troxel and his monumental gifts that provided the bedrock upon which compassionate care and a future cure could be based. It was an unforgettable experience.



The Society's Board of Directors, Medical Advisory Board, researchers and staff.

Special Events

The 7th International Congress of Parkinson's Disease and Movement Disorders

The Movement Disorder Society (MDS) is an international not-for-profit organization representing and serving clinicians, other health professionals, researchers, and policy makers in movement disorders. The spectrum of clinical disorders represented by the Society includes but is not limited to:

- | | |
|--------------------------------|--------------------|
| Parkinson's disease | Blepharospasm |
| Dysphonia | Dystonic disorders |
| Tremor | Gait disorders |
| Progressive supranuclear palsy | Ataxia |
| Tics and Tourette syndrome | Tardive dyskinesia |
| Myoclonus | Spasticity |
| Huntington's disease | |

The 7th International Congress of Parkinson's Disease and Movement Disorders was held on November 10-14, 2002 in Miami, Florida. The Congress brought together nearly 2,500 neurologists, basic scientists and other movement specialists from 30 countries, providing an unparalleled international forum for the discussion of movement disorders.

Sessions covered:

- Updates in genetics, neuroimaging, ground-breaking surgical treatment of movement disorders, and other topics.
- Clinical and basic aspects of movement disorders.
- Medical and surgical therapies.
- Public health issues.



Neurologists and researchers gathering information at the Society's exhibit at the 7th International Congress.

The Society for PSP had an educational exhibit at this prestigious meeting raising awareness about the Society and its programs. The Society booth was extremely well-attended with the most frequently asked questions being:

- "What research is being done in the field of PSP today?"
- "What kind of funding does the Society offer for PSP research?"



Camilla Blain, MD, PSP researcher from London, UK discussing her work with John Steele, MD (one of three neurologists who first described PSP in 1963.)

and then—with much enthusiasm—

- "How do I apply for a grant?"

In addition, Ms. Janet Reno spoke on perspectives related to research efforts, treatment and management options for Parkinson's disease, during the Opening Ceremony of the Congress on Sunday, November 10.



Dale R. Hamrick, MD, Geriatrician of Columbia, SC is reviewing Larry Golbe's MD's "The Diagnosis of PSP for Physicians" CD.



Eleni Trikouli, MD and Maria Bozi, MD from London, UK

THE MOVEMENT DISORDER SOCIETY'S MISSION

- To bring clinicians the latest developments and practical advice for the diagnosis and treatment of all movement disorders and related neurological matters.
- To offer an international forum for sharing new developments in basic and clinical research in movement disorders.
- To publish the pre-eminent clinical and research journal devoted to movement disorders, using print, online and video formats.
- To create professional liaisons with other regional and subspecialty organizations for unifying the many disciplines represented in the field of movement disorders.

GIVE A GIFT ONLINE

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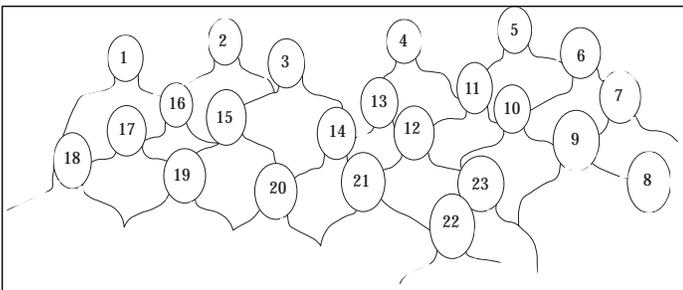
The 2002 International PSP Research Symposium

Funded By The
Eloise H. Troxel Memorial Research Fund
Sponsored By
The Society for Progressive Supranuclear Palsy
Saturday, November 9, 2002 Eden Roc Resort
Miami Beach, Florida

The 2002 International PSP Research Symposium brought together the Society research grantees since 1997 to present their work and benefit from the criticism and inspiration of their colleagues. In this way, the Society hopes to accelerate the pace of research and widen the scientific appeal of work against PSP.



Kurt Jellinger, MD and Hanna Ksiezak-Reding, PhD discuss the presentations at the Symposium.



- | | |
|---------------------------|----------------------------------|
| 1. Mark Ledoux, MD, PhD | 13. Maria Grazia Spillantini, MD |
| 2. Davic Albers, PhD | 14. Junchao Tong, PhD |
| 3. Joseph Higgins, MD | 15. Massimo Tabaton, MD |
| 4. Sarah Augood, PhD | 16. Jaume Campdelacrau, MD |
| 5. Dennis Dickson, MD | 17. Hanna Ksiezak-Reding, PhD |
| 6. Pau Pastor, MD | 18. David Zee, MD |
| 7. Jasmine Henderson, PhD | 19. Eduardo Tolosa, MD, PhD |
| 8. Parvoneh Navas, PhD | 20. Joseph Jankovic, MD |
| 9. John Steele, MD, MSC | 21. Larry Golbe, MD |
| 10. Glenda Halliday, PhD | 22. Nancy Muma, PhD |
| 11. Laurel Bolin, MD | 23. Irene Litvan, MD |
| 12. Kurt Jellinger, MD | |

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.

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

with editorial revisions by Lawrence Golbe, MD

THE SOCIETY FOR PROGRESSIVE SUPRANUCLEAR PALSY BRAIN BANK



Dennis W. Dickson, MD
Mayo Clinic, Jacksonville, FL

The goal of the Eloise H. Troxel Memorial Brain Bank of the Society for Progressive Supranuclear Palsy is to provide neuropathologic characterization of brains of patients with ante-mortem diagnosis of progressive supranuclear palsy. The neuropathologic evaluation uses standardized methods for collection

and banking of fresh frozen and fixed brain tissue; standard gross dissection and tissue sampling; and analysis with routine histology as well as fluorescent microscopy, immunocytochemistry and collection of quantitative and semi-quantitative data. The cases are dissected and discussed at weekly gross and microscopic clinicopathologic conferences attended by neurologists, fellows and research staff, which provides greater awareness of PSP among clinicians and trainees. From frozen tissue, DNA is extracted and subjected to tau haplotype and apolipoprotein E genotype analysis. The neuropathologic and genetic data are maintained in a computerized database that permits easy retrieval of cases matching for defined specifications of a particular research study. Samples of PSP tissue, including frozen samples and fixed tissue as well as unstained paraffin sections mounted on slides, are provided to qualified investigators working on PSP. Priority is given to investigators or studies funded by the SPSP. A copy of the final neuropathology report and a cover letter is mailed to the next-of-kin. The Brain Bank provides not only diagnostic service, but is also a link to basic research on PSP.

Since its inception, the SPSP brain bank has received over 200 brains. Accompanying the brains is clinical information provided by the physician-of-record and a SPSP questionnaire filled out by the next-of-kin. Clinical and genetic features of 180 autopsy-proven cases of PSP were compared with misdiagnosed cases. Of the 180 cases studied, 137 cases had PSP and 43 had other pathologic diagnoses. Corticobasal degeneration (CBD), multiple system atrophy (MSA) and Lewy body disease (LBD) accounted for 70% of the misdiagnosed cases. History of tremor, psychosis, dementia and asymmetric findings were more frequent in misdiagnosed cases. The frequency of H1 tau haplotype (a genetic variant known to be more common in people with PSP than in others) was greater (93% vs. 80%) and APOE 4 (a genetic variant found

in many cases of Alzheimer's disease) was less (17% vs. 41 %) in PSP compared with misdiagnosed cases. Pathologic evaluation of clinically diagnosed PSP remains important for definitive diagnosis, and CBD, MSA and LBD are the disorders most likely to be misdiagnosed as PSP.

SELECTIVE LOSS OF THALAMIC SUBREGIONS IN PROGRESSIVE SUPRANUCLEAR PALSY



G.M. Halliday

J.M. Henderson*, K. Carpenter,
H. Cartwright, G.M. Halliday.
Prince of Wales Medical Research
Institute
University of Sydney.

Movement-related information is channeled through subregions of the thalamus to motor-related regions in the basal ganglia and cerebral cortex. Two major non-cortical inputs to the striatum originate from the substantia nigra in the brainstem and the centromedian-parafascicular complex (CM-Pf)

located in the thalamus. The ventral thalamic (motor) nuclei relay information from the basal ganglia to the motor cortices. While it is established that in both Parkinson's disease and progressive supranuclear palsy (PSP) that there is degeneration of the nigral dopaminergic neurons, there has been little analysis of the glutamatergic thalamus. We therefore evaluated several thalamic subregions in six patients with PSP, nine patients with PD and nine age-matched controls (1, 2). Degeneration in CM-Pf, ventral and non-motor thalamic nuclei were estimated using quantitative neuronal counts. There was significant neuronal loss in the CM-Pf in PD and in PSP (40-55% respectively, both $P < 0.01$). There was also additional loss of the ventrolateral posterior region of the motor thalamus (VLp) in PSP only (30%, $P < 0.05$). In contrast, other adjacent limbic and motor thalamic nuclei did not degenerate in either disease, supporting the selectivity of thalamic neurodegeneration. Our results show that the thalamic CM-Pf and VLp are additional non-dopaminergic sites of neurodegeneration in PSP. Loss of VLp would directly underactivate the motor cortex contributing to parkinsonism in PSP. Also, because the CM-Pf thalamic region provides important sensorimotor feedback to the striatum, degeneration of this region is also likely to exacerbate the clinical signs and symptoms of both PSP and PD.

Lay Abstract

The thalamus is a part of the brain that relays complex information about movement and other functions to other areas of the brain. Since degeneration of selective subregions within the thalamus (the "motor thalamus") would contribute to parkinsonian symptoms, we used unbiased quantitative methods to estimate cell numbers in these thalamic regions in 6 progressive supranuclear palsy (PSP) cases, 9 Parkinson's disease (PD) cases and 9 control (no brain disease) cases. The motor thalamus was intact in PD. In contrast, in PSP there was significant loss of cells in two major areas of the thalamus: the centromedian-parafascicular complex (55%) and ventrolateral posterior nucleus (30%). Loss of these specialized regions within the motor thalamus would further contribute to parkinsonian symptoms in PSP.

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NEUROANATOMY OF EYELID DYSFUNCTION IN PSP



Mark Ledoux, MD, PhD University of Tennessee, Memphis, TN

Eyelid motor dysfunction in the form of blepharospasm, apraxia of eyelid opening, and apraxia of eyelid closure is present in many patients with PSP. Normal eyelid motor function depends on neurons that innervate the orbicularis oculi (OO) muscles that close the eyes during blinks and levator palpebrae (LP) muscles that open

the eyes. The OO muscle is divided into three components: pretarsal, preseptal, and orbital. In PSP, the pretarsal portion of the muscle is frequently overactive. Muscles adjacent to the OO such as the corrugator supercillii contribute to forceful eyelid closure and the frontalis muscle assists with eyelid opening. Persistent frontalis contraction is a characteristic feature of PSP. Typically, motoneurons are preserved until the very late stages of PSP. Therefore, eyelid motor dysfunction in PSP must be due to degeneration of first- and/or higher-order premotor neurons that are part of the circuitry responsible for integrating vertical gaze with eyelid movements.

Retrograde viral transneuronal tracing was used to localize OO premotor neurons within the primate midbrain. Transverse sections through the midbrain were immunohistochemically processed for detection of both virus and choline acetyltransferase. In the midbrain, presumptive first-order premotor neurons were concentrated within the supraoculomotor area (SOA) and within 500 μm of the caudal margin of the caudal central nucleus (CCN). The SOA is located in the ventral periaqueductal gray and consists of the supraoculomotor periaqueductal gray and the supraoculomotor cap. Other presumptive first-order premotor neurons were sparsely scattered in regions of the SOA dorsolateral and rostral to the CCN. There was no evidence of direct synaptic contact between premotor neurons and LP motoneurons within the CCN. A few presumptive first-order OO premotor neurons were located in the contralateral parvicellular oculomotor

nucleus, contralateral nucleus of Darkschewitsch, and dorsal raphe nucleus. These findings suggest that OO premotor neurons within the SOA may regulate LP motoneurons through local interneurons.

Lay Abstract

Eyelid motor dysfunction in the form of blepharospasm (involuntary spasms of the eyelid sphincter muscle), apraxia of eyelid opening (inability to voluntarily open the eyes), and apraxia of eyelid closure (inability to voluntarily close the eyes) is present in many patients with PSP. Normal eyelid motor function depends on neurons that innervate the orbicularis oculi (OO) muscles that close the eyes during blinks and levator palpebrae (LP) muscles that open the eyes. The frontalis (forehead) muscle assists the LP muscle with eye opening when looking upwards. The OO muscle is divided into three components: pretarsal, preseptal, and orbital. In PSP, the pretarsal portion of the muscle is frequently overactive. Motoneurons that innervate the OO and frontalis muscles are located in the facial nucleus. Motoneurons that innervate the levator palpebrae muscle are located in the oculomotor nucleus in the midbrain, which is part of the upper brainstem. Typically, OO, LP, and frontalis motoneurons remain viable until very late stages of PSP. Therefore, eyelid motor dysfunction in PSP must be due to degeneration of neurons that are part of the circuits connecting the OO, LP, and frontalis motoneurons. Electrophysiological studies suggest that the midbrain, which is a major site of pathological abnormalities in PSP, contains critical components of the circuitry coordinating eyelid movements.

Our anatomical studies indicate that several sites in the midbrain may play a role in coordinating LP and OO motoneuron activity. The supraoculomotor area appears to be particularly important spot in this regard. The supraoculomotor area is located just above the oculomotor nucleus, contains brain cells that connect to the superior and inferior rectus muscles that move the eyes up and down, respectively, and contains neurons afferent to OO motoneurons. Therefore, in future pathological studies, it will important to carefully examine the supraoculomotor area for signs of cell death in PSP brains.

SIXTH NATIONAL BIENNIAL PSP SYMPOSIUM VIDEOTAPE ORDER FORM

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Research

LIPOPEROXIDATION, CDK5 ACTIVITY AND TAU AGGREGATION IN PSP



Massimo Tabaton, MD
Department of Neurosciences,
University of Genova, Italy.

The pathologic marker of progressive supranuclear palsy (PSP) is a diffuse formation of intracellular inclusions that correlate with synaptic and neuronal degeneration of subcortical cerebral nuclei. These inclusions are composed of the microtubule-associated protein tau, which forms abnormal aggregates through still unknown mechanisms. We investigated the role of oxidative stress, an aging related event, and of cdk5, an enzyme involved in the normal maturation of tau, in determining the abnormal tau aggregation that characterizes PSP. We found that the products of the oxidation of lipids are increased in PSP brains proportionally to the extent of tau inclusions. Similarly, we demonstrated that the activity and amount of cdk5 is augmented in PSP brains, and that cdk5 is overproduced when neuronal cells in culture are exposed to products of lipid oxidative stress.

These results show that lipid peroxidation favors PSP pathology through the excessive activation of the enzyme involved in tau maturation. Consequently they suggest that anti-oxidant compounds are potentially efficacious in PSP therapy.

Lay Abstract

The pathologic marker of progressive supranuclear palsy (PSP) is widespread formation of aggregates of protein that correlate with loss of brain cells. These aggregates are composed of the protein tau, which forms abnormal aggregates through still unknown mechanisms. We investigated the role of oxidative stress, which is an aging-related event, and of cdk5, which is an enzyme involved in the normal maturation of tau, in causing abnormal tau aggregation in PSP. We found that the products of the oxidation of lipids (fatty chemicals) are increased in PSP brains proportionally to the extent of tau inclusions. This means that there is excessive oxidative activity in the brain in PSP. Similarly, we demonstrated that the activity and amount of cdk5 is augmented in PSP brains, and that cdk5 is overproduced when neuronal cells in culture are exposed to products of lipid oxidative stress.

These results show that lipid peroxidation may cause PSP pathology through the excessive activation of the enzyme involved in tau maturation. Consequently they suggest that antioxidant compounds may be effective as treatment of PSP.

OXIDATIVE DAMAGE IN PSP



Junchao Tong, MD
Center for Addictions and Mental Health,
Toronto, Canada

The antioxidant glutathione level is an important index of oxidative stress and decreased glutathione levels in degenerating substantia nigra of patients with Parkinson's disease (PD) is the cornerstone of the antioxidant hypothesis of PD.

Similar to PD, reduced glutathione level was significantly decreased by 20% in the substantia nigra pars compacta in PSP whereas levels were normal in all the other subcortical (caudate, putamen, thalamus and hippocampus) and cortical (cerebral and cerebellar cortices) regions examined. These results suggest that oxidative damage could be part of the cause of nigrostriatal cell loss in PSP and that antioxidant therapeutic approaches might be warranted in this disorder.

Aconitase activity, which is highly sensitive to oxidative damage, was recently found to be decreased in cybrid cell lines with mitochondria from patients with PSP (Albers et al., *Exp Neurol* 2001; 168: 196-198), implying the presence of a generalized aconitase deficiency. However, we found that aconitase activity in PSP was normal in brain regions without severe pathology including caudate, frontal and cerebellar cortices. These results suggest that global aconitase deficiency in PSP is unlikely and that data derived from cybrid cell models might not always predict similar changes in human brain.

Lay Abstract

We tested the hypothesis that toxic oxygen by-products might cause brain damage in PSP by measuring levels of brain glutathione, an important antioxidant that normally protects cells from such insults. In autopsied brains of patients with PSP, glutathione levels were significantly decreased selectively in substantia nigra, the brain region supplying the neurotransmitter dopamine. Our finding suggests that oxidative damage could be part of the cause of dopamine cell loss in PSP and that antioxidant therapeutic approaches might be useful in this disorder.

MICROARRAY STUDIES OF SIGNALING PATHWAYS IN PSP.



Sarah J. Augood Ph.D
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To search for early molecular markers of abnormal signaling events that may underlie cellular dysfunction in the PSP brain, we have carried out comparative mRNA profiling experiments in the putamen of control and PSP cases - a brain region displaying limited pathology postmortem yet strongly implicated in the pathophysiology of PSP. These Affymetrix GeneChip studies, generously funded by the Erwin and Pearl Poizner Research Fund through the SPSP, revealed that of the 4,021 genes that were called "present", only 66 were differentially expressed greater than 2 fold in 3 out of the 4 replicates; 9 genes were increased (up to 162.0 fold) and 57 are decreased (up to 89.57 fold) in the PSP putamen compared to controls. These 66 candidate mRNAs include the dopamine D2 receptor, a mitochondrial citrate transport protein, a mitochondrial creatine kinase, the CRE-BP1 transcription factor, a tyrosine phosphatase as well as kinesin heavy chain. Many of these are of interest as they have been implicated in the pathophysiology of PSP, in particular the role of mitochondrial dysfunction and oxidative stress. Independent mRNA studies are currently underway to confirm and validate this array data as well as to carry out additional mRNA profiling studies of other PSP brain regions. These data, in addition to yielding additional candidate genes, will provide us with insight into the topography of cellular dysfunction in PSP.

Lay Abstract

PSP is characterized by marked brain cell loss and gliosis (scar tissue formation) in many brain regions. This project looks for the earliest subtle events in this process in hopes of understanding how to prevent it in an early stage before the brain cells die. We have carried out comparative messenger ribonucleic acid (mRNA) profiling, a technique that assesses an early step in the process of a gene being translated into a functioning (or malfunctioning) protein. We used Affymetrix GeneChips, a new technology that permits many different types of mRNA to be identified merely by applying some brain tissue to a computer chip bearing chemicals in a grid of tiny squares. If the type of mRNA corresponding to a certain square is present in the tissue sample, the chip sends a message to a computer, which records and tabulates the data. We used tissue from the putamen of control and PSP cases - a brain region displaying very little obvious changes at autopsy but still suspected because of what we know about the abnormal chemicals and brain circuits of PSP. These studies revealed that, of the 4,021 kinds of mRNA present (each representing a different kind of protein), only 9 are increased and only 57 are decreased compared to persons without PSP of similar age. Many of these mRNAs are of interest as the proteins they represent have been implicated in the cause of PSP, in particular in the role of mitochondrial abnormalities. Additional mRNA profiling studies are currently under way in other PSP brain regions including the frontal cortex, cerebellum, globus pallidus, midbrain and subthalamic nucleus. These data, in addition to yielding other candidate genes, will provide us with insight into the regional pattern of brain cell dysfunction in PSP before the stage when those cells are actually lost. It will also highlight any abnormalities of mRNA that many brain regions in PSP have in common. This would aid our search for the ultimate cause of PSP.

PROBLEMS OF CELL DEATH IN PROGRESSIVE SUPRANUCLEAR PALSY AND RELATED DISORDERS



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Background: The causes of cell death in progressive supranuclear palsy (PSP) and related neurodegenerative disorders, mainly tauopathies, are unknown. Apoptosis, a specific form of gene-directed programmed cell death (PCD), or alternative pathways has been implicated as major mechanisms. Objective:

Aim of the study was to examine the prevalence and distribution pattern of PCD in autopsy-confirmed cases of PSP and related tauopathies and their relationship to pathologic intracellular tau deposits. Material and methods: Brain tissues of 4 autopsy-proven PSP cases, 3 cases of corticobasal degeneration (CBD), 9 AD, 5 of Parkinson disease of the Lewy body type, 3 cases each of dementia with Lewy bodies (DLB) and multiple system atrophy (MSA) (alpha-synucleinopathies), and 7 age-matched controls were examined using routine staining methods, immunohistochemistry for an array of cell death-related proteins, and TUNEL method to detect DNA fragmentation. Results: In PSP, only single neurons in brainstem tegmentum (1/1080 counted cells) were TUNEL positive, with moderate expression of apoptosis-enhancing c-Jun, activated caspase-3 (antibody CM-1) and some heat-shock proteins, while neurons in substantia nigra, basal ganglia and pons were consistently negative. Only 1/5 TUNEL

positive neurons showed co-expression of antibody AT-8 decorated tau-inclusions (neurofibrillary tangles). Some oligodendrocytes in brainstem tegmentum and pontine nuclei were TUNEL-ARP-1 and CM-1 positive, but only 25-30% showed co-expression of tau-positive inclusions (coiled bodies), whereas astrocytes with tau-positive inclusions were all negative. CBD displayed TUNEL- and ARP-1 positive microglia, oligo- and astrocytes (some showing Gallyas- or tau-positive inclusions), but neurons in substantia nigra and other subcortical nuclei were consistently negative.

While in AD only exceptional hippocampal neurons, most without fibrillary tangles, some with granulovacuolar degeneration (CVD) showed apoptosis, in PD and DLB brains, nigral and locus ceruleus neurons with/without Lewy bodies were all negative, and apoptosis was only seen in reactive microglia and astrocytes. Discussion: The detection of apoptosis-indicating markers in only single brainstem tegmentum neurons of PSP, some involved by tau-inclusions, and in few hippocampal neurons in AD with consistent absence of those markers in nigral/ceruleus neurons in PSP, CBD, PD, DLB, and MSA suggests that PCD in these neurodegenerative disorders does not occur necessarily by apoptosis, but rather reflects the combined action of deficient DNA repair and accelerated DNA damage within susceptible cell populations. The formation of pathologic inclusions may be a crucial event in several neurodegenerative diseases, but the pathogenic role of both the rare involvement of neurons and the relationship between pathologic inclusions and glial cell death need further elucidation.

Lay Abstract

Background: Progressive nerve cell loss is a pathologic hallmark of neurodegenerative disorders, but the mechanisms of cell death remain unclear. Apoptosis is a special form of programmed cell death (PCD) that is driven by the action of genes. It is very different from "necrosis," which is the mode by which cells die from, for example, lack of oxygen. Apoptosis has been implicated as a major mechanism in the degeneration of some brain cells in PSP and other neurodegenerative disorders. If apoptosis is an important mode of brain cell death in PSP, then interruption of any of the steps in this process, possibly via medication, could prevent brain cell loss in PSP. Apoptosis can be revealed by observation of increased DNA fragmentation (using the "TUNEL" method) and by measuring cell death-related (apoptosis-enhancing or inhibiting) proteins and enzymes. This project attempted to determine the extent to which apoptosis was a mechanism in the death of brain cells in PSP and similar disorders. Material and methods: Brain tissue was examined from 4 autopsy-proven cases of PSP, corticobasal degeneration (CBD), 3 cases each of dementia with Lewy bodies (DLB) and multiple system atrophy (MSA), 8 cases of Alzheimer's disease and 7 "control" brains from individuals of similar age as the others but without neurological disease during life.

Results: In PSP only rare neurons in the brainstem tegmentum, an important area of cell death in PSP (about 1/1080 counted cells) were TUNEL positive, with moderate expression of one apoptosis-enhancing marker called c-Jun, but much less expression of other apoptosis markers, while neurons in other involved regions were consistently negative. In CBD, AD, PD and DLB, only a few degenerating neurons showed evidence of apoptosis. Discussion: We found that PCD in neurons (electrically active brain cells) and astrocytes (another important brain cell type that is involved in PSP) in these neurodegenerative disorders does not occur by apoptosis, but rather reflects the combined action of deficient DNA repair after an initial insult and accelerated DNA damage within susceptible cell populations, of unknown nature. Directing future efforts to understanding this process of DNA damage could lead to new treatment opportunities for PSP.

Research

GENETICS AND BIOCHEMISTRY OF A MITOCHONDRIAL DEFECT IN PSP



David Albers, PhD
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New York, NY

The etiological basis of progressive supranuclear palsy (PSP) remains unknown, but studies from this and other laboratories have found evidence of mitochondrial dysfunction and oxidative stress in postmortem PSP brain tissue. The precise intracellular defects contributing to these

oxidative and bioenergetic defects are unclear. In the present study we have used cybrid cell lines expressing mitochondrial genes from patients with PSP to measure mitochondrial function via enzyme activities and membrane potential. Lipid peroxidation, an indicator of oxidative stress, was also measured in response to various mitochondrial insults. We have also tested the utility of potential rescue therapies that are currently available for neuroprotective efficacy. Our results demonstrate a clear mitochondrial impairment in these cybrid cells from PSP patients, suggestive of damage to mitochondrial DNA. Further, the observed biochemical defects in PSP cybrid cells can be partially restored by creatine, a supplement that improves mitochondrial function. These data will be presented.

Lay Abstract

There is growing evidence that defects in energy metabolism within brain cells may underlie cell death in PSP. Imaging studies of glucose usage by cells in the brain of PSP patients coupled with postmortem studies strongly suggest an underlying deficit in the function of mitochondria, the cellular supplier of energy. One result from a defect in mitochondrial function is an increase in free radicals, which cause damage to key cellular components. This phenomenon is called oxidative damage. Despite this evidence for mitochondrial dysfunction and oxidative damage in PSP, the specific events that either cause or result from these defects remain unclear. We have carried out a series of studies, generously funded by the Society for PSP, in cybrid cell lines generated from mitochondria isolated from PSP and age-matched control patients to investigate this mitochondrial defect. Further, we have tested various agents that may reduce/rescue the biochemical deficit by improving mitochondrial function. In summary, our results corroborate and extend our previous findings from postmortem brain tissue showing a specific mitochondrial defect in PSP. Further, creatine, a diet supplement, demonstrated previously to have protective effects in animal models of Parkinson's disease and Huntington's disease, appears to provide beneficial effects in PSP cybrids against the mitochondrial defects and subsequent oxidative damage.

DONORS WANTED:

Enthusiastic volunteers needed to contact potentially high impact donors. Volunteers will serve on a special donor committee and will receive names of several prospects to solicit gifts of \$1000 and more. This requires a high commitment and a passionate desire to raise funds to find the cause and cures for PSP. Training and support is available from the office. 1-800-457-4777 spsp@psp.org

SERUM ANTI-TAU ANTIBODIES IN PSP



Laurel Bolin, MD

Laurel Bolin, MD and
James Tetrad, MD
Sunnyvale Parkinson's Institute,
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The astrocyte tau deposition in PSP has led to the hypothesis that astrocytes acting as antigen presenting cells could elicit an auto-antibody response to tau. Astrocytic cryptic fragments of tau in the context of the major histocompatibility complex (MHC) expression and CD80 could elicit an antibody response at the blood

brain barrier interface. To test this hypothesis, sera from PSP patients, PD patients and age- and sex-matched controls was screened by Western analysis for immunoreactivity to bovine tau, which is 93% homologous to human tau. Results of this initial screen indicated that 60% of PSP patients' sera (12/20) was bovine tau immunoreactive. The PSP sera results contrasted with 5% of PD (1/20) and 10% of control (2/20) sera containing tau immunoreactivity. In PSP tissue lysates, two immunopositive protein species in the size range of tau proteins are observed. This immunoreactivity can be blocked by pre-incubation with human recombinant tau. PSP tissue sections incubated with purified IgG from PSP tau immunopositive sera, reveal astrocytic patterns of immunoreactivity while AD sections have immunopositive plaques. Taken together these results suggest that patients with PSP develop auto-antibodies to tau that are specific for this disease. If so, such antibodies could provide a biomarker for PSP. However, further studies that include larger numbers of PSP sera and controls, and purified IgG are needed to confirm these findings.

Lay Abstract

Tau protein accumulates in the brain cells of PSP patients. While we do not know why this happens, we do know that these tau deposits can interfere with brain function. Since PSP is a disease affecting older individuals, and the aging immune system is prone to auto-immune abnormalities (attacking one's own tissue), it is possible that pathologic tau protein causes the PSP patient's immune system to make antibodies against tau. Normally the immune system makes antibodies to "foreign" proteins such as bacterial proteins. As we age, the immune system becomes less selective and may mount an antibody response to our own proteins. Data from a small group (24) of PSP patients and age- and sex-matched unaffected individuals who were "controls" suggests that PSP patients are making antibodies to tau. We are characterizing tau antibodies in patient sera. Using tissue from the Parkinson's Institute's brain bank, donated from patients who in life had PSP, we are observing patterns of immune reaction with these PSP serum antibodies. Since tau deposits are seen in more than one type of brain cell, these antibodies may show us which cell types the immune system is reacting to. These experiments may identify a "biomarker" for PSP in the form of a tau auto-antibody, allowing a more accurate diagnosis of PSP. Furthermore, these experiments may lead to new research strategies for investigating a possible auto-immune component contributing to the pathology of PSP.

Look for Part II in the next PSP Advocate.

Miami Caring and Sharing

Living with a neurological disease like PSP puts families on an emotional roller coaster, and tears can be a symbol of both grief and healing. Sometimes, just meeting another person going through the same experience provides the greatest support of all. An Afternoon of Caring & Sharing was held on November 10, 2002 at the Airport Marriott Hotel in Miami Florida. Over 30 Floridians came together to learn the latest about PSP research and treatment of eye movement problems. Presentations given by Dr. David Zee, Professor of Neurology, Ophthalmology & Otolaryngology at Johns Hopkins University School of Medicine and Dr. Dennis Dickson, Professor of Pathology at Mayo Clinic, Jacksonville were educational, yet down to earth, enabling participants to glean knowledge and understanding of the disease. Bob Krasnicki, a new support group leader in Tampa, Florida, shared a beautiful song that he wrote in memory of his mother Consetta Krasnicki entitled, "I Kissed Away the Teardrops." After hearing Bob's heartfelt story behind the song, families were eager to share their own experiences and enjoyed the opportunity to fellowship with the other audience members. (Read Bob's PSP Story on page 18.)



Dr. David Zee at the Miami Caring and Sharing

So many families tell me that they feel isolated when they first learn that a loved one has PSP. Not only have they most likely never heard of the disease, they do not know anyone in their community, or even their whole state, who has PSP. The Society strives to connect individuals and families with others in their home state who are living with PSP. For more information on support groups, a list of PSP communicators for your state or upcoming events, please contact the Society at 1-800-457-4777 or send an email to: outreach@psp.org

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



Nancy and Donald Aaron at the Miami Caring and Sharing.

Ask the Doctor

Question:

When do you know when Sinemet and Symmetrel are not working?

Answer:

The best way is to slowly discontinue one drug at a time under a neurologist's supervision and observe whether the symptoms worsen. It is important to do this slowly because if the drug is working, its abrupt discontinuation could cause a sudden, severe worsening of stiffness and swallowing difficulty. With Symmetrel (amantadine), abrupt discontinuation can produce a "rebound" or withdrawal effect that can produce a temporary but serious worsening of disease symptoms beyond what they would have been without the medication. I emphasize that medication discontinuation should only be done under the supervision of a neurologist or other physician experienced in the treatment of parkinsonian disorders.



Lawrence I. Golbe, MD

Question:

Is PSP genetic? I know of a family that the older brother is diagnosed with Parkinson's disease, the second son is diagnosed with PSP and the last child has immune deficiency.

Answer:

There is a very slight tendency for PSP to cluster in families, but fewer than 1% of people with PSP have someone else with PSP in their family, and the chance that any individual given relative will get PSP is far, far less than that. PD is a common disease, occurring in 2% of the population at some point in life. That means that one in 50 of any random group of people is likely to have had PD. If someone with PSP (like the second son in the family you mention) has 50 relatives who have reached advanced age, the odds are close to 100% that one of them had PD. If he had only had 10 such relatives, the odds are 20%. So the occurrence of PD and PSP in the same family is probably a coincidence. Childhood immune deficiency is unrelated to PD and PSP.

Question:

I heard about an operation that puts a pacemaker-like instrument in the brain for PD. Can it work for PSP?

Answer:

This "deep brain stimulation" procedure would not work for PSP and has never been tried. In PD, there are some parts of the brain that are actually overactive as a result of degeneration of other areas that normally provide inhibition to them. The overactive areas themselves are not part of the degenerative process. The DBS somehow reduces the overactivity of those areas, which helps the outward symptoms of the disease. In PSP, however, those areas that are overactive in PD do degenerate, so they are underactive. Applying DBS would only further depress their activity and worsen the outward symptoms of the disease.

Question:

How are PSP and Parkinson's disease the same and how are they distinguished from each other?

Answer:

This is answered in detail in "PSP: Some Answers," a

Education

brochure available from the Society, but in summary, in PSP there tends to be more difficulty with balance, speech, swallowing, eye movement and personality. PSP includes less tremor and limb stiffness. PSP responds much less well to medications.

Question:

We keep hearing anecdotally about environmental exposure to potential toxins—i.e., my sister-in-law owned a kennel for 20 years and was exposed to very high levels of pesticides. Is there a national registry to track and document environmental exposure so that a larger picture can develop?

Answer:

There is no such national registry. The main problem with such a registry is that it is difficult to know whether such toxin exposures are more common among people with PSP than among the non-PSP population. It is very difficult to get a perfectly comparable comparison group to join the registry, too, and to examine their past with as much care.

Question:

Is there a medication to help the “stuttering” walk? My husband walks normally on a treadmill though.

Answer:

If you mean the problem where one can't get the first foot going when initiating walking, Amantadine sometimes helps this problem. Occasionally, excessive dosages of Sinemet aggravate the problem and reducing the dosage can help. But reducing medication should only be done under the supervision of a physician experienced in the treatment of parkinsonian disorders.

Question:

Is there a link with PSP and long-standing depression-manic depression/chronic depression?

Answer:

Many types of personality change, including depression, can occur in PSP. While some people with PSP do become disinhibited, I am not aware of any research finding that true mania is more common in PSP than in the general population.

Eating and Swallowing Problems in PSP

Lucy Skelton, Speech and Language Therapist
Newcastle-upon-Tyne, UK

Reprinted from the PSP Bulletin, Winter 2002, Volume 9
The Official Newsletter of the PSP Europe Association

Lucy Skelton strongly advises that anybody diagnosed with PSP who is experiencing swallowing problems should be referred to a speech and language specialist for a full assessment of the swallowing problems and if necessary speech. The following are some problems she has observed with her patients diagnosed with PSP. She lists tips that she hopes will be helpful with these problems.

1. PERSON WITH PSP OVERFILLING MOUTH

(the person with PSP is usually not aware that he/she is cramming food in and forgets)

- Supervision of all eating
- Frequent verbal prompts from the caregiver to swallow one mouthful before takes the next

2. SPILLAGE OF FOOD AND DRINK DOWN FRONT OF CLOTHES

(caused by visual difficulties of looking down at plate and therefore coordinating plate to mouth transfer)

- Raise the level of the plate to nearer eye level to reduce the need to look down with adjustable-height table or a tray with legs placed on table (see OT or equipment shop)

3. DIFFICULTY CLEARING PHLEGM FROM THROAT

(due to thickened secretions, weak cough and weakened swallow)

The following may help:

- Not eating too many dairy products as these increase phlegm production
- Sips of hot water with lemon in, or diluted orange juice—as citrus thin secretions, making them easier to swallow.
- Inhale steam—steam will thin phlegm making it easier to swallow

4. IF CHEWING BECOMES LABORIOUS OR DIFFICULT AND SLOW

- Avoid chewy foods, e.g., red meat
- Eat softer meats & foods, e.g., braised steak, tender chicken, fish in sauce, pasta in sauce, cooked vegetables—lists of ideas available from speech & language therapists

5. STICKING OF FOOD IN THROAT

(e.g. nuts, crisps, lettuce, dry crumbly biscuits or chewy meat)

- Avoid dry crumbly foods, e.g., biscuits or dunk these in a hot drink to soften them
- Soften foods with gravy or sauces or custard
- Alternate sip of drink with every 1 - 2 mouthfuls of food

6. DIFFICULTY SWALLOWING TABLETS

- Take one tablet at a time
- Put each tablet into a spoonful of yogurt or something similar e.g. mousse etc. to swallow

7. COUGHING WHILE DRINKING

- Take small sips at a time
- Swallow one mouthful before take the next
- Chin tuck to swallow—take a small sip, tuck your chin down toward the chest and swallow
- Seek referral to speech and language therapist for full assessment of swallowing and advice

8. COUGHING WHILE EATING

- Avoid mixed consistency foods, e.g., cereal with bits floating in milk
- Instead have foods of all one consistency e.g. porridge or cornflakes, that have drawn up all the milk
- Puree soups to one smooth consistency
- Seek referral to speech and language therapist for full assessment of swallowing and advice

9. WEIGHT LOSS AND INCREASED DIFFICULTY IN EATING OR DRINKING

- Request referral to speech and language therapist for swallowing assessment and to dietitian for nutritional advice

10. RECURRENT CHEST INFECTION IN CONJUNCTION WITH NOS. 7,8 OR 9 ABOVE

- Seek medical advice for treatment of chest infection and request referral to speech and language therapist as chest infection may be related to drink or foods being aspirated

Support Groups As Of March 12, 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. If you would like to help start a support group in your area, please call the Society office at 1-800-457-4777. For information on support groups in your area please contact:

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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 IN FLORIDA!

Two new support groups are now being formed in the Tampa and Orlando areas. If you are interested in attending or would like more information, please contact these individuals directly:

TAMPA AREA:

Bob Krasnicki
813-960-5732
robert.krasnicki@med.va.gov

ORLANDO AREA:

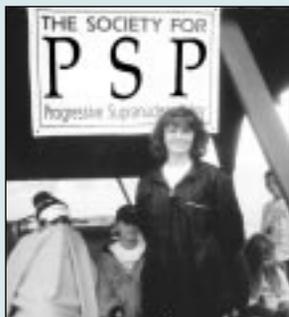
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News From Support Groups

OCTOBER AWARENESS MONTH ACTIVITIES

Taking Steps to Find the Cure

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



Jodi DaRoja
Walkathon Chair

Though the weather outside was frightful, walkers young and old braved the cold, foggy October morning to support the Society at the 2nd Regional PSP Awareness Walk held in Westminster, Maryland. Some enjoyed a leisurely stroll, others a brisk jog, and some were even pulled in a little red wagon. No matter how they chose to complete the 2.5-mile circuit through scenic Westminster, everyone's heart was in the same place that

day—assisting people whose lives have been affected by PSP. The walk was one of several nationwide activities planned in recognition of PSP Awareness Month. For the second year in a row, Jodi DaRoja chaired the walk in loving memory of her grandfather, William DaRoja, who passed away from PSP on August 13, 2001. Mr. DaRoja's family, along with other families and supporters of those living with PSP, joined efforts to raise funds to support the Society's outreach, education and research programs. We were also fortunate to have the support of several wonderful corporate sponsors. Special thanks goes to Provident Bank for placing fliers in its Maryland branches and organizing a team of walkers and to Coastal Productions Studio for capturing this special event on film. The Society also extends gratitude to Bonnie Heneson Communications for its public relations expertise in promoting the event, to The Vernon Company for designing our beautiful souvenir T-shirts, to APW Design for designing and printing our fliers, to WTRR for serving as our media sponsor and to Metro Food Market, Clifton Gunderson, Mark Downs and Mary Kraft & Associates for their generous gifts which helped make this event possible. Most of all, the Society thanks the DaRoja family and every walker who demonstrated their commitment to raising PSP awareness in their communities and across the country.

No, the cool misty weather did nothing to dampen the enthusiasm in Carroll County that morning. In fact, I think it made those autumn leaves look a little bit brighter!



The 2nd Regional PSP Awareness Walk - Westminster, MD

Minnesota PSP Dinner

Charlotte Tripet
Golden Valley, Minnesota

The Minnesota PSP Support group had a successful dinner on October 3, 2002. We had several new families who have had a member diagnosed with PSP come out for the first time. There also were a number of folks supporting families who are caregiving for a PSP patient and 3 persons diagnosed with PSP in attendance. Altogether, we had about 80 people who attended the dinner.



John and Pat Coawlick with Charlotte Tripet

We were fortunate to have speakers who were very helpful in sharing information about PSP. Dr. Sotirios Parashos, a neurologist from the Struthers Parkinson's Center, spoke about current progress in research and the diagnosis of PSP. Cristiane Zampieri, who does research at the University of Minnesota, shared information about eye movement studies in PSP. There have been a couple folks from our group who have participated in this study. The other speaker was Richard Obershaw, founder of the Grief Center in Burnsville, Minnesota, who spoke on "The Stress of Dealing with Change."

We were grateful to the Minnesota Parkinson Association for funding the cost of the dinner. This enabled us to contribute all monies toward research for PSP.



Howard and Darlene Dodge attended the Minnesota Support Group's Dinner with their family.

PSP Swim-A-Thon

Linda Webster
Gulf Shores, Alabama

The second annual PSP Swim-A-Thon was held on October 30 at the Bodenhamer Center in Gulf Shores, Alabama. It was held in memory of my husband, Robert Webster, who died on May 29, 2002 from PSP.

Swim-A-Thon sponsors contributed \$1,160. Twenty-four swimmers participated, including the Gulf Shores High School Swim Team, the GS Recreational Swim Team, and the Master Swimmers. A total of 881 laps were swam, or 24.5 miles.

Thanks to lifeguard Carrie Wilson, and massage therapist Terri Wooley, for organizing the Swim-A-Thon. Local musicians JR Owen and Brent Burns played and sang for us again. Refreshments were donated by Wal-Mart and Winn-Dixie of Foley. The Bodenhamer Center graciously allowed us to use their beautiful pool. Special thanks to the swimmers and sponsors who made the event happen.

News From Support Groups

Five Volkssport Clubs were among the donors. Bob and I were avid Volksmarchers for 14+ years, and in 2000 we became 50-state walkers, having completed one or more of the sanctioned 10 km walks in each of the 50 states. Our last eight states were accomplished only with me pushing Bob in his wheelchair around the course (or as much of it as we could manage), but complete them we did, and it was a huge achievement for us at that point! The five clubs which have donated in Bob's memory as of this writing are: Seacoast Striders of NH, Capital City Wanderers of AL, Twin State Volksmarch Club of VT, Wandering Maine-iacs of ME, and Walk'n Mass of MA.

While the results were good, the Swim-A-Thon was not the festive occasion of last year. The Star of the Show—the whole reason for the Swim-A-Thon—was not there. It was always an inspiration to watch Bob struggling to complete his laps, but enjoying himself and the water immensely. We'd walk and talk, and he'd get to laughing so loudly and gleefully that he'd have everyone at the pool smiling and watching in admiration. Bob was—is—sorely missed.

“A Night In Italy”

Jane Ellen Nickey
Spring, Texas

A PSP fundraiser, “A Night in Italy” was hosted in honor of Dr. William, M. Drake, my dad, who died on Nov. 24, 2000 due to complications of PSP. I invited close friends and cooked dinner serving antipasti, vegetarian lasagna, salad, garlic bread, creme brulee and cappuccino.

I gave a short presentation about PSP after the dinner and had an information table with “security” envelopes for donations. I gave everyone who came tote bags, pens and PSP information. Because everyone donated anonymously, I do not know how much money we raised, but I do know we raised awareness and support for PSP that evening! It was a memorable event!!

Utah's PSP Awareness Benefit

Tracie Sansavera
Ogden, Utah

My mother, Marge Peck, was diagnosed in 1998 with PSP after 2 years of many doctors' visits and a couple of misdiagnoses. I am a military wife far from home and I sometimes feel so hopeless being away from my mom. With October being PSP Awareness month, I decided since I can't do much to help her I would like to try to do something that might help someone else.

When I was planning the benefit, I never dreamed that during this process I would be shown so much compassion from not only my friends, who have been unbelievably supportive, but also from local businesses as well. I never imagined the comfort I would find in speaking with other families in Utah who have been directly impacted by PSP. The benefit was a blessing in so many ways.



Super Event Planner Tracie Sansavera begins the auction.

The night of the event was amazing. Thirty-four people attended the benefit, including 4 families who have been directly affected by PSP. Florence Hanson, who lost her husband, Charles Hanson, in November 2000 was accompanied by her son, Chad. Sheridan Murphy lost his wife, Roylene, August 12th of this year and was accompanied by his daughter, Marla. Ramon Child is currently battling PSP and was accompanied by his wife, Elizabeth.



The talented men of the Quick Wit's Comedy Club.

Everyone enjoyed a delicious meal by the fireplace in the beautiful Ruby River Steakhouse in Ogden, Utah. While we dined, the talented men of Quick Wit's, a comedy club in Clearfield, donated their time and entertained us with their “Whose Line Is It Anyway”-style improv. To top off the wonderful evening, a raffle drawing was held with 22 prizes donated from local businesses as well as a beautiful sculpture created and donated by Florence Hanson. It was great to see Elizabeth Child win a much-deserved massage!

It felt so good to meet other people who know what I'm going through. The other families were thanking me for coordinating the benefit and I don't think they realized how much comfort I received as well. Phone numbers were exchanged, stories were shared and the evening was a success. Those who didn't have a direct connection to PSP left that evening with an understanding of what PSP is, what it does and how it affects entire families. I received calls for several days after the benefit from people who told me how they went home and shared what they learned with family members, neighbors and friends. One gentleman said he left that night feeling like he was part of a big group hug.

My mother is an amazing woman who has touched many lives. I like to believe that through me she has touched many, many more. The benefit raised a total of \$1,277, but the evening accomplished so much more than that. Friendships were made, awareness was raised, compassion was shown and we can only guess how far-reaching that evening truly was.



Tracie Sansavera, Florence Hanson and Chad Hanson with the sculpture donated by Florence for the raffle.

News From Support Groups

PSP Walk-A-Thon

Sherri Cyle Collie
Collinwood, Tennessee



Beta Club students with Mr. Harper.

The Collinwood Middle School Beta Club sponsored a walk-a-thon on October 15, 2002. This was the students' fall community project and students raised money for PSP. This event was organized by Sherrie Cyle Collie. There are 73 students in the Beta Club and they raised \$3,100. Needless to say, this exceeded everyone's expectations. This money was given to the Society for PSP to be used in its research program.

Odell Harper, a member of the community, was diagnosed with PSP in 1998. Mr. Harper was able to attend the event for a short time, accompanied by his wife and caregiver, Sallie. The Club was very happy to see Mr. Harper and had its picture taken with him.

Gift certificates were given to the top three people who collected the most money. Twenty-two businesses helped to support this event. The Beta Club expresses its appreciation to these businesses, and the students, parents, community, sponsors, and the principal for helping to make this walk-a-thon such a success.

(See page 21 - Sallie Harper's PSP Story)

PSP Harvest Festival & Hayride

Marcy Bay Gladle
Canandaigua, NY



The Bay family: (top) Matt and Nancy (bottom) Mike, Mom, Dad and Eric.

It's hard to beat autumn in New York... sunny skies, colorful leaves and just the right amount of crispness in the air. Marcy Bay Gladle organized a Hayride and Harvest Festival benefit for The Society for Progressive Supranuclear Palsy in



Brother Mike and his wagon all loaded for the hayride.

honor of her mother, Joan Bay. Held on October 20, 2002, this event took full advantage of the beautiful fall weather in upstate New York. The afternoon hayride was enjoyed by all, and the kids loved the "moon bounce" attraction and face painting, courtesy of Valerie Bay. Marcy's brother even donated and decorated his own wagon for the festivities, and horses were loaned by the Blood family. Desserts and other refreshments were donated by relatives. Marcy wishes to thank her father, Kenmore Bay, her husband, Chuck Gladle and family members Nat & Jennifer Bay, Eric & Valerie Bay, and Mike & Hollie Bay for their help in putting together this wonderful day. Over \$1,500 was raised to fight PSP thanks to the generosity of family members, friends and even strangers who attended the festival. Marcy and her family look forward to planning the 2nd Annual PSP Harvest Festival next year.



The Blood family loaned their horses and wagon.

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 Oct. Call Kate DeSantis at the Society office or email her at execsec@psp.org.

Join the cause!!

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,

My best friend, Dorothy Domohur, wrote this memorial tribute for her husband, Pete. Pete died from the ravages of PSP, as did my husband William R. Smith. Unfortunately, Dorothy died from lung cancer before she got this to the Society. It would mean a great deal to the family if you could print it posthumously. It was very hard to loose both Pete and Dorothy within such a short time. Thank you for your consideration.

Sincerely,

Loda M. Smith

The Bravest Man

By Dorothy Domohur

My husband was the bravest man I ever knew. His name was Pete.

Tall, handsome, all man, he was my loving husband for 47 years. He was a very active person, keeping busy every moment. He loved to work on projects, helping family members whenever they had a need.

Pete was never sick a day in his life. After he retired, he began experiencing health problems with his vision and balance.

We visited several doctors in the area and we made trips to Cleveland Clinic and the New York Hospital. All confirmed Pete had progressive supranuclear palsy, which was not well known or easily recognized.

PSP is a horrible disease, a man trapped in a body that could not move but with a mind so clear, understanding every thing.

Pete wanted a magic pill to make him well again. Meal times were so frustrating as he became unable to swallow. It was heartbreaking to hear his speech which slowly got worse until he could no longer speak.

Pete would sit and watch TV or listen to the radio during the day. He did not cry during the day, but we did cry at night holding each other. He knew he would never get better, but he never complained as he accepted his fate.

The last words he spoke two months before he died were "I LOVE YOU."

As the illness progressed, many changes took place in the house: a hospital bed in the family room, a lift chair, wheelchair, suction machine and oxygen tank were also needed.

Fortunately we were able to keep Pete at home surrounded by his family. With the support and devotion of my children and my faithful sister – we cared for him. I could not have managed Pete alone.

We will never forget his sweet and sunny personality and his deep love for me and our children.

GIVE A GIFT ONLINE

www.psp.org



A Love Story And A Song

I'd like to share with you a thought-provoking quotation from Suzanne Mintz, President of the National Caregiver's Association. She said, "Anyone can become a caregiver at a moment's notice ... all it takes is a stroke, accident, or a debilitating illness and ... someone you love." This quotation became reality for me five years ago when my mom, Consetta Krasnicki, was diagnosed with progressive supranuclear palsy. My dad, sisters and I were devastated as we read clinical reports regarding the anticipated progression of the disease. We realized my mom's life, as we knew it, was going to change in a very different way.

Fortunately, I was able to take a leave of absence from my job to help my dad provide home health care. What follows is an abbreviated story of my journey into the life of being a "caregiver." My caregiver experiences inspired the lyrics for a song I subsequently wrote entitled, "I Kissed Away the Teardrops." It is a song of love and inspiration which contains a message that I hope will be beneficial to all of you who are now, or have been, or are about to become a caregiver for someone you love.

The day of what became the last time I saw my mom, I was holding her hand as she lay in bed. I remember she looked at me with tears in her eyes and said, "Rob ... please help me." I felt helpless because I knew there was nothing I could really do to bring back the life she enjoyed before PSP. Tears came to my eyes... I hugged her... told her I loved her ... and I wiped the teardrops from her eyes.

*"I held her in my arms... told her tenderly
Things would soon be better... she could put her faith in me
I told her I loved her... and she began to cry
That's when I kissed away the teardrops... falling... from her eyes*

*There were teardrops for another life that suddenly fell apart
And teardrops for the emptiness we both felt inside our hearts
Some tears for the uncertainty of facing the unknown... and now
A tear of joy for knowing she'd never... never... ever... be alone"*

Caregiving is defined in the dictionary as "looking after, or attending to, or being responsible for someone." I realized at that point, a more accurate definition would be that caregiving is SHARING LOVE by looking after, attending to, or being responsible for someone. I found the essence of caregiving to be unconditional love ... and ... that LOVE will sustain a caregiver through the bleakest, saddest, and hardest moments during the caregiving experience.

Caregiving for me, my dad, and sisters required us to learn a lot of new things very quickly. We learned how to become a nurse, physical therapist, occupational therapist, pharmacist, social worker, psychologist, medicare accountant, home-health equipment expert, etc. We pretty much learned the hard way ... by trial and error. We did not know nor were we informed, about the numerous educational and informational resources available to caregivers through the PSP Society. As a result of this experience, I am making it a personal goal to do

Support - Our PSP Stories

whatever I can to promote "PSP caregiver issue awareness." The good people at the PSP Society need our volunteer help to maximize their efforts in this regard. "Informed Caregiving" is much better than caregiving by trial and error ... trust me on this!

I can summarize my caregiving experience as being a continuous rollercoaster ride of emotions—emotions of love, anger, frustration, bewilderment, depression. And occasional elation. I'd like to share a few personal examples of my ride! Experiencing love from the simple statement... "Thanks for making me a beautiful lady again" which my mom said to me after I had bathed her and tried to fix her hair (I'd never be a successful hair stylist) ... Feeling frustrated that I could not find a creative way to improve my mom's morale as her speech and motor skills were lost to the effects of PSP... Anger at seeing this terrible disease slowly rob my mom of her vitality and zest for life ... bewilderment when the disease evoked periods of abnormal hostility in mom which she directed at us (a common effect, I learned, which is related to the disease process and causes occasions of personality change) ... and elation over sometimes seeing her have a good day ... seeing her smile ... seeing her agitation disappear as she listened to an audio-tape I made of piano music I recorded.

Where did all this lead? The cycle finally ended when she passed away three years after being diagnosed as having PSP. I was grateful her emotional and physical suffering had ended and in time, I was able to see her ordeal had actually given me a priceless gift—the gift of being able to appreciate what is truly important in life, and a feeling of tremendous satisfaction in knowing I had done all that I could to make her final year of life a little better.

"I once thought that happiness could be bought in any store

*Diamond rings and fancy cars... clothes rich people wore
Tonight I found out differently... much to my surprise
When I kissed away some teardrops... from her eyes
In that moment I discovered what I could never see
All the riches in the world didn't mean that much to me
But the feelings I had for her... Love held deep inside
Kissed away the teardrops... falling... from her eyes*



Consetta Krasnicki

May God bless you and be with you as you travel down the caregiver road. It is a long and difficult journey but I am sure, at its end, you will also receive the priceless gift my mom gave to me from your loved one.

A final thought ... my mom always said happiness in life comes from a collection of "good" moments. You have added to my collection today by giving me the opportunity of sharing my story with you.

Our Family and PSP

Sallie Harper
Collinwood, Tennessee

My husband that I love and have shared my life with for almost 44 years has been diagnosed with PSP. We live on a farm in a rural community in Wayne County, Tennessee. Dale is 64 years old. We have three wonderful children and four grandchildren. In 1995, Dale started having weakness in his legs. At this time he was working for Teamsters at TVA driving a truck. He also owned his own trucking company, Harper Valley Trucking, and a cattle farm. Dale was a six-foot-tall, handsome and athletic man. He loved the outdoors. He was a very hard-working man. Dale had a few falls the last part of 1995. On February 9, 1996, he had open heart surgery. We thought this would solve his medical problems, but he began having dizziness, blurred vision, double vision, and his eyes were very sensitive to light. We had his eyes checked and were told he had 20/20 vision. The doctor ordered a CAT scan to check for tumors, but he did not have any. By this time, the falls had gotten worse. They were bad enough to leave cuts and bruises.

Our family doctor sent us to a doctor in Birmingham, Alabama. The neurologist there did an MRI, and an MRA along with other tests. Nothing showed up. The neurologist diagnosed Dale with possible Alzheimer's disease. They told him he could not work any more and to file disability. This was a terrible thing for Dale to have to go through. We went for a second opinion at Vanderbilt Hospital in Nashville, TN. Again, he was put through numerous tests. Nothing really showed up but this time he was diagnosed with possible Parkinson's disease. In 1998, we went for another opinion. Dale's swallowing had gotten worse and he was choking on his food. We went to another hospital in Nashville. The diagnosis was PSP. We were given very little information on PSP. We were told to go home and get everything in order. I was told to make Dale as comfortable as possible. Thankfully, we were also told to contact the PSP Society.

It has been a very long road that we have traveled with this disease. PSP has affected every aspect of our lives. It has affected us mentally, physically, financially, and spiritually. Dale has kept his faith in God and has never once asked "why me?" But he has asked the question, "How much longer?". Our strong faith in God and our wonderful children and grandchildren being by our side every step of the way has sustained us. Thank God for church, family, and friends.

Here we are in 2002. We have a wheelchair, hospital bed, lift chair, suction machine, breathing machine, and now a feeding tube. We put the feeding tube in Dale in March of this year. It was the hardest decision to make but I am so thankful we did it because Dale's quality of life is so much better. He hasn't had pneumonia since we put the tube in. His choking and coughing has decreased tremendously. Dale can still talk, though it is slow. He can still walk but he has to have help. Our prayer is to be able to take care of him at home. I have been his fulltime caregiver since 1998. I quit my job so that I could do this for him. We also have home health care and this has been a tremendous help to me. He has a lot of pain across his shoulders and his neck is rigid. He has been getting botox treatments for his pain for a year now. The last time he had his treatment, it did not work.

The PSP Society, and *The PSP Advocate*, have been our salvation. We haven't beat this devastating disease but we can all stick together and help each other through it. We will continue to keep fighting it and try to stay one step ahead of it. We love Dale very much. It has been hard seeing him like this because he was always such a strong man. But as a family, we will get through it.

Support - Helpful Hints

Recipes for a Special Swallowing Diet

FRUIT SMOOTHIE

INGREDIENTS:

- 6 or 7 frozen strawberries
- 1 canned fruit with juice; I prefer tropical fruit mixtures
- 1 banana
- any other fresh fruit you have on hand; if you use this, skip the canned fruit
- 1 single serving any flavor yogurt

DIRECTIONS: Put banana and your choice of fruit with some juice into blender. Mix together and add container of yogurt. Add frozen strawberries and mix. If liquid it is too thick, add more juice and blend.

WARM OATMEAL BREAKFAST DRINK

INGREDIENTS:

- 1 cup apple juice (or fruit juice of choice)
- 1 cup vanilla yogurt or ice cream
- 1 banana
- 1 other fruit of choice
- 1 package of instant oatmeal
- 1 cup of milk or cream

DIRECTIONS:

Heat in the microwave for 1 1/2 minutes. Blend and enjoy!

SMOOTH BROCCOLI SOUP

INGREDIENTS:

- 1 8 oz. package of frozen broccoli
- 1 pkg of dry Lipton noodle soup mix, chicken flavor
- approx 2 cups milk
- 1 small can evaporated milk
- flour or cornstarch for thickening

DIRECTIONS: Cook broccoli in small amount of water, when done, drain off water, and cool, keeping liquid to return broccoli to after being run through the blender. Add pkg of noodle mix to broccoli, adding enough water to cover it all if necessary. Stir well and bring back to a gentle boil. Pour flour into a measuring cup and add some liquid to it from soup mix. Blend to use as thickening for soup. Add milk and flour mixture to pot and blend, stirring often to smooth it out.

CHEDDAR BAKED POTATOES

INGREDIENTS:

- 6 or 7 medium potatoes, thinly sliced
- 2 cans cream of mushroom soup, undiluted
- 1 bag shredded Cheddar cheese

DIRECTIONS: Grease a glass oven-safe pan. Heat oven to 400 degrees. Place sliced potatoes in greased pan. Sprinkle cheese over the potatoes. Spoon mushroom soup over top of cheese. Cover with foil and bake for 1 hour. Remove foil and let bake, uncovered, for about 10 minutes. Blend baked mixture and enjoy.

ZUCCHINI CASSEROLE

INGREDIENTS:

- 4 eggs
- 1 1/2 cups Colby cheese
- 4 cups zucchini
- 1 large white onion
- 1 1/2 cups Bisquick
- 1 can of stewed tomatoes

DIRECTIONS: Dice the zucchini and cheese into large chunks. Mix with all the remaining ingredients. Pour into a buttered baking dish and bake in 350 degree oven for 45 minutes. Zucchini cooks very soft so this should be easy to swallow.

MEAT LOAF

INGREDIENTS

- 2 cups bread crumbs
- 1/2 cup onion, minced
- 1 tablespoon horseradish
- 2 teaspoons celery salt
- 1 teaspoon garlic
- 1/4 teaspoon pepper
- 2 egg
- 1/2 cup BBQ sauce
- 1 1/2 pounds hamburger, twice ground

DIRECTIONS: Combine bread crumbs, horseradish, onions, celery salt, 2 tablespoons water, garlic salt, pepper and eggs. Add beef and mix well. Place in loaf pan and bake at 350 degrees for 30 minutes. Pour off grease. Pour on BBQ sauce and continue baking for 45 minutes. Add more sauce if desired.

HAM AND POTATO CASSEROLE

INGREDIENTS:

- 1 1/2 cups finely chopped ham
- 1 can cream of mushroom soup
- 1/4 cup milk
- 1/8 teaspoon pepper
- 1 tablespoon instant minced onion
- 1 cup sharp cheddar cheese, shredded
- 4 cups potatoes, cooked and finely diced

DIRECTIONS: Combine ham, cream of mushroom soup, milk, minced onion, pepper and in large bowl. Bake at 350 degrees for 45 minutes. Puree in blender and serve.

BAKED STEAK WITH MASHED POTATOES AND GRAVY

INGREDIENTS:

- Round steak—tenderized gently and cut into individual size servings
- 1/2 cup flour
- Durkee, French's or McCormick Mushroom Brown Gravy Mix (3-4 pkgs.)

DIRECTIONS: Flour and brown the steak in oil (not fully cooked!) Mix (per directions on pkg.) gravy mix in a cake pan. Put steak in the gravy. Bake at 350 degrees for 1-1/2 to 2 hours until tender. Puree in blender and serve. Serve with mashed potatoes.

CREAM OF VEGETABLE SOUP (2 portions)

INGREDIENTS:

- 2 oz. (60g) carrots, chopped
- 2 oz. (60g) leeks, chopped
- 2 oz. (60g) turnip, chopped
- 2 oz. (60g) potato, chopped
- 1 pint stock e.g. made with a stock cube
- 1/2 pint of milk
- Salt, pepper and garlic if desired
- Chopped parsley

DIRECTIONS: Add chopped vegetables to the stock, simmer gently until vegetables are soft. Let the soup cool, then add the parsley and blend in blender until smooth. Return to the pan, add milk and seasoning to taste.

CHICKEN & MUSHROOM SOUP (2 portions)

INGREDIENTS:

- 1 can of cream of mushroom soup
- 1 chicken piece, cooked and diced

DIRECTIONS: Warm the soup thoroughly. Add chopped chicken, then liquidize in blender until smooth.

Support - Helpful Hints

Savory Dishes:

CHICKEN/FISH SUPREME

INGREDIENTS:

- Cooked chicken, finely cubed or piece of white fish
- 1 can of condensed mushroom soup

DIRECTIONS: Place chicken/fish in casserole dish. Pour over condensed soup. Heat in oven at 375 degrees for 30 minutes. Smooth in blender and serve.

SMOKED HADDOCK SCRAMBLE (serves 2)

INGREDIENTS:

- 4 eggs
- 1 tablespoon milk
- salt and pepper
- nutmeg
- 1 oz. butter
- 1/2 lb. cooked smoked haddock, flaked
- 2 drops tabasco sauce

DIRECTIONS: Whisk together the eggs, milk and seasoning in a bowl. Melt the butter in a saucepan and add the egg mixture until the foam subsides. Reduce the heat, stirring constantly until the egg thickens. Stir in the flaked fish and tabasco sauce. Continue to cook, stirring constantly, for two minutes.

Drinks

MILK SHAKE

INGREDIENTS:

- 1 glass milk
- 1 small block or scoop ice cream
- Flavoring, e.g. milk shake syrup, coffee or drinking chocolate.

DIRECTIONS: Whisk all ingredients together in blender.

BANANA SHAKE

INGREDIENTS:

- 1/2 pt. milk
- 1/2 very ripe banana, mashed
- Scoop of ice cream

DIRECTIONS: Whisk all ingredients together in blender.

HOT CHOCOLATE

DIRECTIONS: Mug of hot chocolate and 1 teaspoon of dried skimmed milk powder. Top with marshmallows.

Sweet Dishes:

CREAMY FRUIT DESSERT (2 portions)

INGREDIENTS:

- 8 oz. (250g) tinned or stewed fruit
- Small can evaporated milk

DIRECTIONS: Blend ingredients together and serve cold, straight from the refrigerator.

JELLY WHIP (2-3 portions)

INGREDIENTS:

- 1 small jar of jelly
- 1 small can evaporated milk

DIRECTIONS: Dissolve the jelly with boiling water, but only make up to 3/4 pint liquid. Whisk evaporated milk until stiff. When the jelly is cool, add gradually to whipped evaporated milk and chill in the fridge until set.

Cooking to aid in the swallowing problems that PSP causes is a great challenge. Send in your favorite recipes and help compile the "Helpful Hint PSP Cookbook." Please email your recipes to me, Nancy Brittingham, at NancyB501@cs.com or mail to the Society office with attention to me. Thanks!

Some manufacturers have developed ready-to-serve foods for the pureed diet. The following is a partial listing of manufacturers and recipe sources to assist you in achieving the goal of appetizing and appealing pureed foods:

AMERICAN INSTITUTIONAL PRODUCTS (800) 866-7757—Pureed, shaped entrees (meats, hot dogs), bulk fruits and vegetables, molds, single-serve gelled pastries (cookies, waffles, doughnuts, etc.); thickened juice, drinks, milk; thickening powders.

CLIFFDALE FARMS (800) 877-1553—Pureed meats, vegetables, fruits, desserts.

DIAMOND CRYSTAL (800) 225-0592—Pre-shaped pureed foods (meats, casseroles, entrees); Puree Plus (for thickening meats, vegetables, desserts); thickened juices, milk, juice drinks.

MENU DIRECT CORP. (888) MENU-123—Pureed meals for home delivery.

NOVARTIS (800) 622-2689—Thicken Up (fluid and food thickener); Puree Appeal (food enhancer—adds calories, protein, improves appearance and flavor); thickened juice, milk, drinks, milkshakes, sugar-free drinks, coffee; gelled cookies.

NUTRABALANCE (800) 432-3134—thickened water, milkshakes, juices.

TRAVIS MEATS, INC. (800) 247-7606—Prepared pureed meat products.

BECKY DORNER & ASSOCIATES (330) 666-2388—Puree Pizzazz Cookbook by Becky Dörner, RD, LD and Jan Buchheim, MS, RD, LD

BOOKS

Blender-Full: High Protein, High-Calorie Recipes

Los Angeles District California Dietetic Association, P.O. Box 3506, Santa Monica, CA 90408-3506, 213-454-4916. 1985, 24 pages, paperback \$5.25 (+ \$2.50 S&H)

This booklet has 15 pages of tested recipes high in protein and calories. Recipes are prepared with foods typically found at the local grocery store. The recipes are for cancer programs, persons with cystic fibrosis, people with AIDS, frail people, people with dental problems, and people with metabolic stress.

Dysphagia Dining: A Handbook for People with Swallowing Disorders

Alta Bates-Herrick Rehabilitation Center, Department of Nutrition and Food Services, 2001 Dwight Way, Berkeley, CA 94704. 54 pages, spiral-bound \$10.00

This handbook provides general information about swallowing disorders, addresses nutritional concerns, and provides meal planning guidelines. Sample menus for the dysphagia diet and recipes are also given.

A Second Chance: Surviving on Liquefied Meals

Order from Esther Barney, P.O. Box 915, Silver City, NM 88062. 48 pages, paperback \$8.50 (+ \$1.50 S&H)

Esther Barney wrote this pamphlet based on her experience in preparing meals for her husband who had cancer of the larynx. A picture accompanies each recipe, which lists ingredients and the method of preparation and blending. A section with general food preparation guidelines and hints for traveling is included. The author also discusses her husband's illness from diagnosis through treatment.

Satisfying Your Tastes

Order from Evelyn R. Kerrigan & Associates, 603 Greenspring Drive, Gibsonia, PA 15044. 94 pages, pressboard-bound \$22.00 (includes S&H and tax)

Registered dietitian Evelyn R. Kerrigan, M.S., and Sandra L. Livingston, registered dietetic technician, wrote this cookbook which emphasizes recipes that retain nutrient content of foods, contain costs, are not labor intensive, and provide proper consistency for a "safe swallow." Over 75 tested recipes are adjusted for 1, 5, and 15 servings. A blank column is provided for the user's exact production needs. Also included are a nutrient analysis for the recipes and general guidelines for preparation of pureed food.

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PSP EUROPE

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

Michael Koe
The Old Rectory
Wappenham, Nr Towcester, Northamptonshire
NN12 8SQ
Telephone 0044 (0) 1327 860299
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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.

Society for Progressive Supranuclear Palsy Brain Donation Program

For Diagnosis of and Research on PSP

Society for PSP Brain Bank
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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!

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