THE SOCIETY FOR
PSP
Progressive Supranuclear Palsey

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INSIDE

State of the Society

Dudley Moore & Julie Andrews

SPECIAL ENCLOSURES

1999 Baltimore Symposium

Medical Professional's Special Edition

The PSP **ADVOCATE**

First Quarterly, 2000, Vol. 11, No. 1

1990-2000
A Decade of Caring

Part One: by Joanne Armstrong

Our First Five Years as a Volunteer Organization

The Society for PSP will soon celebrate its tenth anniversary! As we celebrate a "Decade of Caring," we should pause to remember and give thanks for many of the persons who have cared for this organization and ensured its stability, growth and continuation in its mission.

As with most patient advocacy groups, the organization started with the courage, vision, enthusiasm and determination of just one person. In our case that person was David Saks of Baltimore, Maryland, who found my name, the only other one in Baltimore, on the list of PSP patients and family members from around the nation who had written to the National Organization of Rare Disorders for information about the disorder, and who, in addition, said they would be willing to correspond and share information with other families. Both David's wife and my father had been diagnosed with PSP. David's August 1, 1990, letter to the other thirty six names on NORD's list asked "Shall we continue to wait for things to happen or shall we get together to make them happen?" On September 5, 1990, his letter to the respondents announced that ten patients or family members indicated a desire to form an organization. The Society for PSP was launched!

Joanne Armstrong, Honorary Member Board of Directors

We organized as a membership organization and asked for an initial $15.00 membership fee and $15.00 annual dues. "If any of you finds these amounts a hardship, send what you can... If any of you can afford to, please send more." It would be well into the first year of operation before the fee structure would cover a portion of the start up expenses of stationery, postage, duplication, telephone fees, legal and other fees to incorporate, register, and get a designation as a 501(c)3 nonprofit organization. We were a truly national organization thanks to the giving nature of our first officers: David Saks, Executive Director, Maryland, Joanne Armstrong, President, Maryland, Mary Anne Memminger, Vice President, Hawaii, Reba Saks, Secretary, Maryland and Pat Enright, Treasurer, Illinois. Mary Anne financed the mailing of our first newsletter in May, 1991, which went to 100 plus addresses. This followed a series of 5 letters to the membership from David Saks. Pat served valiantly for three years as our first treasurer. Quite a feat to handle long distance from Baltimore.

Paula Frakes, an employee of Hoffman La Roche successfully gained time and funding from her employer to plan and execute our first professionally printed newsletter, a four page folded self mailer.

By November, 1990, Dr. Stephen Reich, of Johns Hopkins University Hospital had agreed to serve as Chairman of the Board and Dr. Lawrence Golbe of Robert Wood Johnson Medical School had agreed to assemble a Medical Advisory Board. Meetings in November 1990 and February 1991 with Dr. Murray Goldstein, Director of the National institutes of Neurological Disorders and Stroke and other top scientists at that institution propelled not only the visibility of the organization but initiated our request for research funding.

As the organization's membership grew David, Reba, and I each dealt with health issues that restricted their attention to the organization. We were all saddened when Reba lost her battle with PSP in April, 1993. David's health was also in decline, but he worked courageously for The Society every waking moment, even during months when he was confined to his bed, until his death in September, 1995.

Thanks to many others who volunteered their time, skills and financial resources facilitating the organization to remain focused on its mis-

Continued Page 11

Society for Progressive Supranuclear Palsy, Inc. (SPSP)

FOUNDERS
Reba and David Saks

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Core Director Micronesian Health Studies

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SPSP DIRECTOR
Ellen Pam Katz

**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. (SPSP) 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 rare, neurological disorder related to Parkinson's disease. SPSP provides information, education, support and advocacy to persons with PSP, their families, and caregivers. SPSP educates physicians and allied health professionals on PSP and how to improve patient care. The Society, Director, and staff are under the administration of the Johns Hopkins School of Medicine, Department of Neurology

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The PSP ADVOCATE is a quarterly newsletter published by SPSP that informs members of findings in the area of PSP.

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(In memory of Henry and Jane Ogiba)

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Director's Doings

The Millennium fireworks at the Society began exploding on September 29,1999. On that day Dudley Moore, beloved actor, composer and comedian came forth with his diagnosis of PSP. The public's exposure to PSP was sudden and shocking — a new illness to add to the public's lexicon of fatal and degenerative diseases including Huntington's disease and ALS. The national TV entertainment networks, radio and print media throughout the world contacted us for information and for comments on Mr. Moore's condition. We appreciate, that Dudley Moore and his colleagues contacted us immediately to form a relationship and establish the Dudley Moore Research fund for PSP to be administered by the Society.

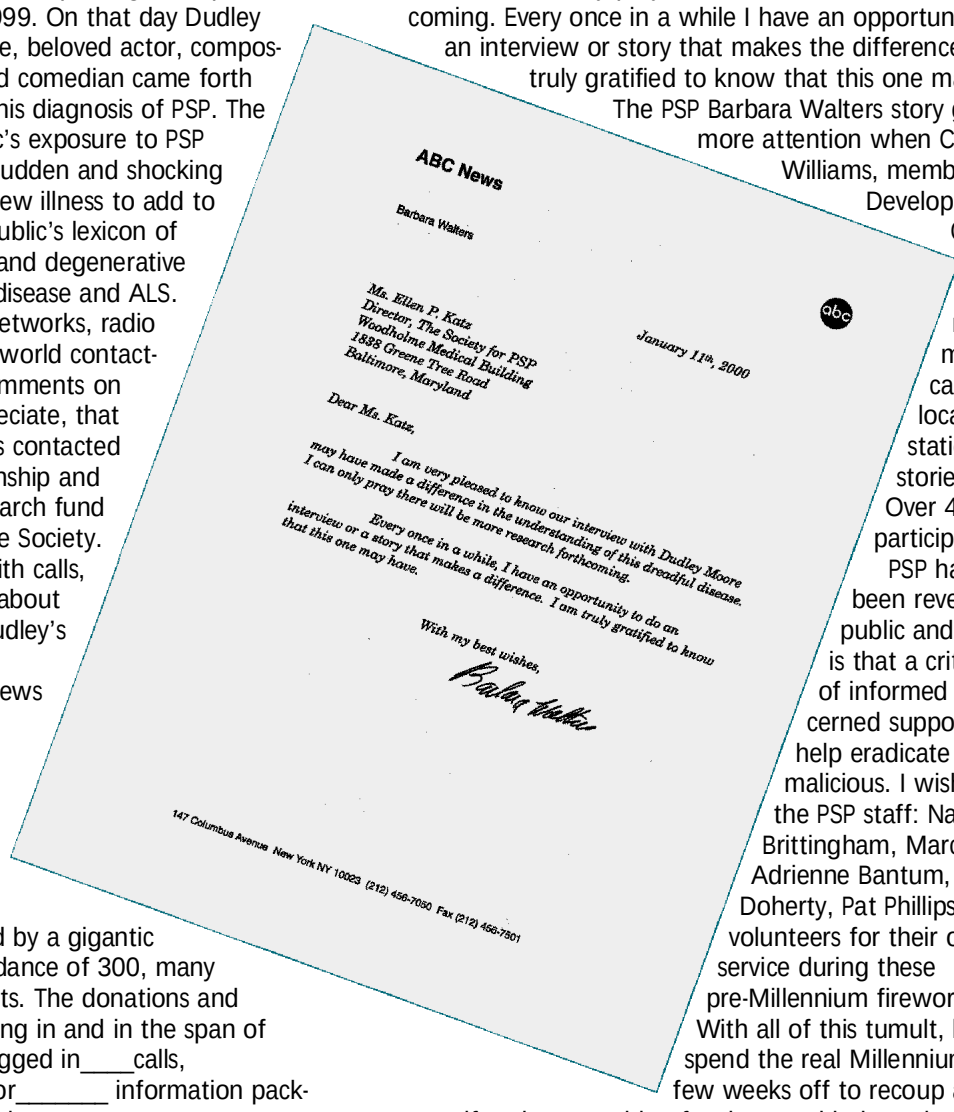
The Society was besieged with calls, faxes and emails as information about the Society was released with Dudley's diagnosis.

At the same time Moore's news erupted, the Society was in the midst of three concurrent and large events: the Annual Giving Campaign, the Fifth Biennial Symposium, and finally, the Society's long-awaited strategic plan.

Our small staff was engulfed by a gigantic Symposium with expected attendance of 300, many vendors, events and special guests. The donations and request for information kept rolling in and in the span of November and December, we logged in____calls, _____donations and requests for_____ information packets, a_____increase over the previous quarter.

The crescendos didn't stop. The symposium was an extraordinary event. The Society thanks Liz Brisson, a member of the Board of Directors, for expertly coordinating the successful event. We welcomed Mr. Jay Troxel, our "certified Guardian angel," Dr. John Steele from Guam and Brian Dallow who brought greetings from Dudley Moore. We also welcomed 30 support group leaders and more than 60 persons with PSP. A week later, we were guests at a gala event in Philadelphia featuring Dudley Moore and Julie Andrews and received a check to establish the Dudley Moore Research Fund for PSP.

The penultimate sounds of drums and symbols was Barbara Walters' deeply moving interview on "'20/20" on November 18. Over I5 million people watched and in a letter to the Society from Barbara Walters she says, "I am very pleased to know that our interview with Dudley Moore may have made a difference in the understanding of this dreadful disease. I can only pray there will be more research forthcoming. Every once in a while I have an opportunity to do an interview or story that makes the difference. I am truly gratified to know that this one may have."



ABC News

Barbara Walters

abc

Ms. Ellen P. Katz
Director, The Society for PSP
Woodholme Medical Building
1828 Greene Tree Road
Baltimore, Maryland

January 11th, 2000

Dear Ms. Katz,

I am very pleased to know our interview with Dudley Moore may have made a difference in the understanding of this dreadful disease. I can only pray there will be more research forthcoming.

Every once in a while, I have an opportunity to do an interview or a story that makes a difference. I am truly gratified to know that this one may have.

With my best wishes,

Barbara Walters

147 Columbus Avenue New York NY 10023 (212) 456-7030 Fax (212) 456-7501

The PSP Barbara Walters story got even more attention when Ceri Williams, member of the Development Committee, spearheaded a national media blitz campaign for local stations to do stories on PSP. Over 40 stations participated!

PSP has finally been revealed to the public and our hope is that a critical mass of informed and concerned supporters can help eradicate this malicious. I wish to thank the PSP staff: Nancy Brittingham, Marcia Tepper, Adrienne Bantum, Claire Doherty, Pat Phillips and volunteers for their outstanding service during these pre-Millennium fireworks.

With all of this tumult, how did I spend the real Millennium? I took a few weeks off to recoup and renew myself and now waiting for the next big bang in our continuing expansion. Happy New Year!

Ellen Pam Katz

Our First Five Years As A Volunteer Organization

Continued from page 1

Ness, later Beth Carveth of Nebraska took on many of the organizational tasks from David Saks in the year and a half before David's death in 1995. Laura Purcell, now Laura Purcell-Verdun and Paula Goldberg, both on the staff of Hopkins volunteered many hours to develop patient services for SPSP members by speaking with patients, planning symposia and writing informational booklets. Dr. David Zee of Johns Hopkins was an early advisor and advocate. Nancy Brittingham volunteered to become the newsletter editor in 1994, a growing responsibility which became a paid position for her in 1999. Thanks to these persons and countless other volunteers, we were able to accomplish the following in the years 1990 - 1995.

Each of these activities broadened our visibility.

1990

- National Parkinson's organizations and five neurology journals announce the formation of the Society
- SPSP works toward gaining space for the discussion of PSP on the main agenda of the 1992 Second International Congress on Movement Disorders.
- SPSP urges the NIH to announce Request for Proposals for research on PSP.
- Our membership numbers more than 30 by the end of the year!

1991

- May 18, SPSP's First symposium for patients, families and carepartners is held at Johns Hopkins Neurology Clinic. 12:30 PM-3:30 PM. Fifty two persons attend. Videotapes of the sessions are made session for families to borrow free of charge.
- The Hartford Courant, Hartford, Connecticut features PSP and the growth of SPSP in an article about the National organization for Rare Disorders (NORD)
- Nearly 1,000 copies of our announcement flyers are distributed at the American Academy of Neurology meeting in Boston, Massachusetts. The first edition of our newsletter is published.
- SPSP encourages interest in and seeks funding for an international symposium of scientists to discuss PSP.
- New and additional language which would describe the effects of PSP are submitted to Social Security Administration for inclusion in the definition of a disability criteria for neurological disorders.
- Visits are made to national legislators to request funding for PSP research through the NIH.
- DuPont grants $2,500 toward producing a 40 minute videotape for neurologists, and neuroscience nurses which depicts presentations on diagnosis of PSP filmed at a conference in Barcelona, Spain in December, 1991.
- Our membership numbers 200 by the end of the year.

1992

- Letters, newsletters and membership forms introducing the society are mailed to members of the Association of University Professors of Neurology. Recipients are encouraged to inform SPSP or any-research being conducted which would be of interest to members, and to also inform us of any proposals for promising research projects.
- An announcement of the Diagnostic Videotape is enclosed. Availability of the PSP diagnosis videotape is announced in the Newsletter of the American Academy of Neurology.
- Further corporate funding is gained for producing the newsletter with the hope that it might become a quarterly publication.
- PSP families and patients are encouraged to consider brain donation.
- A list of "Communicators" is first published in the "PSP Advocate." The names, addresses and phone numbers of persons who have indicated that they would like to exchange experiences with others are listed by state. Informational materials are exhibited at meetings of both the American Association of Neurologists and the American Neurology Association.
- SPSP continues legislative efforts to gain funding for PSP research at the NIH. Congress informed NINDS of its special interest in PSP and its intention to ask for research plans during FY 1994 appropriations hearings.
- Our membership numbers nearly 400 by the end of the year.

1993

- Our first research grant of $2,000 is awarded to Dr. David Rye at Emory University School of Medicine.
- Announcements of SPSP's intent to grant $2,000 to a medical student who devotes Summer, 1993 to an important PSP research project are sent to the dean of students at 130 medical schools.
- Legislative focus changes to requesting that the "National Institutes of Neurological Disorders and Stoke shall establish by 12/31/95, five research centers to conduct intensive research into "Movement Disorders".
- A PSP disability rating scale and staging system are established at the meeting of the International Congress of Movement Disorders.
- Dr. John Steele, one of the 3 physicians who first identified PSP as a distinct neurological disorder in 1963, and who continues to do research on Guam, meets with the SPSP Board of Directors in Baltimore.
- The Second Patient/Family/Caregivers Symposium is held on October l6, 1993. Brigadier Michael Koe attends and is encouraged to start PSP Europe in England.
- "PSP: Some Answers" by Dr. Golbe is translated into Spanish for distribution by SPSP.
- The second and third issues of the PSP Advocate Newsletter have been published; the newsletter mailing list has grown to 1200.

1994

- Dr. Golbe summarizes recent research on PSP at the 11th International symposium on Parkinson's Disease in Rome on March 29, 1994.
- Jordan Grafman, Ph.D., Dr. Irene Litvan and SPSP collaborate on surveys sent to the SPSP mailing list to obtain medical histories, and patient and caregiver responses to to psychological issues related to PSP in the hopes that the results will inspire new paths of investigation here at the NIH".
- The PSP Advocate becomes a quarterly publication.
- Legislation efforts are directed to the Hatfield Bill or Udall Bill which seek an influx of funding into the study of Parkinson's Disease "and related disorders" and which will provide services to patients and families.
- A third annual Summer Student Research Fellowship in PSP is awarded. SPSP installs an 800 telephone number.
- Beth Ness of Bradshaw, Nebraska becomes The Society's Executive Director, as the failing health of David Saks forces him to assume the title of "Administrator".

Continued Page 8

2000?
THIS IS OUR HOPE.....THIS IS OUR GOAL

"Cure for PSP found! Thousands of victims benefit from breakthrough technology that reverses degenerative brain disorder."

Fact, fiction, myth or reality?? We believe the Society has and will continue to play a vital role in making this headline a reality. Although we may be years from its fruition, the Society for PSP has laid the foundation on which a cure can be built.

The year 1999 was particularly significant to reaching a cure as a result of the Brainstorming Conference at the National Institutes of Health funded by Mr. Jay Troxel in memory of his beloved Eloise. Ninety researchers from all areas of the world were exposed to PSP, thereby stimulating research. Requests for grants have increased under the guidance of Larry Golbe, M.D. and our impressive Medical Board of Advisors and the Society has been able to fund many worthy grants.

The year 1999 was also particularly fruitful for the Board of Directors who embraced a year-long collaboration creating the Society's four year strategic plan, "Visions and Opportunities." The goals of those strategic plans are:

- To establish a strong national presence and increase education to persons with PSP, their families, care partners, physicians and allied health professionals
- To generate an increased yearly ongoing revenue for current expenditures, special projects and future funding by establishing a development program
- To strengthen and broaden an effective volunteer leadership program
- To promote and increase progressive supranuclear palsy research

To implement the plan, new initiatives will be targeted by month and year. The goals of year 2000 include expanding and revamping the database, developing the Board of Directors and its structure, and create an office of development staffed by a full-time professional director of development. This person can cultivate and develop new sources of income from major donors, planned gifts and commemorative giving and special events. The Society has collaborated with many devoted volunteers throughout the country who have created and organized new PSP communities including support groups that meet on a regular basis by telephone or by online support including the listserve.

Many exciting connections have been established throughout the National Symposium in Baltimore, November, 1999 as well as regional symposia in Sunnyvale and Anaheim, California and Toronto. Almost 600 persons collectively attended these symposia. They have received the most current information on research, caregiving issues and support. We also made many connections in the medical community by our attendance of the AAN Convention in Toronto.

George S. Jankiewicz, Jr.
Chairman of the Board

In the area of fundraising, the year 1999 was the most successful ever due to: annual campaign in early 1999 that yielded 800 donors and $80,000; a summer mailing to lapsed contacts and non-donors yielded $15,000 and an opportunity to purge the database of lapsed contacts, thus saving the Society money. The Fall campaign has yielded to date $37,000. Donations have increased by envelopes being inserted in the newsletter. Major donors continue to understand our mission and make cash gifts as well as gifts by stocks and requests. The numbers are astonishing, in 1996, the annual revenue was $96,000. In 1997, 1it grew to $206,452 and then Mr. Jay troxel increased it with his generous gift of $446,688. 1998 - $603,372, 1999 - $713,821, 2000 - Already Mr. Troxel has again gifted the Society and all persons affected by PSP with $240.000. We thank Mr. Troxel and all our donors.

How well did we serve our constituency? We sent out 3,700 packets of information to persons requesting for the first time information on PSP. We also created professional packets to physicians. We answered 7,300 phone calls on our 1-800 number and we printed and mailed more than 50,000 newsletters including 2,500 newsletters to Canada, Mexico, throughout Europe and Asia. We processed 5,500 donations and sent personalized acknowledgments to each donor.

The Board of Directors marked many successes including their creation of the strategic plan, revised bylaws and the formulation of a document "Responsibilities of a Board Member." This list of Board expectations ensures that new Board members understand our vision and have the commitment, time and resources to perform the vital role of governance of this dynamic organization. The Board appointed new Board members and said farewell to vital Board members who had reached the ends of their terms of office. They now have become Friends of the Board or Honorary Board members so that their contributions always remain appreciated and link us to our past.

In 1999, the Society experienced many organizational successes in the areas of research, service, fundraising and internal growth. Thank you to the Board, staff, volunteers, donors, physicians, and to you, our supporters, for keeping the mission forefront in all of our actions. Let's make 2000 to 2010 another "Decade of Caring" but also the "Decade to Eradicate PSP Forever." The Society will continue to play a vital role. We can do it! By working together, the Society can move us closer to the cure. Just watch the headlines.

Research - Grants Awarded During the Decade

Research Grant Recipients 1990-1997

(Total for seven years - $70,900)

- Ferritin is Associated with the Aberrant Tau Filaments Present in Progressive Supranuclear Palsy ($9,700)
  Jesus Avila, Ph.D.
  Centro De Biologia Molecular, Madrid, Spain
- The History of Progressive Supranuclear Palsy (PSP) ($1,2000)
  Adolfo Brusa, M.D.
  Corso A. Saffl, Genoa, Italy
- Linkage Analysis in Familial PSP ($10,000)
  Justo Garcia de Yebenes, M.D.
  Universidad Autonoma de Madrid, Madrid, Spain
- Genetic and Environmental Studies of Bodig and Lytigo in Villages of Southern Guam ($10,000)
  John C. Steele, M.D.
  Tamuning, Guam
- Presence and Amount of Glycation and Oxidation Markers in PSP ($10,000)
  Massimo Tabaton, M.D.
  University of Genova; Genova, Italy
- Reaction Time and Acoustic Startle in Patients with PSP, Multi-System Atropy, Barcelona and Parkinson's Disease ($10,000)
  Josep Valls-Sole, M.D.
  Hospital Clinic, Barcelona, Spain
- Haplotype Relative Risk Analysis in PSP ($20,000)
  Lawrence I. Golbe, M.D.; Alice M. Lazzarini, Ph.D.
  Robert Wood Johnson Medical School
  New Brunswick, New Jersey

Research Grants Recipients-1998

(Total $189,200)

- Establishment of a PSP Brain Bank ($53,000)
  Dennis W. Dickson, M.D.
  Mayo Clinic, Jacksonville, Florida
- Trial of Donepezil HCL in PSP Patients ($29,200)
  Irene Litvan, M.D.
  Henry M. Jackson Foundation, Bethesda, MD
- Molecular Studies of the Tau Gene in PSP ($20,000)
  William G. Johnson, M.D.; Lawrence I. Golbe, M.D.
  Robert Wood Johnson Medical School, New Brunswick, NJ
- Oxidative Mechanisms in PSP ($20,000)
  D.S. Albers, Ph.D.; Sara J.Augood, Ph.D.
  Neurology Department
  Mass. General Hospital, Boston, MA
- Tau Gene Mutations in PSP ($20,000)
  Joseph J. Higgins, M.D.
  Laboratory of Clinical Neurogenetics
  Wadsworth Center, Albany, NY
- Mitochondria in PSP ($17,000)
  Russell Swerdlow, M.D.
  Department of Neurology
  UVA School of Medicine
  Charlottesville, VA
- Neuroanatomical Basis for PSP Eyelid Motor Dysfunction ($20,000)
  Mark S. LeDoux, M.D., Ph.D.
  University of Tennessee, Memphis, TN
- Neuropathological Grading Scale for PSP ($10,000)
  Mark W. Becker, M.D.
  University of New Mexico Science Center
  Albuquerque, NM

Research Grant Recipients-1999

(Total $260,929)

- Mechanisms of Neurofibrillary Tangle Formation in Progressive Supranuclear Palsy (PSP) ($20,000)
  Nancy A. Muma, Ph.D.
  Loyola University Medical School
  Maywood, Illinois
- Identification of the Progressive Supranuclear Gene ($50,000)
  Parvoneh Navas, Ph.D.
  University of Washington, Seattle, WA
- Is Brain Oxidative Stress and Damage Characteristic of Progressive Supranuclear Palsy? ($25,000)
  Stephen J. Wish, Ph.D.
  Center for Addiction and Mental health
  Toronto, Ontario, Canada
- Synaptic Protein Loss and Alterations in Growth Inhibitory Factors as a Biological Foundation of Behavioral Changes and Cognitive Decline in PSP ($25,000)
  Elisabeth B. Mucaetove-Ladinska, M.D. MmedSci., Ph.D.
  Roger J. Keynes, MRCP
  University of Cambridge
  Cambridge, United Kingdom
- Role of the Thalamus in Progressive Supranuclear Palsy and Parkinson's Disease ($25,000)
  Jasmine Henderson, Ph.D.; Glenda Halliday, Ph.D.
  Prince of Wales Medical Research Institute
  Sydney, Australia
- Problems of Cell Death in Progressive Supranuclear Palsy ($18,000)
  Kurt A. Jellinger, M.D.
  Ludwig Boltzmann Institute of Clinical Neurobiology
  Vienna, Austria
- Activity and Expression of Antioxidant Enzymes in the PSP Brain. ($20,000)
  Mass. General Hospital
  Harvard Medical School
  Boston, Massachusetts
- Are Impairments of Energy Metabolism Contributory in PSP? ($19.929)
  M. Flint Beal, M.D.
  New York Presbyterian Hospital
  Cornell University, New York, New York
- Ultrastructural and Biochemical Heterogeneity of Paired Helical Filaments in PSP ($18,000)
  Hanna Cazique-Reading, Ph.D.
  Albert Einstein College of Medicine of Yeshiva University
  Bronx, New York
- Mutational Analysis of the Tau Gene in PSP ($20,000)
  Joseph J. Higgins, M.D.
  Laboratory of Clinical Neurogenetics
  Wadsworth Center, Albany, New York

High Prevalence of PSP-like Illness in French West Indies May Hold Clue to PSP Cause

by Dominique Caparros-Lefewre, MD with editorial assistance of Lawrence I. Golbe, MD

One of the most promising leads in the mystery of the cause of PSP has arisen on the island of Guadeloupe in the French West Indies.

After completing her neurologic training in France, Dr. Dominique Caparros-Lefewre was posted to the neurological clinic on Guadeloupe, a French island colony of 430,000 inhabitants in the Caribbean, just east of Puerto Rico. Within a year, she noticed a high prevalence of "atypical parkinsonism," a category that includes PSP. In France, the US and other Western countries, such patients comprise only about 20% of all parkinsonism, while on Guadeloupe, the figure is about 80%. Such patients differ from those with Parkinson's disease in the presence of features such as little or no levodopa response, abnormal eye movement, certain behavioral abnormalities and early appearance of problems with balance, speech and swallowing. Of the 87 such patients on Guadeloupe, 31 had an illness that looks just like PSP.

Of the 56 patients with "atypical parkinsonism" who did not seem to have PSP, many had strong features of amyotrophic lateral sclerosis (ALS; "Lou Gehrig disease") along with parkinsonian features such as tremor or stiffness. This combination of neurological illness strongly resembles that on the Pacific island of Guam, where the "ALS-parkinsonism-dementia complex" (ALS-PDC also known as lytico-bodig) has been known for decades to occur among native people of that island who follow a traditional lifestyle. ALS-PDC is gradually dying out as the the Guamanian people's diet and other traditional practices becomes westernized, although the precise cause of ALS-PDC has not been found.

The brain of people dying with ALS-PDC of Guam resembles that of PSP in the presence of neurofibrillary tangles made of an abnormal form of the "tau" protein, although the precise location of the tangles in the ALS-PDC brain is slightly different from that of PSP and the chemical structure of the tau protein is also slightly different. Two autopsies on patients from Guadeloupe have been performed. Neither brain is fully studied to date, but in one, a patient who had a nearly pure ALS picture during life, the changes in the brain were very similar to those of some patients from Guam. In the other, a patient with what looked during life like PSP, the changes were similar to those of PSP, but also shared certain features with those of most patients with Guamanian ALS-PDC. Neither had Lewy bodies, the hallmark of Parkinson's disease.

People on Guadeloupe who developed the PSP-like illness are more likely than others there to have habitually consumed an herbal tea made from two native plants called "soursop" and "sweetsop," both of which are forms of "custard apple," and to have habitually eaten the fruits of these plants. After the researchers discovered this, they advised all of the patients to avoid these teas and fruits. Of the total of 51 patients, 29 experienced no further worsening of their neurological symptoms at follow-up three years later. Six of the 51 actually improved, and these tended to be the youngest patients, all being under age 65. One of them was able to return to work within two years. The patients with the most severe, progressive cases that failed to respond to discontinuing the teas and fruits were the ones who had previously consumed those items most avidly.

Both plants live also on Guam, where they are used as traditional medicines. However, a relation between them and ALS-PDC has not been investigated.

The soursop and sweetsop, whose Latin names are Annona muricata and Annona squamosa, respectively, contain several chemicals called benzyl-tetra-hydro-isoquinolines (Be-TIQs) and another called tetra-hydro-protoberberine (THPB). Be-TIQ is chemically similar to MPTP, the inadvertent product of "designer drug" manufacture that produced an illness very similar to Parkinson's disease about 20 years ago after addicts injected themselves with it. Furthermore, in laboratory experiments, Be-TIQ is toxic to brain cells that make dopamine - the type of cells hardest hit in both Parkinson's disease and PSP - and can produce slowness and stiffness when given to laboratory rats and monkeys.

The next logical question is whether "ordinary" PSP is caused, at least in part, by consumption of supermarket fruits and vegetables related to soursop and sweetsop. Every plant has hundreds of compounds, and a few of them may resemble BeTIQ or THPB to some extent. But some important questions remain: To what extent does the Guadeloupean form of PSP resemble "ordinary" PSP at the most basic level? What plants in the Western diet might contain sufficient quantities of compounds with toxicity similar to that of BeTIQ and THPB? Do people who develop PSP consume enough of those plants, whatever they may be, to contribute to the causation of their illness? Dr. Caparros-Lefewre and her colleagues on Guadeloupe and in France are attempting to learn more about the diseases on Guadeloupe and researchers elsewhere are starting to examine the question of whether plant toxins may cause "ordinary" PSP outside of Guadeloupe.

New Survey Finds PSP Five-Fold More Common Than Thought

by Lawrence I. Golbe, MD
Professor of Neurology
Robert Wood Johnson Medical School

A careful search of computerized physician records in and around London, England has revealed PSP to be present in 6.4 persons per 100,000 population. This figure is nearly 5 times higher than the previously most widely quoted figure. Its prevalence now appears to be similar to that of amyotrophic lateral sclerosis (Lou Gehrig disease). It is about 5%, not 1%, as common as Parkinson's disease.

The study was performed by neurologists Anette Schrag, Yoav Ben-Shlomo and Niall Quinn of the prestigious Institute of Neurology and the National Hospital for Neurology and Neurosurgery at Queen Square, London. They took advantage of an unusual system in which several primary care practices in the London area have shared a computerized record system since 1994. The 12 participating medical practices covered a population of 121,608 individuals. The researchers searched the records for terms associated with any type of parkinsonian disorder. This yielded 679 patients. Detailed review of the medical records revealed strong diagnostic evidence of other conditions (usually Parkinson's disease) in all but 241. Of these, 202 were living and agreed to complete a questionnaire and to be examined and videotaped. Five of these proved to have "probable" PSP and one had "possible" PSP.

The previous widely-quoted figure of 1.4 cases of PSP per 100,000 population comes from a 1987 study performed by my colleagues and myself in two counties in central New Jersey with a total population of about 800,000. That study used a much less sensitive method. We performed computer searches of hospital records for a specific diagnosis of PSP and interviewed every neurologist and nursing home supervisor in and near the two counties, asking if they knew of any patients with that diagnosis. None of the physicians or nursing homes had computerized records. We did not evaluate records of patients with diagnoses often mistakenly given to people with PSP. It is therefore easy to see how the more modern survey arrived at a higher and more accurate figure. It is noteworthy that none of the six patients with PSP in the new study had received that diagnosis before the researchers evaluated them.

Even the new figure may be an underestimate, however. Drs. Schrag, Ben-Shlomo and Quinn suspect that many people with PSP may not have sought medical attention for early symptoms such as falls, dizziness or personality change, thereby eluding the search of doctors' records.

This news should come as encouragement to patients and their families who have been discouraged to see how attention from scientists and funding sources tends to be directed toward more common conditions rather than to PSP. This new finding may help change that just a bit.

Larry Golbe, M.D. and Irene Litvan, M.D. recognized by the Society for their years of work in finding the cause and cure for PSP.

Continued from Page 21

1995

- SPSP contributes $10,000 to partially fund the publication of the content of a symposium of international scientists held at the NIM on May 5-6, 1995. The purpose of the meeting was to define the clinical criteria for the diagnosis of PSP.
- SPSP President Joanne Armstrong and Board members Dr. David Zee and the Honorable Sharon Pratt Kelly, meet with Dr. Zack Hall, the new Director of NINDS. SPSP asks for support for our legislative plan for five Movement Disorder Centers and seeks further emphasis on PSP research.
- Dr. Lawrence Golbe chairs a session on PSP at the main meeting of the Movement Disorders Society.
- David Saks poses the question, "Should we really change from an all volunteer organization to one with paid staff?"
- The May 3rd SPSP Symposium for patients, families & caregivers is held at Johns Hopkins. Almost 100 persons attended
- SPSP gains office space in the Johns Hopkins Hospital, Outpatient center.
- A full time secretary is hired to answer phone inquiries and distribute materials.
- David Saks, founder, dies in September at the age of 81.

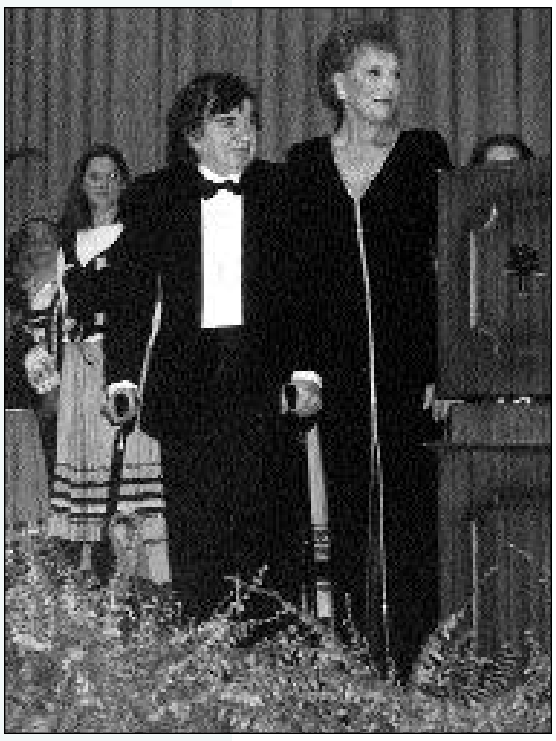
"And what did I do as President throughout these beginning years? I served as David's sounding board and encourager, a typist whose minimal skills were faster than David's method of one finger typing due to the effects of a stroke, a letter writer and envelope stuffer, a postal courier, phone answerer, message taker and a SPSP delegate to meetings at NORD, or the NIH which David's lack of mobility barred him from attending. But perhaps, most importantly, I read the heart wrenching letters and listened on the phone to the tales of frustration and exasperation of PSP patients and families and I was able to respond, "Yes, I know, I've been in your shoes, I emphasize, but now we have an organization that can give you information about the disorder, tell you of a support group, and explain how research is drawing nearer to finding a cause and cure."

THE NEXT FIVE YEARS IN THE NEXT EDITION....

A Night of Triumph – For Dudley, For Julie, For PSP

By Susan Gould, Philadelphia

When Rena Fruchter called last fall to ask what I was doing November 18, I was instantly intrigued. In her understated way I've known since junior high, she said she hoped I could come to "a little concert we're giving that evening." Since "we" was Music For All Seasons, the exceptional organization founded and run by Rena and her pianist-composer husband Brian Dallow, I knew that "little concert" was relative. Committed to providing musical performances for audiences confined in institutions - children's hospitals, prisons, nursing homes, shelters **?** MFAS has a star-studded advisory board that takes center stage to turn a small event into a spectacular happening.



Dudley Moore and Julie Andrews

The "little concert" on November 18 was no exception. Eight hundred people jammed the ballroom of Philadelphia's Park Hyatt Bellevue for this joint benefit with and for the Concerto Soloists Chamber Orchestra, led by conductor Ignat Solzhenitsyn. Rena told me to expect a light program: Ravel's Bolero, a medley from the Sound of Music, Saint-Saëns' Carnival of the Animals, and "a piece by Dudley called Fantasy on a Gypsy Breeze." Of course, I knew that "Dudley" was Dudley Moore, Rena's longtime friend, fellow-pianist and founding President of the Advisory Board of MFAS. I lit up at the prospect of hearing him play one of his compositions and perhaps narrate the Saint-Saëns, with its verses by Ogden Nash.

So I was jolted by Rena's next comment: "You know that Dudley has been ill, don't you?" Rena and I had been out of touch for almost three years (why does life do that to dear friends?), and I had missed any mention of his illness in the media. As Rena described the disease, I knew that I'd never heard of PSP, and I could not imagine anything more cruel and unfair. This brilliantly witty man, equally brilliant as actor and musician, could now hardly walk with crutches, had difficulty speaking, and worst of all, could not play the piano. I thought I would cry. But everybody else was too busy for tears. They were working on triumph.

Within weeks, and just before the benefit, Dudley announced his disease, bringing unprecedented international focus on PSP. The Virgin Healthcare Foundation then announced that it would launch the Dudley Moore Research Fund for PSP at the post-concert dinner. And a dear, dear friend of Dudley's began to work on scores for November 18th.

Did Rena save this news like icing on the cake? She must have remembered that 40 years ago Eliza Doolittle and Queen Guinevere had joined forces to make Julie Andrews my teenage idol, and my lifelong favorite actress.

Julie Andrews! She was coming to Philadelphia to work with Dudley. She would narrate the poetry of Erin J. Sweeney, who was a college student in the early '90s when she won Dudley's and Rena's competition for lyrics for Gypsy Breeze. Then Julie would share with Dudley the narration of the Ogden Nash verses of Carnival of the Animals.

The sold-out concert was unforgettable. Julie's supremely musical, mellifluous speaking voice became the essence of the Gypsy Breeze as it flowed with the evocative score so beautifully rendered by Maestro Solzhenitsyn and his orchestral forces. Then the entire audience rose as one to honor Dudley Moore, the composer and the man.

Next came those Ogden Nash texts! After a momentary hesitation, Dudley came to life with his well-known timing, bringing just the right wry tone and adding some unexpected one-liners Nash would have loved. Dame Julie, as she was shortly to be named on the Queen's New Year's Honour List, matched him with poker-faced wit both Nash's and her own. Her ad libs were impressive, but the real power of her performance was in the gentle and loving way she helped Dudley along when some tongue-tying words became too daunting.

Nobody who was there that evening will ever forget the triumphs. The talent, wit and magnetism of Dudley Moore were set against the background of his own musical creativity.

The courage of Dudley's fight against PSP was recognized in the official program with the launching of the new research fund in his name. The unofficial support for his battle was even more affecting: PSP Society Executive Director Ellen Katz brought Dudley a large scrapbook with the personal messages and good wishes of dozens of fellow PSP sufferers for whom he has become the standard bearer.

And finally there was Julie Andrews, triumphing not just with the power of her speaking voice, but more importantly with the power of her deeply human presence supporting her old friend and co-star. Nobody will every forget it, an event that stays in mind's eye and ear - and in the heart - forever.

Continued Page 10

A Night of Triumph – For Dudley, For Julie, For PSP
Continued From Page 9

Dudley Moore Research Fund for PSP

Created by Music For All Seasons in recognition of Dudley's nine years of service to the organization, this critical fund was launched on November 18, 1999, with a gift from the Virgin Healthcare Foundation on behalf of MFAS. David M. Tait, Executive Vice President of Virgin Atlantic Airways and a MFAS board member, had contacted Virgin Group Chairman Richard Branson to obtain the contribution. Dudley and MFAS have asked the Society for PSP to administer the fund, which has already received many donations.

Ellen Katz, Society Driector presenting a book of well wishes from PSP families to Dudley Moore

"I am so touched that Richard Branson has made this gift to us. I was the first person he interviewed regarding my life and work - he was a teenaged journalist at the time! I look orward to the possible cure that this fund will hopefully produce."

- Dudley Moore

Dick Janney, Joanne Armstrong, Dale Ferris, Brian Dallow, Julie Andrews, Ellen Katz, Liz Brisson, Dr. Stephen Reich and Nancy Brittingham

PSP On ABC

By Ceri Williams

The week of November 8, 1999, The Society for PSP mailed some 3,000 blue postcards to all its subscribers alerting them to the airing of the Dudley Moore interview on ABC's 20/20. On that postcard was my name and number for those of you who wished to contact me to make yourselves available for tie-in interviews on your local ABC stations.

On November 12, my phone started ringing off the hook. An avalanche of calls, which continued until 20/20 aired, led me through a week like none I'd ever had. Four hundred of you contacted me, overwhelmed me, and confirmed for me the enormous need for a public face to be given to this disease. I felt your isolation. I heard your newfound hope from Dudley Moore's public PSP diagnosis.

I met a great many wonderful and interesting people. The seeds for numerous projects we can cultivate together were planted. I look forward to pursuing them with you.

Thank you all for coming forward. Thank you for vacuuming your houses before the cameras came. Thank you for ironing your shirts and getting your hair done. And especially thank you for persuading family members to expose a very difficult chapter in your lives.

Thank you to Karen Kennemer, another PSP volunteer, who returned many of your phone and email messages. Without her help, numerous PSP stories would not have made your local news.

Many of you were urged to contact your stations directly as there was not time for us to connect you to your local ABC medical reporters. Thank you to those of you who did. Thank you for enlisting your neurologists and thank you to them for arranging their schedules in order to tell their sides of this story.

The following cities are those in which I know stories ran. From those of you who contacted your stations directly I suspect there are more. If your story ran and your city is not listed here, please let me know at the address below. We did air in: Los Angeles, Philadelphia, Boston, Atlanta, Cleveland, Denver, Sacramento, Orlando, Raleigh, Kansas City, MO, Salt Lake City, Norfolk, Harrisburg, Austin, Green Bay, Jackson MS, Augusta, Anchorage, Wichita Falls, and Newport News.

During the week these stories ran, I assembled a file of all of you who wanted to take part. However, I know some of you fell through the cracks and my files are not complete. I am now requesting that you get in touch with me again if you would like to be a part of future publicity efforts. Contact me by mail or email rather than telephone. I would like to invite all new friends of the Society to do the same. I need your name, your PSP connection, how long you've been living with PSP, your address, your phone number and what type of interview (TV, radio or print) you are available for. If your neurologist is available please include his or her contact information. There are many cities which were not represented during the 20/20 tie-in week. So please write to me and become part of the group for future publicity projects. I have only approached TV so far but will be contacting radio, and eventually print.

I want to hear your ideas on how we can garner more media coverage. If you have an upcoming event where we could include local press, let me know. Roger Brisson's "Climb for a Cause: Conquer PSP" is a perfect example of a story which television loves to cover. We need to create more of these. Those of you with media or PR experience who would like to become part of these efforts, please get in touch.

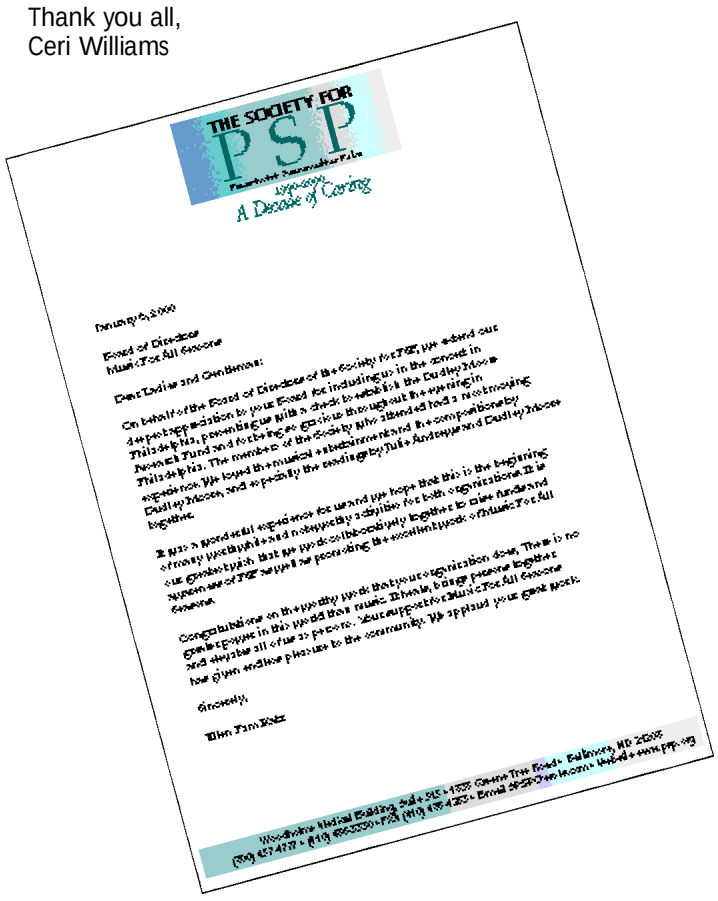
For enabling this project to have such a visible launch, I want to thank Dudley Moore, as do so many of you. Thank you, Dudley, for making public your diagnosis. And thank you for inviting the 20/20 cameras into the difficult corners of your most recent life. I hope you know how many people you are helping and how grateful we all are.

From all that aired on ABC that week, both Dudley Moore's story and your local tie-in stories, approximately 1,000 new people have contacted The Society for PSP. There are, I'm sure, a great many more people who need to be reached and we will find them.

I am a media publicity producer. My connection with PSP is my father who lived with this disease for about nine years. I am a recent member of The Society for PSP's Development Committee. Using my media skills, I want to do all I can for those touched by this unforgiving disease.

Please contact me at:
15445 Ventura Blvd., #46
Sherman Oaks, CA 91403
medianet@earthlink.net.

Thank you all,
Ceri Williams


THE SOCIETY FOR
PSP
A Decade of Caring

Los Angelos Regional PSP Symposium

for Persons with PSP, Families, Caregivers and Allied Health Professionals

Saturday, April 29, 2000

LOCATION: Jules Stein Eye Institute
UCLA School of Medicine
100 Stein Plaza
Los Angeles, CA 90024-7000
(3190) 825-5000

TIME: 8:30 a.m. to 3:15 p.m.

SCHEDULE:

8:30-8:45 Registration

8:45-9:30 **Diagnosis of Progressive Supranuclear Palsy**
Neal Hermanowitz, M.D.
Director of the UC Irvine Movement Disorder Center
Eisenhower Medical Center, Rancho, CA

9:45-10:30 **Current and Future Strategies for Therapy of PSP**
Jeffrey Bronstein, M.D.
Assistant Professor, UCLA Department Of Neurology
Director, UCLA Movement Disorder Programs

10:30-10:45 **Break:** Coffee, Tea and Refreshments

10:45-11:30 **Family Adjustments in Chronic Neurological Disease**
Susan Imke, R.N., M.S.
Gerontological Nurse Practitioner

11:30-12:00 **The Gift of Brain Tissue to Research**
Dennis W. Dickson, M.D.
Neuropathology Consultant
Mayo Clinic
Jacksonville, FL

12:00-1:00 **Lunch** included

1:00-1:45 **Hospice**
Lucille Sevigny, R.N., B.A.
Long Beach Memorial Hospital Hospice Association
Pharmaceutical Management of PSP Symptoms
Wayne Tomasada, Doctor of Pharmacy
Long Beach Memorial Hospital

1:45-2:15 **The Society for PSP and You**
Carol Marchi, Board of Directors

2:15-2:30 **Break**

2:30-3:15 **"How Do I Feel?"**
Breakout Session for Persons with PSP
Susan Imke, R.N.
Director of Education CTC
National Parkinson's Foundation

REGISTRATION FEE:
$40 per person
Limited scholarships are available.
Make the check out to: The Society for PSP
Mail check and registration form to:
The Society for PSP c/o Carolyn Cheek
23009A Nadine Circle, Torrance, CA 90505

Must bring own wheelchair.

Questions or for more information contact Carolyn Cheek at Cheekspeak@aol.com or (310) 534-8623.

Hotels in the area that guests may contact for reservations:
- Higler House (310) 208-3945 (800) 826-3934
- Royal Palace Westwood (310) 208-6677 (800) 631-0100
- Westwood Plaza Hotel (310) 475-8711 (800) 472-8556

Directions to the site:
Conveniently located within UCLA at the corner of Westwood Blvd. And Le Conte Ave. From the airport, take the 405 northbound to Wilshire, turn right (east) on Wilshire to Westwood Blvd. Turn left onto Westwood Blvd. from Wilshire. After crossing Le Conte Venue, turn right into the Stein Plaza. The parking area is located immediately to the right (adjacent to the Doris Stein Eye Research Center) just beyond the Doris Stein Eye Research Center is the Jules Stein Auditorium. From the parking lot there is a stairway up to the Auditorium, an elevator and a ramp. The Auditorium is located at the very rear of the parking lot.

TEAR OFF REGISTRATION FORM

California Regional PSP Symposium

Name _____ Person with PSP ❑ Yes ❑ No

Address _____ Uses Wheelchair ❑ Yes ❑ No

_____

Phone, email, fax _____

Other guests write on additional piece of paper.

$40.00 registration fee per person _____ number of persons attending Total amount enclosed. $ _____

❑ I cannot attend but wish to to make this contribution to help underwrite the costs of this symposium. $ _____

Please make check out to The Society for PSP.

Mail check with registration form no later than April 15 to: Carolyn Cheek 23009 Nadiane Circle, Unit A, Torrance, CA 90505

The Fifth Biennial PSP Symposium For Persons with PSP, Families and Caregivers

Saturday, November 13, 1999
B.W.I. Marriott, Baltimore, Maryland

More than 300 people, including 60 persons diagnosed with PSP, gathered together at the Fifth Biennial PSP Symposium to learn more about progressive supranuclear palsy and to offer support to each other. The Society is extremely fortunate and appreciative to offer a program including leading medical experts in the field of progressive supranuclear palsy.

The special presentations included:

"Focus on PSP Research"
Lawrence I. Golbe, M.D.
Professor of Neurology
Robert Wood Johnson Medical School

Irene Litvan, M.D.
Chief, Neuropharmacology
Defense and Veteran Head Injury Program
Henry M. Jackson Foundation

"Eye Problems with PSP"
Dr. David Zee
Professor of Neurology
Ophhalmology and Otolaryngology
Johns Hopkins University School of Medicine

"Treatment and Management of PSP"
Dr. David Riley
Associate Professor, School of Medicine
Case Western Reserve University

"Swallowing Problems with PSP"
Laura Purcell Verdun, MA, CCC.
Research Speech Pathologist
National Institutes of Health
Assistant Professor, Johns Hopkins University of Medicine

"How I Feel as a Person With PSP"
John C. Steele, M.D., Fellow
American College of Physicians
Core Director Micronesian Health Studies
Stephen Reich. M.D.
Associate Professor of Neurology
Johns Hopkins University School of Medicine

"A Caregiver's Panel Discussion"
Carol Marchi
Outreach Coordinator
Parkinson's Institute
Sunnyvale, California

Developing and improving support group field service was a topic of discussion at Fridays evening's meeting of current Support Group Leaders and those interested in staring a group.

What a team!! Dr. John Steele recognizes Roger Brisson for his courage and determination in climbing Mt. Aconcagua and establishing the Margaret Parker PSP Research Fund. Dr. John Steele recognizes Liz Brisson for her countless efforts in supporting the Society for PSP.

During the program, the Society for PSP recognized Mr. Jay Troxel for his overwhelming continued financial support and friendship. Research in PSP research has dramatically increased due to Mr. Troxel's generosity. The Society was also honored that, Brian Dallow, longtime musical colleague and friend to Dudley Moore, attended the symposium to learn more about PSP as well as convey Dudley Moore's message of concern and his earnestness in promoting awareness of PSP. Brian Dallow announced the "kick off" for the Dudley Moore PSP Research Fund.

Many activities surrounded the symposium. On Friday night, there was a dinner to gather early arrivals so they could meet each other. A meeting was held for all present support group leaders and those interested in forming a group. A national support group task force is forming to develop ways to improve the Society's field support initiatives. On Saturday night, there was another dinner and the Society's Board of Director's presented an overview of the organization's strategic plan for the next three years. Goals, strategies and opportunities were discussed.

Ellen Katz, Director, The Board of Director's and Liz Brisson, board member and chairman of the symposium committee, thank all the supporters of the Symposium. Individuals, families, corporations and pharmaceutical companies special gifts made the symposium possible. A special note of thanks is extended to Mrs. Carol Hutchinson for her gift of $15,000. Another special thank you to the staff of the Society, Marcia Tepper, Adrienne B. and Claire and Doris McRay and Linda Blute, Society volunteers, for their tremendous efforts in coordinating the symposium. Karen Kennemer, Society volunteer, devoted countless hours in establishing a vendor data and obtaining corporate sponsorship for the symposium. The Baltimore Washington Marriott has to be commended for their service and attention to the special needs of persons with PSP and their families. As one person commented,"I noticed the extraordinary attention given to the comfort of persons with PSP by everyone, including the hotel staff. Thank you for making these special arrangements to ensure that everyone was well-taken care of from arrival to departure."

Dr. Stephen Reich, who has worked with the Society since its beginning, concluded the symposium with some positive remarks about coping with PSP. Dr. Reich offered these suggestions using the word "HOPE"

H -humor, honesty
O -optimism
P -persistence, problem solver
E -exercise, education

Ellen Katz, Director, and Brian Dallow, friend and musical colleague of Dudley Moore

David Riley, M.D., Jay Troxel, Irene Llitvan, M.D. and the Director of the Office for Rate Disease NIH

Attendees share their support during lunch

Special Events - 1999 Syposium Honor Roll

PSP PARTNERS ($15,000)
Mrs. Carol Hutchinson

SPONSORS ($1,000+)

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Ms. Lidia Bertoldi	In Memory of Raymond Bertoldi
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The Society thanks Mrs. Carol Hutchinson for her gift of $15,000 to support the Symposium

The publications of the PSP Advocate for the Year 2000 have been generously funded by Jay Troxel in memory of his beloved wife, Eloise C. Troxel

Support Group News

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. Please reach them at:

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PSP and Singing

Dear PSP Friends,

Recently at the Symposium in Baltimore, I was discussing a singing experience with my dad. When his speech was garbled and in whispers, he still could belt out hymns in church and familiar songs on the radio. I know that singing is controlled by a different part of the brain that is not affected by PSP and holds with it many emotions. But, I thought my dad's singing was a unique experience for us. I wish we had made this "discovery" sooner and developed more ways to use it to make his life more enjoyable. I wrote a message on the listserve inquiring if anyone else had a singing experience to share. Here are some of the responses:

◆ I received a Christmas Miracle yesterday. We were taking a moment to relax. The living room was dark except for the tree lights and Christmas music was playing. I heard someone singing, I looked over and Ed's mouth was moving. He was singing the words with the music and I could hear the words distinctly but quietly. He has not attempted to speak in over a year in any recognizable manner. This was the best present I could have ever received... to hear his voice again.

◆ When Wayne and I would travel in the car and motorhome, we would sing along with tapes and the car radio. Until about two weeks before he died, his singing was much more understandable than his talking. He was especially fond of the "Reader's Digest's Sing Alongs" especially Beryl Ives.

◆ I noticed Bill would sing "opera" about ordinary things to communicate and it would make him smile. I would try old Beatle songs that he used to know by heart . So we just "sang" out our requests sometimes and made a song out of that. It kind of went along with the stories I would make up based on his low lung capacity . I would use soft whispering/whistling sounds as part of the story and he would do the sound effects.

◆ Even though Len's speech was slurred, etc., he still could get out all the words of "Minnie the Moocher!" When we left New York, his day care center gave him a farewell party. Despite the fact that he was usually quite reticent, he and I sang "Minnie." He knew the words better than I did and was so good... he had to do an encore!

◆ On Christmas Eve, John was determined to go to candlelight service at our church even though he is slipping very rapidly and his body is starting to shut down. After spending most of the day in bed and barely speaking, he and I went to church with four of our children. He sat there and sang every hymn, prayed The Lord's Prayer and held his own candle upright! It was a very touching and emotional time for us... surely the last time he will be there. His courage continues in spite of his miserably failing body. John has always loved to sing and often sings when he had great difficulty speaking.

(John died on Jan. 13, 2000. Our sympathy to John's devoted family.)

Canadian Support Groups Continue to Grow

The physical and emotional needs of Canadians with PSP and their partners are tremendous. This is evident by their shear attendance at our support group. On an average, we have between 25-50 people attending our sessions, that is like a conference! Our membership has grown considerably over the past year. In fact, we are proud to say that there are other support groups blossoming all over the country. What strikes us, as group faciliators, is the willingness of both the individual with PSP and their care partner to connect with others facing similar challenges. It is great to see one person with PSP meeting another person with their same illness for the first time. Care partners share advice and different strategies they have tried to help their family member, as well as themselves better cope. In our support group, we feel that a very important component is to divide the group in half for part of the meeting. This enables care partners to connect with others as well as it gives them an opportunity to say things that they may not be able to express in front of their loved one. As well, it provides the person with PSP the same opportunity.

Left to right: Jane Zakem Snow, Ruth Storey, Mrs. Zakem

As our support group continues to grow so do their needs. Our goal is to establish a PSP Canada working with The Society for PSP in the United States as they continue to provide international service. However, we have been facing many challenges along the way. First and foremost, a volunteer is required to coordinate all our efforts. There are several people who have come forward to volunteer their services such as mailings, etc., however, we continue to miss the central link. Therefore, we are searching for that one special volunteer who has the time to be our "traffic cop" and who could work with other support groups uniting these PSP efforts throughout Canada. If anyone is interested in this position, please email Janice Stober at stoberj@hotmail.com.

The Dawe Family

A Trip With PSP

Jim and Mirriam Barron Pullman, WA

Searching For a Cause

Christmas of 1995, we rented a cabin on the Oregon coast. On the next to last day, my wife Mirriam (age 60), had an unexpected and unexplained fall into a tide pool and cut her face with no other damage. After this fall, she had some balance problems but nothing that seemed serious to either of us. In September, 1996, she fell on the steps on her way upstairs and broke her hip.

In the hospital, our daughter and I noticed changes in her mental and emotional condition. She wept as if embarrassed to be there. She cried when friends stopped in to see her. Her recovery was slow and we saw the early signs of PSP but did not know it at the time. She had several falls during the winter and spring but without any damage.

Our family doctor recommended a psychiatrist. He thought she was depressed and finally convinced her to try prozac. At 40 mg., there was a significant improvement in her negativity and her attitude was more even. But, she still had rambling conversations and balance problems.

In June, 1997, I found her lying at the foot of the steps in a large pool of blood resulting from a head wound requiring eight stitches. During the following week, she had a MRI investigating signs of stroke or tumors; it was negative. Three visits to a neurologist followed and no diagnosis was made. I know the vertical gaze palsy was present at the time, but the neurologist must not have thought it significant and I had not yet tumbled to learn what it meant. Two more falls in the summer resulted in a broken rib and a head injury requiring three stitches. She lacked energy, initiative and interest in anything.

In the same June of 1997, some old friends from Wisconsin came for a three day visit. We had not seen each other for 10 years and I asked them to jot down their impressions and observations of Mirriam.

- Uses awkward motions
- Losing coordination between her eyes and hands
- Spilling regularly
- Mutters in tones too low to hear
- Does not focus on anything for extended period of time
- Walking is slow and unsteady

The best guess of the psychiatrist and neurologist was that it was some form of frontal lobe deterioration causing the mild dementia and also the balance problem. I knew that I now needed an expert. In November, we saw a neurologist in Spokane who was quite capable and made a tentative diagnosis of progressive supranuclear palsy. He could not be sure though because he had only seen one or two cases. In January, 1998, we went to a movement disorder neurologist at the University of WA Medical School and he confirmed the diagnosis of PSP.

During the interim, I had found some information on the web about PSP and learned more about the disease. Our family physician had not ever seen a person with PSP... he said he had never heard of PSP. He was a good student and learned all he could from the information I provided to him.

Adapting To Living with PSP

We now were well aware that our retirement years were not to be as we had hoped. I bought some small size bubble wrap, cut it to size and taped it to sharp table comers, bathroom sinks and places Mirriam might fall. I found my old bicycle helmet and inserted pads so it would fit her and changed the strap to velcro closure so she could put it on and off. She adjusted to the helmet much better than I expected and had no problem wearing it on public. I had two vertical floor to ceiling poles installed by her living room chair and kitchen chair. We also put in a gate at the top of the stairs so she could not fall down. We installed grab bars an adjustable shower hoses in the bathrooms. By mid July, Mirriam could no longer walk without assistance.

A major problem was her impulsive and reckless attempts to do the same things she used to do. When I was out of sight, she was apt to try to get up and do something across the room and invariably fell down. In her case, by the fall of 1998, she would no longer do that and would sit still while I did errands, shopping, etc. I am sure to be back within an hour and a half

I realized we needed to do some serious estate and financial planning to cover as many contingencies as possible We both already had signed health care directives. Mirriam signed over her durable power of attorney to me and I signed my power of attorney to our son and daughter. I made provisions in case of my death that Mirriam would have sufficient resources from our home, a survivor's annuity from my retirement pension and an IRA in her name that would provide up to 8 years of nursing home care. The remaining assets, if any are left, will go to our children. I cannot emphasize strongly enough that people should do this sort of planning and paperwork as soon as possible and before an emergency comes along and it is too late. I have copies of all those papers as well as a statement I keep updating on our assets and debts in the possession of the person who will be my executor if I die. In addition, I have written a several page document on Mirriam's condition that lays out all the current issues and how to care for her. I carry a note prominently labeled in my wallet with instructions in case of emergency to look for that briefcase and it also has phone numbers for the executor and our children. Finally, to cover the possibility of me having a heart attack or stroke at home and leaving Mirriam alone, I have a deal to call the next door neighbor morning and evening. If I do not, they will call to check on us and, if no answer, will come to see if we are OK.

Dealing With Progression

PSP has some good and bad aspects. The good thing is that it moves slowly and the caregiver can adjust gradually to each new stage and be ready for it. The Society for PSP provides information and support. The listserv sponsored by

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Our Trip With PSP

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the Society but not moderated by them is a place where we can exchange information and support every day. If you do not have the computer capacity to join in you should do so promptly if you can. The bad thing is PSP does not quit until the end. We have done fairly well with this trip so far, but it is still in transition. Mirriam is still able to eat most foods, but with help. I have to feed her about 80 percent of the time. We are using soft foods and, if we have a good steak, I barbecue it and then grind it to a minced form and put gravy on it for her. We are on the verge of having to thicken liquids. In fact, we already did for a couple weeks and then she had a modified barium swallow test. It showed that she did quite well if she did a dry swallow after each bite or drink to get the last dribble down the right way. The speech therapist suggested we go back to thin liquids for now. Her voice is growing softer and getting harder to understand so she may lose her ability to speak sometime in the future.

With the grab bars and much assistance from me she can still get in and out of the bathtub, but before too long we will have to move to a transfer shower bench. In only a month or two, her left arm and hand have began to freeze and clench into a fist. She is finding it difficult to get that hand open to get it over the grab bar and, when she can no longer do it, getting into the tub will not be safe.

We have several people who will come and stay with her for an hour or two or three if needed and I have an arrangement to hire another lady for up to a day of "adult sitting." I have paid attention to the advice to be sure and take care of the caretaker and I am doing that regularly. I can get in a half hour walk before she gets up and on week days I get off to the gym to spend up to 30 minutes on an exercise bike. Several folks have suggested I will soon have to put her in a care facility or have much more help, but I don't think so. As long as my health is good I should be able to take care of her at home. The type of care and the time demands will change, of course. From discussions with others on the listserv who are doing the same thing I think we can continue as we are. Old advice is still the best. Take it one day at a time, but be prepared as well with contingency plans.

In Appreciation

Lynda Blute, extraordinary PSP Volunteer

In 1999, she volunteered 215 hours, spending over 100 hours in her car traveling 3500 miles to work for the Society.

Esther's PSP Story

Esther (King) Rupp grew up in Northwestern Ohio, graduated from college in Indiana and attended seminary in New York City. Along with her husband, she was a missionary in the Dominican Republic for 18 years and had four children. Esther then became a school teacher in the United States and was also involved with an insurance company.

When Esther was about 70 years old, she began to notice several health changes. She said that her fingers would not function like they used to when she was playing the piano. Tripping, balance problems and writing difficulties were contributed to aging complications. After months of visiting different physicians including chiropractors and other alternate medical procedures, we told our family doctor that this was more than just the aging process.

This began more than a year of visiting local specialists including neurologists. Esther underwent multiple MRI's as well as other tests - all without a definitive diagnosis. One neurologist thought it might be an unusual form of Parkinson's disease. We then traveled to the Indiana Medical Center in Indianapolis several times over a period of a few months. A movement disorder specialist told us that it was a case of brain cell degeneration and could be one of at least 50 diseases. He did not suggest a specific diagnosis.

By now, Esther's normal, active life's activities changed to a person using a cane, walker and then a wheelchair. Her speech greatly diminished and eating became very difficult even with special preparations. She still had enough movement ability with her fingers allowing her to hold a small hand held computer and punch in brief messages.

In October, 1995, we visited the Mayo Clinic in Minnesota and were informed of the diagnosis of progressive supranuclear palsy or PSP. We are deeply grateful for home services making it possible to keep her with us at home. Esther is mentally alert although movement is very difficult. She can blink answers to questions and can smile. In 1998, we moved in with our daughter who worked as a school guidance counselor. When the house next door became available, another daughter and her family who were returning from missionary service in Spain moved in. Having family at hand, grandchildren coming in and out with school stories and doings making for happy times regardless of such devastating circumstances were countless treasures.

Because we were able to obtain a gurney, we were able to take Esther in our van several times to our son and family who live in Columbus, IN. Unfortunately, another son lives in Alaska and few trips are planned to their home because of the distance.

We know that our bodies were made to wear out so that we can get new and better ones. We await that day for Esther and for ourselves. Blessed hope! Andrew M. R.

Dear Friends,

I am hoping to compile a broad cross section of personal stories that encompass the family of progressive supranuclear palsy. There will be similarities throughout all the stories, yet each story will also be unique. What may help one with the disease process may also help another. Please take this opportunity to share and care. Each of our stories will be filled with courage, creativity, and perseverance.

Please send your "stories" to me via: email:103301.640@compuserve.com OR 6 Bramston Drive, Hampton, VA 23666

Praying for a cure,
Nancy Brittingham, Editor, The Society for PSP

PSP, Acknowledging / Meeting the Challenge

Susan Hunt, Consultant in grief, loss and pain management

All chronic illnesses present challenges. Even the most mild get tiring and frustrating sometimes. But a severe, ongoing, increasingly debilitating and life-threatening illness, such as PSP, challenges the individual and all those around them, to come up with every ounce of strength, endurance and courage they can muster, day after day and year after year.

There are no solutions. There are no "fixes". The medical profession is doing all it can to learn about the disease and find ways to ameliorate its effects, but a cure appears far down the road and even the professionals become discouraged. For individuals living with the disease, the days, weeks, months and then years stretch on, bringing a sense of hopelessness, of loneliness and helplessness. The present is miserable. Prospects for the future are dark and forbidding.

Grief, anger, fear and despair are absolutely normal reactions to life with PSP. Even the most determined and courageous individual who is involved with the disease will have some periods of hopelessness and discouragement. PSP is, after all, a terrible illness. No one who receives a diagnosis of PSP, or whose family member or friend receives one, is **EVER** prepared to deal with such a devastating "life sentence".

There are times when an individual who is impacted by PSP really needs to vent, needs to stop and acknowledge just how hard it is. It doesn't mean they are "giving up" or that they are " feeling sorry for themselves". Rather, it is a courageous and healthy step toward better management of their situation. Submerged, suppressed feelings do drain our energy and can lock us into a "frozen" position. We can't examine the feelings, yet we can't move or function because of them.

Whether you are the individual with the disease, or are in some way loving and supporting someone who has it; whether you are just starting the journey, or have been dealing with it for a long, long time, the following exercise may be helpful. It is an excerpt from a workshop designed to provide tools for living more successfully with a devastating illness, such as PSP. You are encouraged to enter this "exploration" with tenderness toward yourself, letting go of any judgments of yourself and gently accepting where you are at this present moment.

Objectives of this exercise

1. Acknowledge and validate the struggle of living with PSP.
2. Examine and strengthen the tools used for managing the physical, mental, emotional and spiritual stress and pain that accompany PSP.
3. Affirm that there is potential for meaningful living beyond the pain and begin to explore that potential.

Select a quiet, comfortable spot where you can be alone, or with someone you trust and with whom you can be totally "real". Don't rush and don't feel you have to complete all of the exploration at one sitting. Allow yourself to sit with the feelings that come up, to process anything that surfaces, before moving on. Remember, NONE of the feelings are wrong! They are just feelings, like being hungry when you haven't eaten. They come naturally, as a response to what is happening in your life.

I. Personal Exploration:

Write in a journal or on a sheet of paper, talk to someone or reflect within your own thoughts:

- What's hardest for you today?
- What's the most difficult/painful part of your situation right now (physical and/or emotional)?
- What are the feelings you are holding in your body right now?
  - – Physical feelings
  - – Mental attitudes/feelings
  - – Emotional feelings
  - – Spiritual thoughts/feelings

Sometimes words are not enough to really express how we are feeling. If it feels like it might be helpful, take a piece of paper and explore how the above feelings might look, if you can draw them. If you have some crayons or colored pencils, use colors that seem appropriate to your feelings. Draw shapes, words, designs, whatever feels right.

If drawing doesn't work for you, just sit quietly and imagine or talk about the feelings using "pictures", colors, words, shapes, until you can "see" them clearly. It's perfectly OK to just talk to yourself, if that is helpful in formulating and clarifying.

Go back and look at what you have written or drawn. Review quietly for a minute, what you have discovered about your feelings at this moment in your life.

Summarize it in words, on paper, if you can. Where are you right now? What do you need (that is within the realm of possibility) right now? Is there a way to meet that need?

II. Tools for managing PSP:

On the paper you have or the thoughts you have expressed, make a list of everything you do to manage your situation. What, especially, do you do to help you manage the stress you experience, dealing with PSP? Be sure to give yourself credit for all you do to take care of you. Notice the areas where you may need to find some new ways to cope. Following are some suggestions that may help:

1. It's very hard to retain your sense of humor, when you are dealing with PSP. The illness just goes on and on, - and then gets worse. Remind yourself to try to look for the humor in situations, as difficult as that may be. Find ways to laugh. Rent a funny movie. It can be very healing.

2. Remember to stop and breathe. Consciously take a deep, gentle breath and then release tension as you exhale. Do this often.

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PSP, Acknowledging/Meeting the Challenge

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3. Make time for pleasure, whatever that means for you. It may just be sitting at the window, watching the clouds or the birds or listening to music. Consciously set aside time for your enjoyment.

4. Make yourself a "healing box", or a "healing book" of pictures and writings. Include things you love, things that remind you of who you still are inside, and things that make you laugh. Keep it handy, so you can refer to it whenever you need cheering up.

5. Learn the gift of receiving with pleasure and thanks. People feel good about doing things for others. Let them do things for you.

6. As much as you can, avoid people and situations that drain you. Search out situations and companions that energize you, "feed" your spirit.

7. Engage in loving "self-talk". You are doing the very best you can in a very difficult situation. Validate, appreciate the beautiful parts of you. They ARE still there!

8. When you are short-tempered, or feel you have made a "mistake" of some kind, be gentle and forgiving of yourself, just as you would be of someone else.

9. Remind yourself that you are not alone. Seek support when you need it. The journey is long and we can't always be "up". Allow yourself the "down times" and let someone appropriate help you with them.

10. Open yourself to spiritual support and healing, whatever that means to you.

Are there other sources of information you can turn to, to learn more about coping skills?

III. Acceptance:

What feelings come up when you hear this word? Write them down or talk about them if you can. What about the word "healing"?

Would it ever be possible for you to fully acknowledge (accept) the reality of what is happening to you or your loved one, and then perhaps begin to look for some sort of healing, beyond the physical? This could be connected to your religious beliefs, but it does not have to be. You might want to jot down some thoughts at this point. What would "healing" look like or feel like, to you?

[Remember! No self-judgment! This is just an exploration into where/who you are right now. You may, or may not, be ready to take in Section IV, yet. If not, let that be OK for now. Either way, the exercise thus far may have shown you just where you are RIGHT NOW. That information alone can be very helpful as you try to live the best way you can with your situation. You can proceed with Section IV or come back to it later, if you choose to. Do whatever feels right for you.]

IV. This IS your life!

It's not what you wanted or expected. It is sometimes overwhelming and it certainly isn't "fair". There are some very painful things you cannot change. How do you want to play the hand you have been dealt?

This is not the choice you want, but it is the choice you have.

- Write down your response.
- Save it. Review it occasionally, as you go on with your life.
- Change it if and when you wish to.
- Try to remember, every day, that you DO have choices -and the choices you make affect the quality of your life and of the lives of those around you.
- Allow yourself to grieve when you need to. Its not weakness. It keeps you emotionally healthy.

-If you made it all the way through to the end of this (no matter how long, how many tries, it took), congratulate yourself! This process in NOT easy. You might just want to do something very special and indulgent to reward yourself! You surely deserve it!

Support Group News

Minnesota Support Group

The Minnesota Support Group has made a move from the University of Minnesota to the Struthers Parkinson Center.

The Struthers Parkinson Center is part of the Methodist Hospital Health System Minnesota where individuals come for medical appointments, day programs, exercise classes, rehabilitation services and seminars. It is located at 6701 Country Club Drive, Golden Valley, Minnesota.

We meet on the second Thursday of each month from 1:00 to 3:00 p.m. The first hour we meet with the Parkinson's support group and during the second hour, we separate into our individual groups. The PSP group meets with a nurse from the center who helps to answer questions and share information. One of the benefits experienced by PSP caregivers is they are able to bring their loved one with PSP to participate in the ongoing day programs scheduled.

For further information, please contact Charlotte Tripet at (612) 546-1694 or Struthers Parkinson Center at (612) 993-5495.

Ask a Doctor

Lawrence I. Golbe, M.D.
Chairman, The Society for PSP Medical Advisory Board
Professor of Neurology
Robert Wood Johnson Medical School

Is the visual problem the most important part of PSP?

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

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

Yet another eye problem in PSP can be abnormal eyelid movement - either too much or too little. A few patients experience forceful involuntary closing of the eyes for a few seconds or minutes at a time, called "blepharospasm." Others have difficulty opening the eyes, even though the lids seem to be relaxed, and will try to use the muscles of the forehead, or even the fingers, in an effort to open the eyelids ("apraxia of lid opening"). About 20 percent of patients with PSP eventually develop one of these problems. Others, on the contrary, have trouble closing the eyes and blink very little. While about 15 to 25 blinks per minute is normal, people with PSP blink, on average, only about 3 or 4 times per minute. This can allow the eyes to become irritated. They often react by producing extra tears, which can itself become annoying.

What about the speech problems?

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

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

Please forward your "Ask A Doctor" questions to the Editor, email 103301.640@compuserve.com, fax (757) 838-6086 or mail to the Society office.

Doris McCray and her husband Harry, who has PSP, were Mr. and Mrs. Santa Claus despite all of the challenges PSP brings! They also contacted their local television station with the 20/20 tie in and were interviewed in their camper in Myrtle Beach.

Support - Helpful Hints

Dear Nancy,

It was a pleasure for me to meet Honey Shara of the Shirley Walker Company at the symposium in Baltimore. I understand that Honey's company has been a long time friend and supporter of the Society and has worked with many persons with PSP and their families. I was very interested in learning about her product because I am looking for a sturdy walker for my mother. Honey Shara and I got to talking and I learned that her mother had double hip replacements due to arthritis over ten years ago. Honey soon learned that the "standard lift and place" walker was too weak to offer her mom support. Her mother fell and did not trust the walker so she would not use it. Determined to help her mom regain her mobility and independence, Honey researched all the walkers she could find and ended up finding the Swedish Leber rollator and found it to be far superior to the other walkers. That is why she formed her company and became the US distributor of the rollator.

I bought one and my mother has been using it for a couple of months. It is great! We both like the large wheels and the padded seat. It folds up very easily as well. It is of top quality construction. I just thought I would pass this on in your "Helpful Hints" section. If anyone wants more information about the rollator, call Honey Shara at 1 (800) 848-9255 or (201) 224-7600.

Sandra M. from FL

Dear Nancy,

The symptoms of PSP are dramatically changing the life that my husband and I had planned together for our retired years. We get through each day with our faith enriched by our deep love for each other after 38 years of marriage and the support of family and friends. I would like to share a "Helpful Hint" with others.

My husband has had major changes in his ability to speak. He speaks in a very low volume and with a monotone pitch. His excess saliva production and drooling compound his speech impairment. As we became frustrated in trying to understand him, he became even MORE frustrated trying to communicate his thoughts. This prompted us to investigate voice amplifiers.

A voice amplifier will enhance the loudness of speech but will not improve the clarity. There are many different types of amplifiers available. One can use a microphone positioned near the person's face. A small microphone can be worn on the shirt with the amplifier in a pocket. The hand held microphone and-speaker on a karaoke machine also work well. The following companies market amplification systems. Call them and ask for catalogs. You can make a decision according to your needs and finances.

1. Park Surgical Company 1-800-633-7878
2. Luminaud, Inc. (216) 255-2250
3. One to One Communications (913) 764-4072
4. Radio Shack in your local area

We all have to be creative and help each other. With thanks for the Society and the ADVOCATE.

Editor's Note: This information is provided as a service. The Society for PSP **DOES NOT ENDORSE** these or other products and neither the Society nor its staff have financial interests in these products. Information is offered with the intention to inform others about products that may help to maintain independence and improve the quality of life. Please check with your physician.

If you have any helpful hints, medical devices, equipment, or services you can recommend to other PSP families and caregivers, please write:

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PSP Advocate
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Suite 515
1838 Greene Tree Road
Baltimore, MD 21208
Fax: 757-838-6086
email: 103301.640@compuserve.com

Sue and Hal Bagett renew their wedding vows last fall.

Welcome to the PSP Email Listserve

Welcome to the support group for persons with PSP (PWPSP) and their caregivers (cg). There are over 250 subscribers to this list and about 90 percent are caregivers or family members of a PWPSP. There are several subscribers who have PSP or a closely related neurological disease. Some of the subscribers are surviving family members of now deceased PWPSP. This group is very supportive and for any question you have someone on the LISTSERVE has been there. The information available here is based on the experiences of caregivers who have lived day by day with someone with PSP. Guidelines and objectives were created by a nine member committee of listserve members.

OBJECTIVES

The discussion group began on January 14, 1998 and is sponsored by the Society for PSP (SPSP). It is not moderated and depends on the civility and judgment of its participants to meet its objectives as follows:

1. Exchange of information on caring for a PWPSP. This includes questions, answers and discussion about care issues.
2. Sharing information about the progression of PSP over time based on published research and experience of the caregivers.
3. Expressing support to others when they need sympathy, celebration or a pat on the back. Virtually all of this should be PRIVATELY SENT TO THE RECIPIENT RATHER THAN TO THE LISTSERVE.
4. Sharing backgrounds on the medical and family history of the PWPSP.
5. Providing periodic updates on the PWPSP when conditions change.

There is no pressure to send messages to the LISTSERVE and you are welcome to "lurk and listen" to what is going on. When you feel comfortable to speak up, just jump in and plunge ahead keeping within the guidelines outlined in this message.

It is common when referring to the PWPSP in a posting to the LISTSERVE that at least once you indicate the age and length of time he/she has had PSP. Thus, Sam (65/3) means Sam is 65 and has had PSP for at least three years.

GUIDELINES/Rules of the Listserve

These guidelines are intended to deal with the fact that the LISTSERVE has over 250 subscribers at all stages of dealing with PSP. Some have just recently had a family member diagnosed, some have been dealing with it for many years and others are in stages between these extremes on the PSP journey.

1. Postings should fall within the boundaries of the five objectives above.
2. DO NOT SEND ATTACHMENTS TO THE LISTSERVE. It causes problems to many subscribers with incompatible computers. Only send attachments directly to those who request them from you. It is OK to mention an item on the list which you can send as an attachment and invite requests. You should only send it directly to those who request it. An attachment is a document or image file that you "attach" to your e-mail message using the protocol of your e-mail program. It is a file connected to the e-mail and needs to be opened separately.
3. DO NOT HIT THE REPLY KEY for most messages you send to the LISTSERVE. In most cases it sends to all subscribers the original message and they do not want the LISTSERVE cluttered up with it a second or third time. You should address a new message to the LISTSERVE, noting in the subject line the earlier post or other subject to which you are responding, with your comment or reply to the first message. In some cases you may edit out the clutter at the beginning and end of the first message in your reply.
4. IDENTIFY YOUR TOPIC IN THE SUBJECT LINE. It is OK to post a note that is off the PSP topic, but you should be careful to so indicate in order to let people skip it if they wish. Some possible choices are:
   - PSP - Nutrition
   - PSP - Therapy
   - Off Topic - Joke
   - Off Topic - New Experience
   - Off Topic - Respite

   You can think of others that are descriptive. It is important to do this as a courtesy to others on the LISTSERVE who may want to pick and choose what they read due to limited time or other resources.
5. Replies to individuals should NOT be sent to the LISTSERVE, but should be sent directly to the person to whom you are responding. This includes things not of direct interest to everyone on the list. It will sometimes be a judgment call, but consider it carefully first.
6. An occasional joke or poetry to the LISTSERVE is OK, but exercise your judgment. Humor and inspirational items help us all survive this journey with PSP.
7. Greetings for events marking birthdays, anniversaries, or other major events including condolences should be sent directly to those for whom the message is intended. As the LISTSERVE grows it is not appropriate that personal messages be sent to all subscribers.
8. Do NOT send HTML-formatted messages to the LISTSERVE. Some subscribers can only read text format.
9. Forwarding messages. You may sometimes want to forward a message to the LISTSERVE or an individual. You should definitely edit the message before forwarding it. If it has gone through several persons it will be pretty well cluttered up and in that format is not appropriate to send to the LISTSERVE.
10. Give and take banter. NO PROFANITY. Many on the LISTSERVE have benefitted from give and take in a humorous vein over the last couple years and it is hoped that can continue. The problem is how many of these posts are appropriate. This too is a judgment call and should not be halted, but kept under some control. Just stop and think before sending off that first impression.

ON LINE SERVICES

Website: www.psp.org
Listserve: requests@hydra.welch.jhu.edu
Subscribe psp your name

Regular Report of Gifts

November 1 thru February 15, 2000

SPECIAL GIFT OF $200,000
Jay Troxel-dontation to the Eliose Troxel Memorial Research Fund
PSP PARTNER $50,000
Blonder-Altschul Family Philanthropic Fund
Wallis Foundation
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Harold W. and Barbara Fox Living Trust
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PLATINUM-$5,000 AND OVER
Allergan
Den Mar Foundation
Barbara and Jack Kelley in memory of Henry and Jane Ogiba
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Lane Stokes
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Richard Collopy in memory of Lenore Collopy
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Sandra Delany in memory of Florence Jiosi
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HMS Group in memory of Lillian Eshelby
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Sharon Huber in honor of Phil Huber
Eugene Irminger

Regular Report of Gifts

November 1 thru February 15, 2000

SILVER SPONSORS $2500 - $499 continued

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Uniworld Group Inc.
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John & Marie Zimmerman in honor of 41st Wedding Anniversary

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Julia Browne in memory of Jeanette Allen Love
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Eric Christiansen in memory of Robert Christiansen
Julia & Thomas Christo in memory of Olga S. Arnold
Citizens For Ryan in memory of Wilbur Nathan Daniel

Regular Report of Gifts

November 1 thru February 15, 2000

PATRONS $100 AND OVER continued

Tom & Bev Clark in honor of Tom's 61st Birthday
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Brian & Sharon Deiling in honor of Lois Deiling
Lois Deiling in honor of Lois Deiling
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Talley Fox in memory of Rush B. Winchester
Julie Frankenfield
Edward Frankstone
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Eugene Hamilton
Dorothy Hamler in memory of William Hamler
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Arnold Hegwer
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Herr & Sacco Inc. in memory of John Harold Brown
William Herrman
Lincoln Herzeca in honor of Claude & Maureen Dorsy

Regular Report of Gifts

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Doris Lee
Barbara Leidner in memory of Jerome Blonder
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Linda Lewis in honor of Marjorie Clark
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Caroljane Lux in memory of Miriam Clift
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M Rosenblatt & Son Inc. in memory of Alverta Deller
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Ltc. Peter & Jana Mansoor in memory of Audre McGranahan
Arthur Marks in memory of Don & Bea Heck
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PATRONS $100 AND OVER continued

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Joseph Metivier
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Gary Mills in memory of Rev. Ralph E. Mills
Vernon Mitchell in memory of Robert Schertler
Mobil Foundation
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James & Mabel Nevins in memory of Margaret Vaccaro
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Robert & Shelly Pavis in memory of Eugene Scawary
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Charles Powell
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Helen Puls in memory of Mary Piszczek
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Marcella Redeker
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Miguel Rivera in honor of Peter Stephinson
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Elinor Savage
Cathy Scarbrough
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Stephen Schmaltz
John Schmidt in memory of Don & Bea Heck
Ruth Schmitz in memory of Adam J. Schmitz
Peter & Anna Scholz in honor of Peter Scholz
Sally & Ott Schroeder
Maureen O'Toole Scott in memory of John J. O'Toole
William Scruggs, Jr. in memory of William Scruggs
Shirley Serby in memory of Kenneth Serby
William Shane
Muriel Shapiro in memory of Jerome Blonder
Merri Lea Shaw
Shaw, Licitra, Bohner, Esernio & Schwartz in memory of Ben Asarch
Adrian Shelton in memory of Ward Millar
Barbara Sheng in memory of Lenore Collopy
Thomas & Melonni Shields in memory of Geraldine Trissler Kelley
Eric Siegel
Ray & Marianne Simmons
Martin & Norma Simon
Martha Singer in memory of William Singer
Thomas Smalshof
Gail Smith in honor of Robert Smith
Robert Smith
Ben & Margaret Smolenski
Irene Smolicz in memory of Don & Bea Heck
Patricia Smyth
A.T. & Kearney Snyder in memory of John Harold Brown

Regular Report of Gifts

November 1 thru February 15, 2000

PATRONS $100 AND OVER continued

Jeannette & Matthew Sorrentino in memory of Grayce Krause
Robert & Judith Spare in memory of Don & Bea Heck
James & Marie Sparks
Arthur Spaulding in memory of Don & Bea Heck
Melvin L. Spence in memory of Sarah Nelson
Hank & Darlene Spiller in honor of Martha Keilbey
Dixie Spivey in memory of Maurice Wilkinson
Clyde & Leslie Spooner in honor of Leslie Spooner
Alvin Sprouse in honor of Mary Thomas - Christmas
Bruce Stackhouse in memory of Jane Stackhouse
Ronald Steiger in memory of Julia Poling
Alden & Shirley Stephens
Patricia Stix
Marni Storey in memory of Lavonne Storey
Roger Storey in memory of Margaret Parker
Strauss-Goodman Family Foundation, Inc.
Lorraine Strobel
Robert & Carolyn Strom in honor of Robert Strom
Helene Strongman in honor of Helene Strongman
Elizabeth Swartzwelder in memory of Sanford Kaufman
William & Sally Swezey in memory of Don & Bea Heck
Barbara Talbot in memory of John Harold Brown
John & Dorothy Talotta in memory of William Singer
Barbara Tanner in memory of Tommy Tanner
Nancy Terrill in memory of Aileen Starke
The Jewish Community Federation of Cleveland in memory of Jerome Blonder
The K Group in memory of Nancy Feaman
The Pfizer Foundation Matching Gifts Program
Marion Thompson in memory of Malcolm Thompson
Margaret Tidball in memory of Maurice G. Tidball
John & Jocelyn Tillman
Brendan & Lori Timmins in memory of Peter Couves
Genevieve Todd in memory of Charles Todd
Jennifer Todd in honor of William Todd
William & Margo Todd
TRAC in memory of Don & Bea Heck
Kim Trimble
Charlotte Tripet in memory of Thomas Tripet
E.H. Trolinger
Mary Trotta
Win & Eva Tuck in memory of Jack Crenca
Betty Tucker
Lawrence Tull in memory of Delores Tull
Mrs. W. Ford Turnball in memory of Ford Turnball
Elizabeth & Timothy Turnbull in memory of William Singer
Unity Order of Amaranth
Patricia Urani in memory of Angelo Urani
Eileen Urbanowski in memory of Nancy Feaman
Ruth Urso in memory of Paul Urso
Stephen Vaccaro in memory of Margaret Vaccaro
Donald Van Brunt in memory of Grace Van Brunt
Bill & Joanna Venard
Helen Verstraeten in memory of Hector Verstraeten
Rebecca Vincent in memory of Wandis Wells
John & Susan Voigt
Kathleen Vorwick in memory of William Padgett Mitchell
Barbara Vosburgh in memory of John Hellebush
Chow Thin Wai in honor of Lee Bee Imm
Gerald & Doris Waldron in memory of Don & Bea Heck
Brendan & Mary Ellen Walsh in memory of John Hellebush
Chantal & Tom Walsh
Dr. Walter S. Walter
Warren Truss Co., Inc.
Helen Weary in memory of John Hellebush
Paul Welk in memory of Mary A. Weinzirl
Don & Doryce Wells in memory of Richard Dumke
Ann Werner in memory of John Hellebush
Jane Werner in memory of John Hellebush
Elnora Wheatley
Harry & Priscilla Wheeler
David White
Tommy White in memory of Tara T. White
Emily Wieser in memory of Charles Wieser
Barbara Williams in honor of Shirley Stephens
James & Susan Wilson in memory of Douglas Harkleroad
Jennifer Woebke in memory of Audre McGranahan
Richard Wood in memory of John Harold Brown
Working Concepts Inc. in memory of Harold Roberts
Billy H. Young in memory of Sarah Nelson
Helen Zabel in memory of Robert Zabel
Rick & Nancy Zehrer in memory of Don & Bea Heck
Robert Zeppa in memory of Rush B. Winchester

Society for Progressive Supranuclear Palsy Brain Donation Program

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

The purpose of the Society for PSP Brain Donation Program is:

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 / E-mail: SPSP@erols.com
SPSP, Inc. Woodholme Medical Building, Suite 515
1838 Greene Tree Road, Baltimore, MD 21208

The Society for PSP, Woodholme Medical BuildingSuite 515, 1838 Greene Tree Road, Baltimore, MD 21208
1 (800) 457-4777 1 (410)

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

Send me copies of:

- ❏ #1 PSP Some Answers (Overall guide To PSP)
- ❏ #4 PSP ADVOCATE-Newsletter
- ❏ #6 Swallowing Problems
- ❏ #7 Personality Changes
- ❏ #8 Helping the Helpers who Care for People with PSP
- ❏ #9 Eye Movement Problems with PSP
- ❏ #10 1999 National Symposium Video Tapes-3 pack $75 plus $7 shipping in US and $10 outside.
- ❏ #11 PSP Fact Sheet (1 page summary-can be duplicated and distributed)
- ❏ #12 Reprint of feature article, Baltimore Sun
- ❏ #13 Medical Professional's Journal Review/PSP Advocate
- ❏ #14 Brain Bank Information Packet
- ❏ #15 Physician's Referral Cards
- ❏ #16 Giving Envelopes
- ❏ #17 The Society for PSP/National Institutes of Health PSP Brainstorming Conference/Dr. John Steele meeting with the Maryland Support Group $25 + $3 shipping in US and $5 outside.
- ❏ #18 Beautiful Acknowledgment Card to someone special for any occasion and will personalize your message. By donation only.
- ❏ #19 Planned Giving Information

Mail to: _____

_____

_____

Fax to : _____ Email to: _____

FOR PHYSICIAN'S ONLY:

- ❏ #2 Video "The Diagnosis of PSP" (Rec. For clinicians and faculty) $30 +4 shipping in US and $7 outside
- ❏ #19 Medical Professional Packet (Grant Award Information/PSP Rating Scale/copies of all other info.)

❏ I no longer wish to receive the PSP Advocate and by sending this will save the Society the expense.

❏ My new address is: _____

_____

_____

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

Name _____

Address _____

City _____ State _____ Zip _____ Country _____

Fax _____ Email _____

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

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

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

Name _____

Address _____

Phone/Fax/email _____

Check/Charge to: ❏ Visa ❏ Mastercard ❏ American Express

Card number _____ Expiration Date _____ Signature _____

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