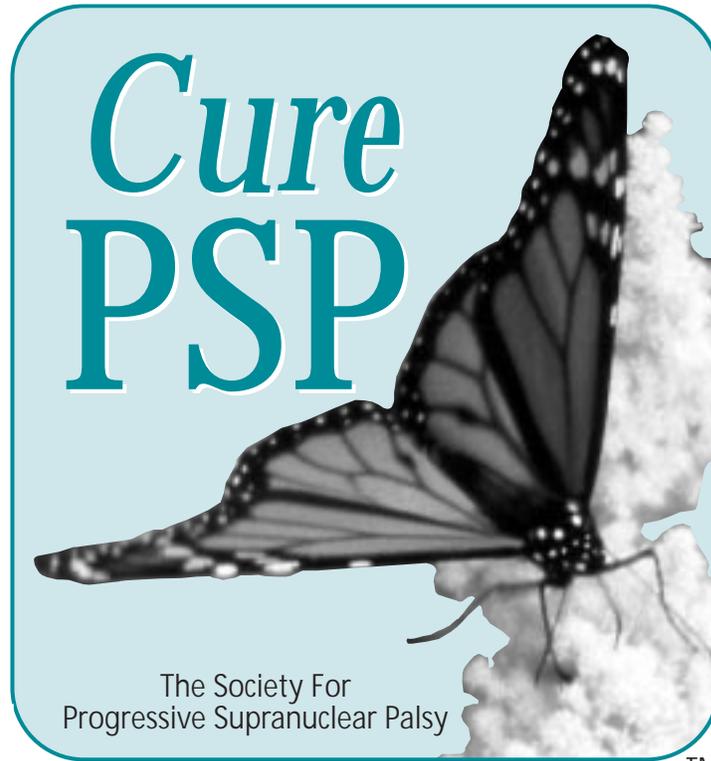


Woodholme  
Medical Building  
Suite 515  
1838 Greene Tree Rd.  
Baltimore, MD 21208  
1 (800) 457-4777  
1 (410) 486-3330  
FAX:  
1 (410) 486-4283  
email:  
SPSP@psp.org  
website:  
www.psp.org

## "The PSP Butterfly Pin of Hope"



### INSIDE

**"An Update of Our Progress"**  
- From the  
**Chairman of the Board**

**"Coping with Mobility Issues in PSP"**

WE ARE  
LAUNCHING OUR  
NEW WEBSITE  
WWW.PSP.ORG  
*Visit the new,  
expanded, energetic,  
and educational  
website soon to be  
launched!*

The Society for PSP is pleased to introduce the "PSP Butterfly Pin of Hope." The beautiful monarch butterfly signifies HOPE and represents the Society's determination to find the cause and cure for PSP. Because of a special gift to the Society, the initial offering of the "PSP Butterfly Pin of Hope" will be free of charge. Anyone wishing to order this handsomely designed pin, please fill out and mail/fax the order form below or email the Society office at SPSP@psp.org. A limit of two pins per family while supplies last.

We hope that you will wear this "PSP Butterfly Pin of Hope" wherever you go to help create awareness and educate others about this devastating disease.

The Society thanks special PSP volunteer and Board Vice Chairman Liz Brisson, Society Director Ellen Katz and *PSP Advocate* editor Nancy Brittingham for being instrumental in the creation of this pin. Roger Brisson, Liz's husband, gifted the Society with one of his professional slides of a monarch butterfly, allowing the Society sole copyrights on this logo. John Hargett, graphics designer at Gear Up Printing, masterfully recreated the original monarch onto the Society pin. The

Society is also thankful to our donors, *Barbara and Jack Kelley*, for the initial offering of the "PSP Butterfly Pin of Hope" given in memory of Henry and Jane Ogiba, beloved parents of Barbara Kelley and the *PSP Advocate* editor.

#### ORDER FORM:

Name \_\_\_\_\_  
Street \_\_\_\_\_  
City, State Zip \_\_\_\_\_  
Telephone # \_\_\_\_\_  
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one pin     two pins

Return form to:

The Society for PSP  
1838 Greene Tree Road, Suite 515  
Baltimore, MD 21208  
or email: SPSP@psp.org  
Fax: 1 (410) 486-4283

# The Society for Progressive Supranuclear Palsy

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Reba and David Saks

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

The Society for Progressive Supranuclear Palsy, Inc. (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.

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

## EDITOR

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(757) 838-0777 • FAX (757) 838-6086  
(In memory of Henry and Jane Ogiba)  
Assistant to the Editor: Debra Thompson  
(In memory of Lois Croft Davis)

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# The Society for PSP

## An Update of Our Progress

Last October, the Society commemorated its tenth anniversary with the family of its founders, David and Reba Saks, and many friends of the Society. As hard as it is to believe, another year has gone by since that time. Upon reflection of our anniversary, I thought it appropriate to consider where we have been, where we are now, and where we are going.

The mission of the Society has long focused on three objectives: to research the cause and cure of progressive supranuclear palsy (PSP), to provide support to caregivers and persons with PSP; and to provide educational materials to both caregivers and physicians in order to increase awareness of the symptoms of the disease and to provide assistance in day-to-day living. Based on that mission, a four-year strategic plan was developed in late 1999. The goals of the strategic plan are:

- To establish a strong national presence and increase education about PSP to persons with PSP, their families, caregivers, physicians, and allied professionals.
- To continue to generate and increase yearly ongoing revenue for current operation expenditures, special projects and future funding by establishing a development program.
- To strengthen and broaden an effective volunteer leadership program.
- To promote and increase PSP research.

First founded in 1990 and after several years as an (all-volunteer) organization in which important groundwork was established, the Society has seen tremendous growth in many areas since the addition of professional staff in late 1996. In that year, the Society received total contributions of less than \$90,000 and had expended \$31,200 in research grants. Despite those modest totals, the foundation for growth had already been established through the development of the *PSP Advocate* newsletter, the establishment of a Medical Advisory Board committed to diligently evaluating grant applications, and the continued commitment of the Board of Directors.

Since 1996, the progress of the Society in accomplishing its mission can be measured in many quantitative ways. For 2001, we are budgeting for contributions in excess of \$1.1 million, due to the generosity and commitment of thousands of donors like you who have been affected by the disease in some way. We are funding more than 37 research grants with budgeted expenditures reaching close to one million dollars. The *PSP Advocate* newsletter circulation has increased from 2,000 issues in 1996 to more than 12,000 issues per quarter in 2001. Caregiver support groups have increased from 40 just two years ago to more than 75 as of this writing.

Taking a closer look at where we are in meeting our three primary objectives reveals that, although we have accomplished much, there is much, much more for us to do.



George S. Jankiewicz, Chairman

Education and development of a strong national presence - We are just beginning to scratch the surface of our potential for progress in moving forward on this goal. We are currently recruiting a Director of Outreach & Education to further develop informational, referral and networking services to persons and families affected by PSP and to provide educational materials to enhance the awareness of PSP. In the meantime, a committee of volunteers is very capably handling the responsibilities of providing educational services to a growing number of support groups. These volunteers have also organized regional symposiums in Philadelphia and Boston for 2001 that supplement our National Symposium in Baltimore (scheduled for May 17-18, 2002). Enhancements to our web site are also now in development that will allow for the timely dissemination of new materials and events. In addition, board members, staff and volunteers attend conferences, such as those sponsored by

the American Academy of Neurology and the American Academy of Ophthalmology

Funding of operating expenditures and special projects - This is another area in which tremendous progress has already been noted. Again, however, we are just skimming the surface of our potential. We are recruiting a Development Director to focus on the cultivation of donors, planned giving, and corporate and foundation giving. Our success in meeting our goals has been due to your generosity and commitment. Through an increase in a coordinated volunteer effort, we envision the development of a national support base with an increased emphasis on a coordinated series of fundraising events that will also be designed to raise national awareness of PSP.

Volunteer Leadership - We have created a recruitment committee to provide the Society ongoing information about potential Board leadership volunteers and to coordinate a volunteer database to match opportunities to available talent. There are many opportunities for volunteer help, as the Society has established committees in the areas of finance, public relations, development, web site design and development, human resources, outreach and education, and has many opportunities to help support events such as symposiums and seminars. The ultimate success of the Society in accomplishing its mission is dependent on the continued availability of strong volunteer support.

Research - Our strategy has been to fund quality projects that project the promise of shedding additional light on the nature of PSP and that may lead to the development of medications that slow its progress and/or alleviate symptoms. As regular readers of the *PSP Advocate* already know, this ongoing research has been successful in uncovering many of the intricacies of how PSP develops, although definitive causes have remained elusive so far. Unfortunately, much

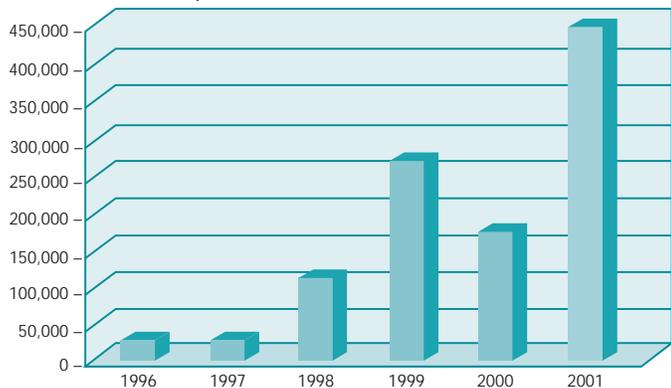
Continued Page 4

# The Society for PSP

more research is needed to discover medications that have an impact on the progress of the disease. We will continue to generate funding to develop the base of scientific knowledge needed to make strides in PSP prevention and cure. Research breakthroughs require focus, patience and resolve. I am confident that our efforts will ultimately bear fruit.

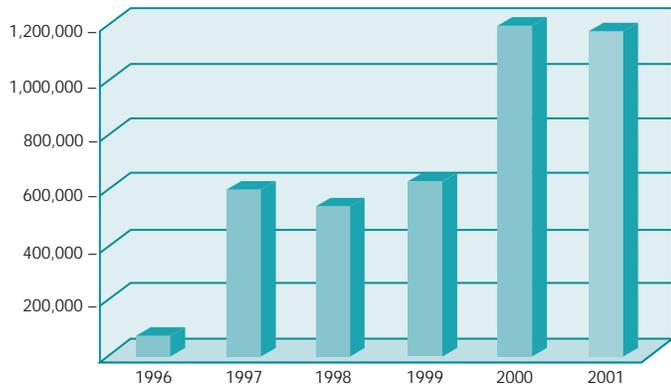
Thank you for your continued support. I encourage you to be an active participant of our ongoing development as we continue to carry out our mission. We have only begun to tap into our potential.

Research Expenditures for the Years 1996-2001\*



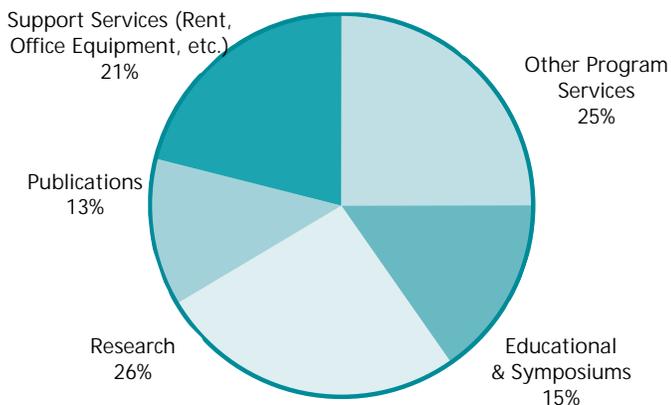
\*2001 Budgeted Numbers

Contributions for the Years 1996-2001\*



\*2001 Budgeted Numbers

Classification of Expenditures for Year Ended December 31, 2000



## Meet the Society's New Assistant Director

I am the new Assistant Director for the Society for Progressive Supranuclear Palsy. When I joined the Society team on April 23rd, I did so with the usual excitement of starting a new position in a new company. What I did not expect was the commitment level of virtually everyone I have met - from the staff to the Board and the people we serve. Everyone is fully invested in the cause of eradicating PSP. Meeting a few persons with PSP and their caregivers has given me a closer view of the "whys" of this dedication and commitment. It has allowed me to appreciate what is happening in and around the Society - PEOPLE CARE!



It is so wonderful to be a part of something this important. I am ready to put forth my best to make sure the Society's goals are exceeded. My expertise is in human resources, technology, finance, and daily operations. I have worked for several small for-profit companies, helping them through the 'start-up' phase, as well as led a global training department for a larger company. My variety of experiences has taught me to be ready for anything and take advantage of everything. I love working with people and now some of my favorites are the staff right here at the Society for PSP. The collaboration of board members, committee members and volunteers is fantastic. I get up every morning excited to come to work. That's a blessing!

I look forward to serving the Society for a long time.  
Jackie Allison

## Why I Give

by Jay Troxel

Ellen Katz casually gave me an assignment that initially seemed not difficult: to describe, personally and in general, why people give charitably. Numerous reasons come to mind readily; these range from the practical or self-serving, such as tax advantages and public acclaim, to the basic human desire simply to help others and to contribute in ways that benefit society in general.



Introspection reveals for me two essential motives: the desire to preserve a memory of my late wife, Eloise, combined with an urge to be of help to as many of my fellow beings as possible.

Impelled by both of these, my first response was to establish the Eloise H. Troxel Grant Research Fund, which is managed very capably by The Society for PSP. Grants have been awarded to researchers in at least nine countries: it is hoped that continued research, with the help of other funding, will discover alleviation, if not a cure, for the baneful effects of PSP.

In general, I believe that the primary impulse to giving rises above these two factors. I am convinced that an innate urge to help others is a part of being human. This may be expressed variously as compassion, piety, a desire to improve the lives of human beings in need, a desire to make one's community a better place to live, or a belief that one's own good fortune demands repayment in some manner.

*Continued Page 5*

Why do these impulses or urges exist? I am convinced that these human traits simply obey a transcendental direction, governance if you will, which is basic in the spiritual contemplation of virtually all diverse cultures of mankind. Judaism, Islam, Hinduism, Buddhism, and Christianity all admonish their adherents to give without expectation of reward, simply in order to help those in need as a matter of love for mankind.

It is important, however, that giving is directed so that optimum results are possible. In this respect, The Society for PSP has my unending gratitude. The gift of money is but a mere first step. Money by itself is inert; it must be put to use by people. Those who administer the Society have used the available funds superbly; they have given life and meaning to my own contributions.

In two other areas, the Society has been outstanding and I am grateful for the continuing results. The transformation of *The PSP Advocate* from a rather simple house organ into a professional publication is a major achievement. Under the guidance of Nancy Brittingham, it has evolved into a source of information both for professionals and for victims of PSP and their families.

Third, the Society itself has gained in stature and is attaining a place of growing importance in the world of medical research. Through the efforts of the Society and its medical advisors, gone are the days when victims of PSP were improperly diagnosed largely as the result of paucity of information and knowledge now available.

In short, I believe that charitable giving is driven by a desire to be of help to society, and that its rewards are awareness of the beneficial effects so produced.

## Dudley Moore Tribute Yields \$50,000 for PSP Research

*Thank You, Dudley and  
Music for All Seasons  
for your wonderful gift!*

The Society for PSP is pleased to announce it has received a gift of \$50,000 from the proceeds of the Gala Tribute to Dudley Moore sponsored by Music For All Seasons' benefit salute, "Dudley Moore: A Man For All Seasons" at Carnegie Hall on April 16, 2001.

"I am very pleased to be able to send you a check for \$50,000 from our April 16 Carnegie Hall event. I will be very interested to know what research projects are available to fund at the present time.

I was glad that many representatives of the Society for PSP could attend the event, and I thank you for the gift you presented to me that evening. I hope that the enclosed check will help to find a cure. We'll all keep working on this!"

With my good wishes,  
Dudley Moore

## Interaction of Parkin Protein with Abnormal Form of Tau

Paul S. Fishman, M.D., Ph.D., PI  
George A. Olyer, M.D., Ph.D., Co.PI  
Department of Neurology,  
University of Maryland School of Medicine, Baltimore, MD

Neurofibrillary tangles (NFTs), a major feature of the pathology of PSP, are composed of abnormal forms of the protein tau. Mutations in the tau gene result in an inherited human disease: fronto temporal dementia with Parkinsonism (FTDP) with clinical and pathologic similarities to PSP including NFTs. Genes from FTDP patients cause degeneration of brain cells in animals and accumulation of abnormal tau in cells grown in culture. One of the recently identified genes involved in inherited forms of Parkinson's disease, called parkin, has been shown to be an enzyme involved in the pathway for elimination of abnormal and potentially toxic proteins. We have shown that parkin can reverse toxic effects of production of abnormal proteins, which accumulate in cells grown in culture. Introduction of a gene, which drives production of parkin protein in these cells, improves their survival and reduces the amount of two different abnormal proteins also produced by gene introduction. We will test whether parkin can also reverse the effect of production of abnormal tau in cultured cells. We will introduce mutant tau genes from FTDP patients into these cells and monitor their survival as well as the accumulation of abnormal tau. We will then assess the effects of treating these cells with the parkin gene. Parkin may play an important role in the elimination of proteins such as abnormal forms of tau in both FTDP and PSP.

**Funded by The Eloise H. Troxel Memorial Grant**

## Finding the cause and effect of a bioenergetic effect in PSP

David S. Albers, Ph.D.  
Department of Neurology,  
Weill Medical College of Cornell University

Progressive supranuclear palsy (PSP) is a neurodegenerative disorder that is characterized by the appearance of supranuclear gaze palsy and extrapyramidal symptoms. Although the etiological basis of PSP is unknown, studies from this and other laboratories have found evidence for mitochondria dysfunction and oxidative stress in PSP. The present proposal will focus on the role mitochondrial dysfunction plays in the pathogenesis of PSP. In particular, we will utilize mitochondrially transformed cells (cybrids) generated from PSP patients to investigate mechanisms of neuronal degeneration resulting from mitochondrial dysfunction, particularly disturbances in calcium homeostasis, oxyradical production and mitochondrial membrane potential. Moreover, the utility of potential rescue therapies that improve overall mitochondrial function will be tested for possible neuroprotective effects. To determine whether functional mitochondrial abnormalities result from genetic mutations, we will sequence mitochondrial DNA from PSP cybrids to identify polymorphisms and/or mutations that could account for mitochondria dysfunction. Together, these studies will examine comprehensively mitochondrial dysfunction in PSP by combining functional biochemistry with mitochondrial genetics. The significance of these studies can only be inferred at present. Nevertheless, this study should shed important insight into the mechanisms of cell death in PSP and may facilitate the development of new, improved therapies to treat this debilitating movement disease, and more importantly, offer new hope to affected patients and their families.

**Funded by The Pearl and Erwin Poizner  
Memorial Research Fund**

# Research

## Grants Funded By The Society For PSP

### 1990-1997

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) \$1,200  
 Adolfo Brusa, M.D.  
 Corso A. Saffi, Genoa, Italy

Linkage Analysis in Familial PSP \$10,000  
 Justo Garcia de Yébenes, M.D.  
 Universidad Autonoma de Madrid  
 Madrid, Spain

Genetic and Environmental Studies of Bodig and Lytgo 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 Atrophy, Barcelona and Parkinson's Disease \$10,000  
 Josep Valls-Solé, 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

### 1998

Establishment of a PSP Brain Bank \$53,000  
 Dennis W. Dickson, M.D.  
 Mayo Clinic, Jacksonville, Florida

Trial of Nonepezil HCL in PSP Patients \$29,200  
 Irene Litvan, M.D.  
 Henry M. Jackson Foundation, Bethesda, Maryland

Potential Role of Mitochondrial Defects in PSP \$20,000  
 M. Flint Beal, M.D.  
 Weill Medical College of Cornell University  
 New York, NY

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  
 Piscataway, New Jersey

Oxidative Mechanisms in PSP \$20,000  
 D.S. Albers, Ph.D.; Sara J. Augood, Ph.D.  
 Neurology Department  
 Mass General Hospital, Boston, Massachusetts

Tau Gene Mutations in PSP \$20,000  
 Joseph J. Higgins, M.D.  
 Laboratory of Clinical Neurogenetics  
 Wadsworth Center, Albany, New York

Mitochondria in PSP \$17,000  
 Russell Swerdlow, M.D.  
 University of Virginia School of Medicine  
 Charlottesville, Virginia

Neuroanatomical Basis for PSP \$20,000  
 Eyelid Motor Dysfunction  
 Mark S. LeDoux, M.D., Ph.D.  
 University of Tennessee, Memphis, TN

Neuropathological Grading Scale for PSP \$10,000  
 Mark W. Becher, M.D.  
 University of New Mexico Health Science Center  
 Albuquerque, New Mexico

### 1999

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 Palsy 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. Kish, Ph.D.  
 Centre for Addiction and Mental Health  
 Toronto, Ontario, Canada

Synaptic Protein Loss and Alterations in Growth Inhibitory Factors as a Biological Foundation of Behavioural Changes and Cognitive Decline in PSP \$25,000  
 Elizabeta B. Mucaetova-Ladinska, M.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  
 Sarah Jane Augood, Ph.D.  
 Massachusetts 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

# Research

Ultrastructural and Biochemical Heterogeneity of Paired Helical Filaments in PSP \$18,000  
 Hanna Ksiezak-Reding, 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

## 2000

Regulation of Human Tau Gene Expression and its Role in PSP \$20,000  
 Jane Wu, Ph.D.  
 Washington University School of Medicine  
 St. Louis, Missouri

Environmental Factors and Detoxification Mechanisms in PSP \$20,000  
 Rosemary H. Waring, MA, Ph.D., Dsc, FRCPath  
 The University of Birmingham  
 Birmingham, United Kingdom

Are Matrix Metalloproteinases Involved in the Pathogenesis of PSP? \$20,000  
 David S. Albers, Ph.D.  
 New York Presbyterian Hospital  
 Cornell University, New York, New York

Effect of Lipoperoxidation on cdk5 Activity and Tau Protein Aggregation: A Model of PSP Pathogenesis \$20,000  
 Massimo Tabaton, M.D.  
 University of Genova  
 Genova, Italy

## 2001

Dopa-resistant Parkinsonism in Guadeloupe: Evaluation of Isoquinolines Deviates and Acetogenines Toxicity in Rats \$50,000  
 Dominique Caparros-Lefebvre, M.D., Ph.D.  
 University Hospital, Guadeloupe, France

MRNA Profiling in the Post-Mortem PSP Brain: Identifying Abnormal Signaling Pathways \$47,500  
 Sarah Jane Augood, Ph.D.  
 Massachusetts General Hospital

Comparisons of Region Specific MRNA Expression Profiles of PSP Brains with those of Alzheimer, FTDP-17, Pick Disease and Non-Affected Brains, using DNA Microarray Technology \$45,000  
 Vinzenzo Bonifati, M.D.  
 Peter Heutink, Ph.D.  
 Erasmus University  
 Rotterdam, The Netherlands

Mechanisms Regulating Neurofibrillary Tangle Formation In PSP \$42,406  
 Nancy A. Muma, Ph.D.  
 University of Washington, Seattle WA

Tau Auto-Antibody Production in PSP \$38,976  
 James W. Tetrad, M.D.  
 Laurel M. Bolin, Ph.D.  
 The Parkinson's Institute  
 Research and Treatment Center  
 Sunnyvale, California

PSP Advocate, Third Quarter 2001

Regulation of Human Tau Gene Expression and its Role in PSP \$25,794  
 Jane Wu, Ph.D.  
 Washington University School of Medicine  
 St. Louis, Missouri

Characterization of the Molecular Mechanisms Leading to PSP \$45,000  
 Dr. Justo Garcia de Yebenes Prous  
 Fundacion Jimenez Diaz  
 Madrid, Spain

Interaction of Parkin Protein with Abnormal Tau \$40,000  
 Paul S. Fishman, M.D., Ph.D.  
 University of Maryland School of Medicine  
 Baltimore, Maryland

Finding the Cause and Effect of a Bioenergetic Defect in PSP \$49,775  
 David S. Albers, Ph.D.  
 Weill Medical College of Cornell University  
 New York, New York

**Total Grants Funded \$985,480**

## Society for Progressive Supranuclear Palsy Brain Donation Program

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

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

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

To obtain informational packets about brain tissue donations, please contact the Society for PSP.  
 Phone: (800) 457-4777, (410) 486-3330 / E-mail: SPSP@psp.org  
 SPSP, Inc. Woodholme Medical Building, Suite 515  
 1838 Greene Tree Road, Baltimore, MD 21208

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

# Special Events

## The Philadelphia Symposium May 21, 2001

By Ellen Pam Katz, Executive Director

The PA Symposium was sponsored by a generous gift from Barbara and Douglas Bloom in memory of Sophie Shapiro. This "PSP Awareness Day" was organized by Gwyn Vernon, MSN, CRNP, and a volunteer on the Society's Board and Outreach and Education Committee. She was assisted by Jane Wright, the leader of the Philadelphia support group. Other persons who assisted included Janice Clements, co-chair of the Society's Outreach and Education Committee, Nancy Brittingham, Editor of *The PSP Advocate*, members of the Outreach and Education Committee, and Karen Kennemer, a volunteer from Texas who secured vendors for the event.

One hundred persons attended, including 14 persons with PSP, 10 allied health professionals including physicians, a researcher, a nurse, a social worker, a physical therapist and a dietitian, Society Director, Ellen Katz and approximately 75 caregivers/family members. They were extremely appreciative of the information presented and learned they were not alone. The great majority of the attendees had never met another PSP family. Several were in support groups. Attendees traveled from PA, MD, VA, NY, NJ, OH and DE and were equally distributed from these states.

The event was beautifully organized and presented with Gwyn serving as moderator and introducing speakers. The attendees learned about the basics of PSP, current research, physical therapy and dietary techniques for the practical management of PSP. The attendees also learned about the activities of the Society and the need to create more support groups, enlist the support of volunteers and raise funds for patient services and research.

The event was very successful as expressed in the evaluation sheets returned by the attendees. The Society seeks to replicate these regional symposia in many communities to establish a network of support and information to persons profoundly impacted by PSP.

Congratulations to the volunteers who did such a superb job of organizing, promoting and presenting this highly educational and insightful event. Also, many thanks to the Bloom Family for remembering Sophie Shapiro in such a meaningful way.

*Continued Page 23*



*Speakers: Ame Golszewski, MS, CNSD, Stephen Gollop, M.D., Millie Bickling, MSW, Gwynn M. Vernon, MSN, CRNP, Heather Ciari, LPT and Janice Clements*



*The Society for PSP thanks all our corporate sponsors for their support in helping to present the PA Symposium. When calling these companies for information and placing orders, please mention that you learned about them through the Society for PSP and the PA Symposium.*

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# Special Events

## Fight PSP Fundraiser in NY City, May 18, 2001

May 18th was an evening full of smiling faces, good music and dancing.

The Fight PSP Fundraiser was held at Paisleys, one of downtown Manhattan's hot spots. The theme for the fundraiser was "FIGHT PSP." Several celebrity-signed boxing gloves were collected for silent auction. Some celebrities included Barbara Walters, Samuel Jackson, Danny Glover and Herbie Hancock. Several

companies donated items to be raffled: Roots Canada contributed a leather briefcase; The Discovery Channel sent 3 huge stuffed animals; a bear, a crocodile and an elephant, and Intel contributed a computer Sound Morpher.

The turnout was overwhelming. Doors opened at 9:00 PM with a \$65. cover charge and open bar till 1:00 AM. By 9:05, a line formed out the door. Families flew in from all over, friends brought friends, and Society friends came in from all over New England. Maria's father, who is diagnosed with PSP, attended the event. He was touched and overwhelmed by the support of people surrounding him that evening.

Everyone who attended was given party favors. Capstone Apparel donated 200 baseball hats with "Fight PSP" embroidered on the front. Pad Printing Specialties donated 300 mini boxing glove keychains with "Fight PSP" printed on the knuckles. It was a night to remember.

We are proud to present the Society with a check for over \$10,000. to go directly toward research in finding a cure for PSP.

Thank you all for the support. The PSP Society was a major supporter and helped us get out hundreds of invitations and give us a voice.

Maria Coccodrilli  
Rick Juneja



Maria Coccodrilli with her dad  
Robert Coccodrilli



Party Planners:  
Rick Juneja, Bob Juneja and  
Maria Coccodrilli

## Fundraising Ideas

You can plan a special event to raise funds! Here are some ideas. If you need help, the Society will help locate other PSP families in your area who might want to assist you.

- SILENT AUCTION - Acquiring tangible and intangible items from retailers at no cost or a nominal fee to display for bidding.
- DINNER DANCE - Providing an atmosphere for a sit-down or buffet dinner followed by an evening of dancing. A theme is often used to attract an audience such as a 50's or 60's dance, square dancing, etc.
- SHOWS - Purchasing a block of tickets to a show at a local theater and selling them to constituents. A reception may be held in conjunction with the theater experience.
- LAS VEGAS NIGHT - Providing games for gambling and various stations for winning prizes. Guests have the opportunity to "play at the casino" for the evening. A dinner may accompany the plans for this type of event.
- MOVIE PREMIER - Publicizing a movie and enlisting guests to watch the movie on a designated evening or afternoon in which proceeds benefit your cause.
- CONCERT - Hiring a talented, either nationally or locally known, celebrity/singer or group to perform. Arranging the event on the opening night of a celebrity concert is one option. Sometimes performers may donate their services.
- MARATHONS - A walk-a-thon or dance-a-thon recruits generally large numbers of people to participate in a physical activity that brings in funds through pledges made in advance.

- LETTER WRITING CAMPAIGN - Use this sample letter to send to friends and family. Ask for contributions for the holiday season with holiday gifts made to the Society to remember or honor a loved one. The Society will send you giving envelopes and fact sheets to include with each letter. We can also help you personalize the letters. These requests are sure winners for raising funds and awareness!

### Sample Fund Raising Letter

Dear \_\_\_\_\_ (Personalize the letter):

I'm writing to you because so many of my dear family and friends have expressed a desire to do something to honor \_\_\_\_\_ who is a tragic victim of progressive supranuclear palsy. PSP is a devastating neurological disease. \_\_\_\_\_ has suffered with this for \_\_\_\_\_ years. Currently, he/she can no longer \_\_\_\_\_ and his/her condition continually progresses downhill. As members of her family, we are suffering too. We also know that this disease has no known cure.

We are receiving valuable support services from The Society for Progressive Supranuclear Palsy, a national organization serving patients, families and health professionals. Educating families and health care professionals are among the goals of the Society. We receive their helpful newsletters and other informational mailings. The Society also funds research to find the cause and cure.

What can you do to help \_\_\_\_\_ and others who have PSP? We are asking you to make a gift to the Society in honor of \_\_\_\_\_. Your tax-deductible gift will be used for education, support and cutting edge research to find a cure for this cruel disease. (As the holiday season nears, we ask that instead of purchasing gifts for our family, you make a donation to the Society.) Enclosed is information about PSP and the vital work the Society performs.

I thank you in advance for your generosity. Your gift means a lot to me and my family.

When you make your gift to the Society, they will notify me of your heart-felt contribution. You will also receive a receipt for your tax-deductible gift. Your gift will be placed in a special fund established in \_\_\_\_\_ name.

Thank you.  
Sincerely,

## Coping with Mobility Issues in PSP

Heather J. Cianci, PT, GCS  
The Dan Aaron Parkinson's Rehabilitation Center  
Philadelphia, Pennsylvania

*This article was written with information taken in part from her presentation at the Spring 2001 Philadelphia Regional PSP Symposium*

As a physical therapist working in a center dedicated to the treatment of movement disorders, I have the privileged opportunity to meet and work with many people diagnosed with PSP. People with PSP want to stay as mobile as they can throughout the progression of their disease. Unfortunately, as PSP progresses, mobility becomes more challenging, not only for the person with the diagnosis, but also for the loved-ones.

Commonly in PSP, we see muscular tightness, slower movement, loss of eye control, ataxia or imbalance, increasing falls and the progressive inability to ambulate. It is important to note that those with PSP are not just battling the disease, but also the changes that typically occur with aging. Changes in eyesight and hearing, and loss of tissue elasticity and muscle mass, each affect mobility in their own way. Because of this fact, I recommend that as soon as someone is diagnosed with PSP, they begin physical therapy. People with PSP can stay as functional as possible if they initiate stretching and strengthening exercises at an early stage of the disease, and if they learn as much as they can about safety and body positioning. The health and well-being of the caregivers should also be considered. Through education, caregivers and patients will keep mobility activities and ADL's (activities of daily living) as safe and easy as possible.

Muscular tightness affects mobility in several ways. Poor posture can lead to chest wall tightness, which in turn can impact the ability to take full breaths. Those who sit for long periods of time in wheelchairs are likely to develop hip tightness and decreased pelvic mobility. These results can make the skin prone to breakdown, especially along the sacrum and buttocks. To prevent these problems, a professional wheelchair assessment must be performed to ensure proper positioning and cushioning. Patients and caregivers should be aware that the wheelchairs typically rented from Medicare or other insurance carriers are mainly for transporting someone from place to place, not for long-term sitting and comfort. It is important to note that those in wheelchairs must move to stand or shift their weight every half hour to allow for better blood flow and muscle and joint flexibility.

The areas of the body that most commonly become tight are the neck and trunk, the chest wall, hip flexors, hamstrings, and ankles. Sometimes the hands also tighten, and this can make holding a utensil or a walker difficult. Hands that are progressively becoming "stuck" in one position are best treated by an occupational therapist who can make recommendations and positional splints if needed. The facial muscles also can experience changes. These small muscles help with chewing, speaking and facial expressions. Tightness here can make

these tasks challenging. Simple exercises like opening the mouth as wide as possible and raising the eyebrows at the same time can help with loosening the muscles. When the time comes that chewing and swallowing become too difficult, or perhaps unsafe, a speech and/or nutritional therapist needs to be contacted.

### POSTURE

Posture is something that many of us do not think about until it becomes a problem. Poor posture can lead to difficulty



with breathing, range of motion at the joints, and overall mobility. Sitting in the "slumped" posture can cause the muscles along the chest wall to become short and tight, while the back muscles lengthen and become weak. This "slumped" posture also causes the pelvis to tilt backward, leading to a loss of the natural curve of the low spine. Over time, this can make standing straight difficult. There are several preventative measures that one can take to help facilitate better posture: 1) Sit in a chair that allows the hips and knees to be level; you never want your knees higher than your hips when sitting.

2) Use a lumbar roll or small towel roll along your low back to promote the natural curve. 3) Have the proper wheelchair. 4) Make sure you sit up straight against the headboard if you watch TV in bed. 5) Leave reminder notes around the house or have loved-ones remind you to sit up straight. And finally, 6) Perform posture strengthening and stretching exercises daily. (\* Please contact your local PT or our facility for a list of exercises)

### EXERCISE

I believe that it is the combination of four elements that makes up a truly beneficial exercise program: a) stretching, b) strengthening, c) aerobic conditioning, and d) relaxation / meditation. For the first two elements, I use the phrase "stretch the front, strengthen the back" to help people



remember their program. Most of the muscles or areas that need to be stretched are located on the front of the body (with the exception of the hamstrings and trunk) - the face, front of the neck, pectorals/chest wall, shoulders, trunk, hip flexors, hamstrings and ankle extensors. Most of

the muscles or areas that need to be strengthened are on the back of the body (with the exception of the quadriceps and ankle flexors) - the back of the neck, triceps, the back, hip extensors, quadriceps and ankle flexors.

For the third element, aerobic conditioning, I recommend

# Education

end of the pool, biking on a stationary recumbent bike (this promotes better posture than an upright bike), and dancing.

Most importantly, the conditioning exercise you chose needs to be fun, enjoyable, and safe to perform. A good program should be performed for 20-30 minutes, 3-4 times per week.

The final element, relaxation / meditation, is often overlooked when planning an exercise program.



However, I consider it just as important as the other elements. Learning to breath properly can help relieve tension and anxiety, and it can make the other elements easier to perform. An easy way to see if you are breathing properly is to place one hand on the top of your chest, and the other on your stomach. Take in a deep breath and feel which hand rises first. If the top hand rises first, you are not using your full lung capacity. This can cause you to become fatigued more easily. You must learn to feel your bottom hand rise first to ensure your lungs are filling from the bottom to the top. Massage, aromatherapy, and music can also have a calming effect on the body. Allowing yourself just 15 minutes a day to devote to relaxation can help you to feel more centered and in control.

## ADAPTIVE DEVICES

As mobility and ADL's become more challenging, many people need to look toward home modifications and adaptive devices. Many devices are easily affordable and some are even covered by insurance carriers. Bedrails can make turning and getting in and out of bed easier and safer. Elevated toilet seats or handrails allow ease with transfers in the bathroom. A tub seat prevents people from having to precariously stand on one leg while swinging the other into the tub. There are devices to make dressing, bathing, cooking, cleaning, and even recreation easier. Your local PT or medical supply store can guide you to the best products for you and your loved-ones.

Home modifications such as placing handrails in all stairwells, buying lamps that turn on and off simply by a light touch on their base, and removing all throw rugs, can make the difference between safety and serious injury. It would be impossible to discuss all of the modifications that can be made in a home within this article. Your local PT or OT can perform an assessment of your home and make recommendations, as well as provide you with more information on fall prevention.

I am often asked which walking device is best for those with PSP. The answer is that there is no one device that is right for everyone. Everyone presents with different needs at different stages. Generally though, 4-wheeled, rolling walkers with hand brakes and fold-down seats are the best. They tend to have thicker wheels, which are good for most floor surfaces, and are sturdy and durable. The fold-down seat allows people to sit and rest when needed, acting as a wheelchair. Again, I recommend an assessment by a rehab professional for the best device.

## MOBILITY TECHNIQUES

I recommend that everyone have a one-on-one session with a PT to learn the proper ways to transfer to and from the bed, chair or wheelchair, car, bathtub and the floor. There are very specific techniques to follow to ensure ease and safety for those with PSP, and their loved ones. One example is how to properly stand from a chair: 1.) Scoot to the edge of the chair surface first. 2) Next, position your feet behind your knees. 3) Remember, "nose over toes"; lean forward and push up with your arms. 4) Your weight needs to be forward on your toes, if your toes lift up off of the floor while standing, you will probably end up back in the chair! Never begin to walk right after standing; take a second or two to gather yourself and then begin.

Learning as much as you can about PSP and the role that physical therapy plays will help you to stay ahead of the disease. Take an active role in your treatment and focus on your strengths. Join your local support group and stay current on advancements in medicine and rehab. Remember something Dr. Martin Luther King, Jr. said: "The ultimate measure of a person is not where they stand in moments of comfort and convenience, but where they stand in times of challenge."

## When You're the Caregiver of One Who's Ill

by James E. Miller

*Jim's interest in these topics is both professional and personal, having been a caregiver for a family member with a serious illness.*

You may have become a caregiver only recently, or you may have begun a long time ago. You may have taken on this role temporarily, or you may expect to have it as long as both you and the one for whom you are caring are alive. The two of you may live under the same roof, or you may not. You may be close, or you may be at a distance. This experience may be a labor of love, or a labor of loss, or a labor of obligation, or hardly a labor at all.

Whatever your situation, you know that being a caregiver can be a demanding task. Our society idealizes self-sufficiency, yet the very nature of your circumstances may require you to turn to others for help. Your caregiving responsibilities may consume you, absorbing your time and your psychological energy and your physical stamina. You may find yourself overstretched, trying to handle commitments to your job, or to other family members, or to yourself, or, as is often the case, to all of the above. You may feel ill-prepared to assume your role, or ill-equipped, or ill-suited.

It's quite possible you may have a different response: you may feel gratified you can help and quite confident of your abilities. Your concerns may be few.

Because no two situations and no two caregiving relationships are exactly alike, the suggestions presented here are general in nature. Adapt them to fit your individual circumstances. Pass over some ideas and expand others. Do what's right for you. You'll know.

**TREAT THE OTHER AS THE EQUAL HE OR SHE IS.**

The unfortunate truth is this: the other's injury or illness or disability may become such a focus it almost replaces the rest of his/her identity. This process, initiated by family and friends as well as by professionals and strangers, is often unintentional and unconscious. But it is not unimportant. It is a destructive act.

*Continued Page 12*

# Education

## When You're the Caregiver of One Who's Ill Continued from Page 11

The tendency to diminish and dehumanize the other occurs in various ways. You may make decisions for them without bothering to consult them. Or you may treat them as helpless by doing things they are capable of doing on their own, things they even wish to do. You may use infantile language, as in, "What are we going to wear today, dear?" You may find yourself feeling pity rather than empathy.

Never forget: the person you're caring for is just as unique and just as complex as before. They are just as sacred as ever. And that person deserves to be respected and treated as such. Ask yourself: if you do not treat them as a valued equal, who will?

### SOME WAYS YOU CAN BE CONSCIOUS OF RELATING TO THE OTHER AS AN EQUAL INCLUDE:

- Expect the other to maintain as much control over their life as they wish and as they are able. Support them in this.
- Validate what you esteem in the other by what you say and do. Make sure the other knows what you respect about them.
- If the other has changed a great deal as a result of this experience, look beneath the surface and treasure their heart and soul.
- Be accepting of the other's place on their journey, even if it's not where you believe you would be. For starters, you can't know for sure how you would respond in the same situation. In addition, it's not your role to change the other person. Only they can do that.
- Relating to the other as your equal is healthy, but it is not always easy to do. The other may not agree with you—and has that right. The other may get angry—and has that freedom. The other may test you and try to alienate you, to see how committed you are to staying with them. The other may take out their frustrations on you, when they're really upset about something else. You may be a "safe target," or the only target available to them.

### WHEN YOU HAVE TIMES OF STRAIN, HERE ARE SOME WAYS TO HANDLE IT:

- Honestly look to see if you have been treating the other as less than equal, even in small ways. If you have, admit it. Then strive to change.
- Visualize yourself in the other's situation. Ask yourself what you might feel, how you might behave, what you might be tempted to do.
- Listen as non-defensively as you can to any words of anger. If the feelings directed your way are justified, talk them through. Be genuine. If the feelings are really directed elsewhere but they happen to land on you, try not to take them personally. Be understanding.
- Take a break if you feel hurt or impatient or critical. Find ways to unwind.
- Remind yourself what you already know: strong relationships can withstand difficult times. In fact, successfully navigating such times can make your relationships even stronger.

### CARE FOR THE OTHER BY CARING FOR THEIR ENVIRONMENT.

- People who are ill or incapacitated appreciate comfortable surroundings. They like to be in control of their environment as much as they're able. Most people prefer something home-like and personal. They also, more often than not, like their setting to have signs of life and

hope. As a caregiver, you can play a major role in helping to shape an environment that is pleasing, comforting, and fitting.

- The atmosphere you help create and how you help create it will depend a great deal on the site. A healthcare facility will set certain bounds. Staff efficiency, infection control, and access to medical equipment are only a few of the factors determining the look and feel of those spaces. Some facilities can accommodate the preferences of patients and families more than others. Be sure to check first.

Most of the following suggestions apply to a person in a home setting, but some can be adapted to institutional use.

- A nearby telephone is usually desired. Would a portable phone or a speaker phone help?
- Contact with the outside world can be important. Any TV should be at a height they can easily see and the remote control needs to be at hand. A radio, newspapers, magazines, and books can provide additional information and entertainment.
- A bed table or lap desk will have untold uses.
- Writing materials for letters, notes, personal thoughts, and journaling can be placed within easy reach.
- For music lovers, a tape deck or CD player can bring hours of pleasure.
- Pictures and mementos of loved ones, favorite places, and significant life events will buoy the person.
- Adequate sunlight really helps, as well as being able to rest directly in the sunlight a part of each day.
- Incandescent and natural lighting are kinder to the senses. Most fluorescent lighting is less so.
- Adequate moisture in the air and well-circulated air refreshes and cleanses.
- Affirming posters, pictures, and artwork can brighten the room and anyone within the room.
- Bringing nature's beauty inside is a healing act—things like plants, flowers, and other natural objects.
- A window that's easy to see can do wonders for one's healing. What about a bird or squirrel feeder just outside?
- Alternative "resting places" can offer choices of positions as well as scenery.
- A comfortable chair encourages relaxing visits with you or with others.
- The display of a symbol of one's faith may be appropriate.
- Fragrances and air fresheners can be renewing.
- If the other is an animal lover, consider making arrangements for a pet.

Remember there is an energy to a clean and orderly room. Re-arrange bed coverings and straighten personal effects from time to time. But place those effects to suit the other's tastes, not yours. And if the other wants things left exactly as they are, leaving them alone will be another way to show you care.

*(Jim Miller offers many more suggestions for caring for someone who's ill or incapacitated in his book When You're the Caregiver: 12 Things to Do If Someone You Care For Is Ill or Incapacitated. The other half of this book is entitled When You're Ill or Incapacitated: 12 Things to Remember in Times of Sickness, Injury, or Disability. Jim has created various other print and audiovisual resources both for caregivers and for those in their care. James E. Miller, Willowgreen Publishing, 10351 Dawson's Creek Boulevard, Suite B, Fort Wayne, IN 46825, mail to: [jmiller@willowgreen.com](mailto:jmiller@willowgreen.com) 219-490-2222.)*

## Your Guide to Making a Decision Regarding a Feeding Tube

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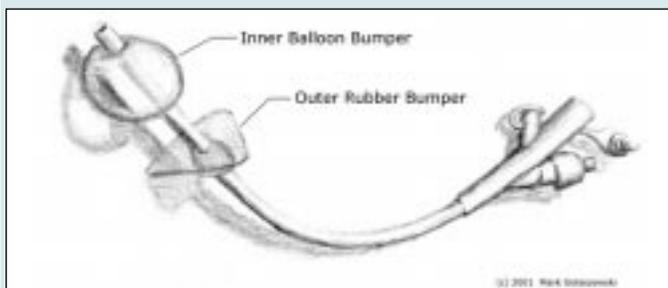
One of the most difficult decisions you may face while living with progressive supranuclear palsy (PSP) is whether or not to have a feeding tube placed. Before you can determine if a feeding tube is right for you and your caregivers, you need to know the facts. More often than not, many people discard the thought of a feeding tube before they even know what it is, or how it is used. The following is a detailed description about feeding tubes to assist you in making a decision as to whether a feeding tube is right for you.

### What is a feeding tube?

A feeding tube is a silicone or polyurethane catheter or tube that is inserted into the gastrointestinal (GI) tract to provide an alternate route for nutrients, liquids or medications. Most commonly in patients suffering from PSP, the feeding tube is inserted into the stomach. There are two types of stomach feeding tubes: 1) Percutaneous Endoscopic Gastrostomy (PEG tube) and 2) Gastrostomy (G-tube).

### How is a feeding tube inserted?

The PEG TUBE is placed while you are under "conscious sedation" (you are medicated so that you will not feel any pain). The doctor places a tube in your mouth, passes it through your esophagus and into your stomach. This tube contains a very small camera which enables the doctor to visualize the inside of your stomach. A small incision is made into the outside of your abdomen leading to the inside of the stomach. The PEG tube is then inserted into the incision into your stomach. A small balloon-type bumper is inflated with sterile water and air to hold the tube close to the stomach wall. Another rubber bumper, located outside the body, is placed on the skin to hold the feeding tube in place. There are no sutures or stitches involved in the placement of a PEG tube. A PEG tube is pictured below.



A G-TUBE is placed while you are under general anesthesia. This differs from the PEG tube procedure in that it requires that you be put temporarily on a ventilator while the tube is surgically placed. Like the PEG tube, there is a balloon-type bumper on the inside of the stomach to keep the tube tight to the stomach wall. The G-tube is secured to the outside skin with a few stitches or sutures to hold it in place. If a PEG tube placement is unsuccessful, a G-tube is placed.

### Main reasons a feeding tube are placed:

1. Recent aspiration (food or liquid in the lungs)  
pneumonia
2. Difficulty swallowing or any change in food/liquid consistency
3. Weight loss (without trying)

### Other reasons to start considering a feeding tube:

1. Difficulty taking medications
2. Difficulty taking enough fluid or water (recurrent dehydration)
3. Increased coughing or choking with food or liquid

### Misconceptions about feeding tubes:

1. "If I get a feeding tube, I will never eat again."
  - For some individuals who can no longer eat or swallow, a feeding tube can act as an alternate means to provide the necessary nutrition to sustain life.
  - However, for those individuals who are still capable of eating, but may not be consuming enough, or are losing weight without trying, a feeding tube can offer a means of supplemental or additional nutrition.
  - Sometimes a feeding tube is placed to offer a means of supplying additional fluid or water to prevent dehydration or to deliver medications, and not for supplying food at all!!
  - For those who are NOT at risk for aspiration, eating IS encouraged after a feeding tube is placed.
2. "A feeding tube is just going to be another burden on me and my family."
  - Daily care of a feeding tube is minimal.
  - A feeding tube can decrease the stress for both you and your caregivers by possibly alleviating the pressures associated with eating or mealtimes to consume adequate food.

**Remember... A feeding tube may be recommended for reasons other than providing nutrition.**

## AMERICAN ACADEMY OF OPTHALMOLOGY MEETING (AAO)

Nancy Brittingham will represent the Society at the Annual Meeting of the AAO in New Orleans on November 11-14 at a booth filled with PSP information. Last year, hundreds of physicians were enlightened by the Society's presentations of the symptoms and diagnosis of PSP. It is vital to educate this important group of physicians who may see symptoms of PSP before anyone else.

# Caregiver Tips

By Ken Todd and Jen Todd Gray

The following are tips we learned in caring for our father. While most of these tips are not new, these are the things that we found to be particularly helpful. Our medical and drug decisions were based on the advice of several research neurologists who are experts in degenerative brain disorders.

### DIETARY SUPPLEMENTS AND MEDICATIONS:

Always consult with your physician before changing your routine.

- Vitamin E (D-Alpha), 1600 mg/day. This was recommended by several research neurologists as possibly being beneficial in patients with degenerative brain disorders, such as PSP, Parkinson's and Alzheimer's.
- Calcium with Vitamin D, 500 mg/day. This strengthens bones to help withstand multiple falls.
- Grape seed extract for muscle soreness. We used the brand name Grapenol by Solaray. Our dad always had soreness when he exercised, and he saw improvement after only ONE dose. We started with 50mg/day and worked up to 50mg 3x/day. It ultimately eliminated his muscle soreness. This was recommended to us by another PSP family, who learned of it from their movement disorder clinic.
- Elavil for saliva control, up to 150mg/day. This prescription drug is actually an anti-depressant, but one of the side effects is dry mouth. Taking this at bedtime reduced the number of coughing/choking incidents at nighttime in the hopes of avoiding aspiration pneumonia. This was recommended by one of our neurologists.
- Botox injections for hyperextension of neck. This reduced choking incidents at mealtime, allowed his head to bend forward so that he could see better when going down stairs, and reduced neck discomfort. Recommended by one of our neurologists.

### AIDS TO HELP COPE WITH SYMPTOMS:

Here are some tools that helped our dad and mom deal with the challenges of daily living. While most of these suggestions may not be new, they were significantly helpful to us.

- Using a wedge when sleeping. This helps prevent saliva from trickling down the throat, which causes coughing / choking when sleeping.
- Pinning a terrycloth hand towel on pillow with large diaper pins with plastic heads. The towel absorbs excess saliva during the night and can be easily changed without having to change the pillowcase.
- Using a bed rail. This helps to prevent rolling or getting out of bed unassisted. We purchased a child bed rail from Kmart.
- Drinking with straws. This helps to significantly reduce choking on liquids. If drinking too fast, just pinch the straw.
- Thickening liquids. Thickening all hot and cold beverages to the consistency of tomato juice also helps to reduce choking.
- Using an electric toothbrush with prescription fluoride toothpaste. The toothpaste (we used brand name Prevident) must be purchased from your dentist or pharmacy. Using the prescription oral rinse Peridex can also be helpful.
- Using wide, wrap-around plastic sunglasses made to fit over regular glasses. These help with light-sensitivity. You can purchase them in an optical shop.
- Using a seat alarm. A weight-sensitive pad used on a seat cushion or mattress will alert a caregiver when the person with PSP tries to get up alone. The model we used was the Chair-Check Sensor Mat from the Bed Check Corporation, Item # 65815-030. Call 1-800-523-7956 to order.
- Using 1/2" heel lifts in shoes. This helps to shift weight forward to prevent falling backward.

- Using a sturdy leather belt (1 1/2-2" wide) for a walking aid. In addition to eliminating the need for two belts, our father preferred to use this instead of a gait belt because it was less conspicuous and more comfortable. (Our mother preferred this too.)
- Using a heavy-duty walker. A regular walker can be dangerous since it doesn't prevent falling backwards. We first learned of a heavy-duty weighted walker from the PSP Advocate. The model we used was called the Oscar from the Shirley Walker company. Call 1-800-848-WALK to order.
- Transportation. We found using our Jeep Cherokee made it much easier for our dad to get in and out of the car because it sat much higher than a sedan.
- Handrails. Install in multiple areas in the home as necessary.
- Entertainment. Our dad listened to audio books and CDs when he could no longer read. Your local library should have many available, and may even have a delivery service.

### EXERCISE AND PHYSICAL THERAPY:

Every neurologist and physical therapist our dad saw said that his exercise and physical activity significantly improved and prolonged his mobility and flexibility. They felt he did better longer because of his exercise and strength conditioning. Shortly after being diagnosed, we contacted a local physical therapist to develop a comprehensive exercise and strength training routine. This was our father's routine:

- Physical therapy: One-on-one sessions with the PT for one hour two to three times per week.
- Flexibility class: One-hour class two times per week.
- Home exercises: In addition to class and physical therapy, he had a daily routine of home exercises using resistance bands and free weights. In addition, he did facial exercises, tongue exercises, and neck exercises to keep as much mobility as possible.
- Stationary bicycle: 30 minutes two times per day. It is helpful to watch TV while riding to help pass the time.
- Walking: For the first three years after diagnosis, our parents walked 2 miles, 5-7 times per week. After that, they walked fewer times per week for shorter distances. When our dad could no longer walk long distances, he continued to ride the stationary bike.

Our dad hoped to continue to be a part of the research process that would ultimately lead to the "answer" for PSP. He is doing just that today. His brain was donated to the Mayo Clinic brain bank for PSP research. We feel that finding the cause and cure of PSP is within reach if everyone associated with this disease contributes to the effort. Our mom and dad were very determined and courageous in fighting this disease. Our dad never lost hope, and we're still not giving up.

The following items can be purchased from The Lighthouse Catalogue for the visually impaired. Call 1-800-829-0500 or visit <http://www.lighthouse.org> to order.

- TV remote controls: Universal Remote - big numbers and buttons with lighted keypad. Item #3022 - \$39.95
- Voice Activated Remote - Item # 1760 - \$59.95
- Talking wristwatch (our dad loved this): Leather Band: Item # men's 1570, women's 1571 - \$49.95, - Chrome Band: Item # men's 5531, women's 5532 - \$49.95
- Telephone: Big Photo Phone - press a large photo button and the phone automatically dials that person. Item #2134 - \$39.95
- Reading Aid: Closed Circuit Television System - Handheld scanner magnifies text and pictures on to TV screen. Item # 7201 - \$449.

## Ask the Doctor

By Lawrence I. Golbe, M.D.  
Society Medical Advisory Board Chairman

### Question:

I found your site following a search. We heard today that the brain can be affected by aluminum. My mother-in-law died of PSP some 14 years ago, when little was known about the disease. We have often wondered whether there could be a link to the intake of aluminum sulphate. As their water supply was direct from the hills, my father-in-law used to add tablets of aluminum sulphate. (I understood that he did so to harden the water which was very acidic) There were always large jars of the tablets in the kitchen. My mother-in-law would be the main consumer as everyone else was at school, college or work. I feel it would be of interest to know – if only to prevent others from having this dreadful disease. To see an active, knowledgeable person degenerate to someone with a 'trapped body and brain' is something that I would not wish on anyone.

Many thanks, Pauline B.

### Answer:

Thanks for your interesting observation. I was able to find 2 studies in the medical literature that measured the aluminum content of brains of people who died with PSP. They disagreed as to whether aluminum was present. There have been no published attempts to look for a link between PSP and actual exposure to aluminum during life.

As you may know, about 15-20 years ago, there was suspicion among scientists that aluminum in cooking pots and deodorants was the cause of Alzheimer's disease. That has now been disproven, but it's still true that injecting aluminum into the brain of a laboratory rabbit stimulates the formation of neurofibrillary tangles resembling those that occur in the brains of people with PSP and Alzheimer's.

It's difficult to do a survey of aluminum exposure, as people usually don't know the aluminum content of their diet and drinking water. You also have to consider the content of the dust in their houses in these studies – and you have to consider all of the houses they lived in since birth, a daunting task. One way around this that I can think of is to identify genes that control the ability of the body to get rid of excess aluminum, and to see if these genes are any different in patients with PSP than in people of the same age without PSP.

I'll definitely keep this issue in mind in designing future studies of PSP.

### PSP FAMILIES NEEDED

Families needed with living persons diagnosed with PSP for local media stories to help increase awareness of PSP.

Please offer your family for a local story. You will be connected with a medical reporter who will come to your home.

To help please contact:  
Ceri Williams  
15445 Ventura Blvd., #46  
Sherman Oaks, CA 91403  
T: 818 343 3259  
medianet@earthlink.net

**MARK THE DATE!**  
**The National PSP Symposium for  
Persons with PSP, Families,  
Caregivers and  
other Allied Health Professional**  
**May 17 and 18, 2002**  
**Baltimore, MD**  
*More details to follow*

### WE NEED YOUR HELP!!

The Society is seeking potential corporate / business sponsors to help support the National PSP Symposium. Large corporations, both national and regional, including department, drug, and supermarket chains, restaurants, banks, and consumer products manufacturers most often have "departments of corporate giving" or their own foundations through which they funnel charitable gifts to the community, including cash grants to non-profit advocacy organizations for educational conferences and other worthy projects.

Look around your community and help us to identify these hometown corporations. If you know of any potential sponsors please contact the Society for PSP at 1-(800)-457-4777, (410) 486-3330, FAX (410) 486-4283 or email [spsp@psp.org](mailto:spsp@psp.org).

Please provide contact information, the names of the president/CEO, sales/marketing directors and the person in charge of corporate giving.

Thank you for your assistance.

## Upcoming Events

### OCTOBER IS PSP AWARENESS MONTH

October 2001 is designated as our Second Annual PSP Awareness Month. This is the time that we are asking all persons affected by PSP to join together nationally and educate others about this devastating disease. We are asking you if you are able, as Society liaisons and friends, to plan some activity that will raise awareness of PSP.

### NEW ORLEANS AFTERNOON OF CARING & SHARING

The Society for PSP will be sponsoring an afternoon of "Caring and Sharing" for persons with PSP and their families. A movement disorder specialist and a speech and language pathologist will be attending the meeting. It will be on Saturday, Nov. 10, 1:30 - 4:30 pm at the New Orleans-Best Western Landmark Hotel, 2601 Severn Avenue Metairie, Louisiana 70002. A registration brochure will be mailed during the first week of Oct. to addresses in the state area. If you have not received a brochure by Oct. 15 and wish to attend, please call the Society office at 1-800-457-4777 or 410-486-4283.

# Support Groups

*PSP Support Groups will encourage and organize activities that foster communication, exchange and interactions of comfort and mutual benefit to Support Group members who are family, friends, caregivers and persons with PSP. The Society would like to thank the following Support Group Leaders and Communicators who take their time and show their concern by sponsoring support groups, and phoning/visiting PSP families. If you would like to help start a support group in your area, please call the SPSP office at 1-800-457-4777. For information on support groups in your area please contact:*

## ARIZONA

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RENAE VALDES-BIRCH  
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## ARKANSAS

PATSY CUNNINGHAM  
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# News From Support Groups

## HOUSTON



For the one-year anniversary meeting of the Houston support group, a merry band of music makers shook up the usual meeting pace to mark the special occasion. Otherwise known as the Over the Hill Gang, this personable group of free-lance musicians, committed to bringing music to the lives of others for the sheer joy of it all, rendered their sing-along, toe-tappin' tunes with talent, grace and charm. The Gang, most of them senior citizens themselves, performs fee-free for any organization that requests their services, but they find special pleasure, they say, in playing gigs for hospital groups and nursing home residents. Iris Rushing, the Gang's skilled accordionist and wife of band leader, Earl Rushing, has been diagnosed with multiple system atrophy.

The Houston support group has continued to maintain an aggressive speaker program which this spring included:

Lee Ann Harry, RN, BSN and Community Education Liaison for Houston Hospice, Inc. described the growth of the modern hospice movement from its 1960s inception in a London residential suburb to what it is today, a coordinated and comprehensive program of care for critically ill patients for whom aggressive and curative treatments are no longer practical or desirable. Important concepts of hospice care that Ms. Harry emphasized are: 1) Hospice cares for the entire family, not just for the patient; 2) Spiritual "care" never reaches beyond the comfort level of the patient and the family; and 3) With hospice, life's final days are as tranquil and as painfree as possible.

Helen Cohen, Doctor of Education (Ed.D) in Occupational Therapy and Rehabilitation and also Associate Professor and Director of the Baylor Center for Balance Disorders, discussed the benefits of having a balance evaluation. She walked us through what to expect during the evaluation process and stated the importance of asking outright whether or not the therapist can, in fact, design a program of therapy that will improve the patient's balance. Sometimes the answer will be no, she said. Warning against the dangers of falls for people of any age, Dr. Cohen strongly suggested that all bathrooms, where many falls and serious injuries occur, should be equipped with safety grab bars.

Jeff Sherer, Doctor of Pharmacy and Clinical Pharmacy Specialist for the Baylor College of Medicine's Geriatric Service, discussed steps to take to make certain we get the greatest benefit from the prescription drugs we take and repeatedly emphasized that doctors often do not explain to patients much about the drugs they are expected to take and, therefore, it is essential that the patient ask the right questions: What kind of drug is it? What is it supposed to do? What side effects might occur? Is there a generic or another similar drug that has been on the market for some years that will provide the same benefits for less money? Dr. Sherer strongly suggested buying prescriptions at a single pharmacy so that the potential for adverse interactions is more readily detectable. He cautioned care in the purchase of herbs and nutritional supplements because they are not regulated and there is no certainty that a bottle actually contains the product and strength noted on the label in most cases. This problem can be minimized to some degree, he said, by purchasing supplements from only reputable manufacturers who would not want the adverse publicity that would attach should the company be charged with improper labeling. Dr. Sherer also offered the interesting fact that drug manufacturers pay to have their drugs listed in the Physicians Desk Reference (PDR). If a drug is not listed in the PDR, it may be too new to have met the publication deadline or its manufacturer chose to not list it for some reason.

Wesley Wright, an Elder Law specialist, focused on the subjects of Advance Directives, Medicaid Planning for Nursing Care, and Guardianship for the Incapacitated during his presentation. Under Medicaid planning, Mr. Wright specifically addressed the group on the use of a Qualified Income Trust (QIT), an income-sheltering device that enables

an individual with assets to legally qualify for Medicaid-paid nursing care without having to spend assets down to the poverty level. (The QIT income sheltering device, known in Texas as a Miller Trust, may not be available in all states.) In fact, Mr. Wright cautioned against spending down or distributing assets without legal advice because such actions could result in penalties being imposed by the state in the form of waiting periods, which could then leave an individual who might have otherwise qualified under Medicaid exposed to the high retail cost of nursing care for the months of disqualification.

Advance Directives include the Powers of Attorney for Property, the Durable Medical Power of Attorney, Directive to Physicians or the Living Will, and the Declaration of Guardian in the Event of Incapacity. Mr. Wright stressed the importance of every individual having advance directives in place prior to the time of any incapacitation to ensure that an individual's personal wishes are observed and to also lower the probability of the need for guardianship procedures which are far more complicated and to be avoided, if possible, with advance directives. Two points to remember according to Mr. Wright are: 1) Do not assume you cannot obtain nursing home Medicaid because you have assets. Medicaid is not just for poor people; and 2) Get your advance directives in place. Doing so could save your estate a lot of money.

## One Year Anniversary of the Houston Support Group

# News From Support Groups

## October is PSP Awareness Month

### Minnesota Support Group Plans Second Annual PSP Awareness Dinner

The Minnesota Support Group will have their second annual dinner Thursday, October 25, 2001 for PSP Awareness Month. It will be held at the Mayflower Congregational Church on Diamond Lake Road and Interstate 35W at 6:00 PM. We will have professionals available to answer questions and a social time together. A flyer will be sent out to all who receive the Advocate with more specific information. Reservations can be made by calling Charlotte Tripet, 763-546-1695 or Pearl Johnson, 651-257-1843. We look forward to meeting all of you who are traveling the journey of PSP or have traveled the journey in the past. Please come and support each other. Money raised from the dinner will go to support PSP research

### Three Walkathons Scheduled for October 20

The Society invites its friends and supporters to participate in area walkathons to raise awareness and funds for PSP.

- Baltimore, MD, 9:00 am-12 noon, Carroll County Farm Museum, Westminster, MD. in memory of William DaRoja. 2½ miles through scenic, historic Westminster (suburb of Baltimore). For more information call Jodi DaRoja at 410-751-1615.
- Los Angeles-Torrance, 9:30 am, 243 S. Broadway. Scenic walk along beautiful Redondo Beach, 2, 4, or 6 miles. For more information call Carolyn Cheek at 310-534-8623 or e-mail cheekspeak@mindspring.com.
- Sacramento Valley-Fair Oaks Park in Sacramento County, 10:30 am-2:00 pm, Fair Oaks Boulevard, 2 miles. For more information call Carol Platt at 916-332-6041.



*The publication of the PSP Advocate for the Years 2000 and 2001 have been generously funded by Jay Troxel in memory of his beloved wife, Eloise H. Troxel*

## NORTHERN VIRGINIA



Back Row:

Maggie Bloom, Howard Rosen, Janet Baldwin, Kathy Sands

Front Row: Virginia Orr, Fran Eck, Terry Jenkins

## ALTERNATIVE SUPPORT GROUPS

By Fran McMahan  
Rochester, Washington

PSP crept into our lives by inches but the havoc it wreaked was immeasurable. We wandered, dazed, in a wonderland of medical mystery, while PSP relentlessly ravaged my husband in a 16 year-long battle. During the most grievous times, I held him close and vowed that his ordeal would not be in vain.

One year after his death, I began to fulfill that promise. Asked to speak at a Christian Business and Professional Women's luncheon, I decided to share our story. Present, among others, were medical personnel who insisted, "You must get your message out" and launched me into speaking around the state. With this unexpected platform, I narrowed my focus to address key issues facing caregivers.

At the time, I had never met another person with PSP. Indeed, many doctors knew even less that I did about the disease. So I worked with support groups for several other brain diseases, finding the same pain among all the caregivers.

Several years later I came across a PSP patient quite by accident. Her caregiver said that a Society for PSP had been organized and gave me the address. I called at once and offered my services. Rosemary Taylor contacted me and asked me to cover western Washington as she had been trying to handle the entire West Coast alone. I explained my work to her and agreed to be available for PSP caregivers as patients turned up in this area. I also continued with my other responsibilities for some time.

During my own caregiving days, I was unable to find suitable help and for the last eight years of my husband's life, I was necessarily homebound, except for brief trips to a store. Other than my elderly parents, who were in their nineties, I had no family in the area.

That circumstance was the crucial factor that eventually led to my primary pursuit of working with isolated caregivers with no available families. An encounter with a distraught

*Continued Page 19*

## ALTERNATIVE SUPPORT GROUPS

*Continued from Page 18*

woman at a seminar where I was a participant was the catalyst. Her eyes and her demeanor said “hopeless” and her cryptic monotone replies seconded it. Clearly, that was a woman at the breaking point. I made a visit to her home the following day.

Her husband was an advanced Alzheimer’s patient and they had no family. Grasping for answers, I asked if they were affiliated with any church. Having previously been a Director of Christian Education, it was a natural question for me to ask. They had attended a church some time back, and with her permission, I arranged to meet the pastor. He provided a list of names of woman I could contact to ask for help.

Meeting with them privately, I rallied several women to commit to a 12-week experiment: I proposed to bring a support group to the caregiver’s home. After much discussion, with the caregiver making all the final decisions, we decided on a weekly luncheon every Tuesday. We brought in all the food and took out all the mess. We had a time of fun and fellowship—lots of hugs and laughter. When the 12 weeks were up, all of the women recommitted except one and she provided a replacement. Unexpected perks were that some of the husbands became involved and soon a porch and ramp sprouted on the house. As folks came to know this caregiver, sympathy turned into genuine caring. My greatest joy was seeing this couple’s last days spent surrounded by loving friends.

Of course, among my colleagues, the consensus was, “This will never work. You can’t use support people who know nothing about the disease and the problems.” Yet, it did work! Normal support groups are ideal when one can attend them but caregivers that are isolated at home need more than just knowledge. They need companionship and caring. In fact, they are thrilled to talk about something other than the illness. I was available for the nitty-gritty, day-by-day caregiving questions. (I facetiously said that I could have passed the nursing boards by the time my husband died.)

With such success in the experimental group, it was a given that the others would spring up. Over time, I began to pick out leaders in the groups and then move on to start new ones. I continued to attend established meetings, rotating among them. Knowing that leaders may burn out without encouragement, I brought them together at my home over salad luncheons to discuss potential problems and toss around new ideas.

I live on five acres with plenty of space for RV’s and I began hosting a weekend planning retreat here each September. We planned an entire year at a time and worked together making decorations. We celebrated all caregivers’ and patients’ birthdays and anniversaries. We made every holiday festive with decorations and treats. When appropriate, we brought in Christmas trees and decorated them, always making sure to handle the after-Christmas cleanup. Undoubtedly, my previous work in leadership training and retreats birthed my methods and elaborate plans are not necessary. More than the jollity, caring is what touches the hearts.

The point is, everyone has unique experience and abilities. The key here is not necessarily to duplicate what we did, but to “see a need and seek to solve it.” Certainly, our meetings

are not for every caregiver. Some very private or burdened people would be overwhelmed with such an idea. For those it fits, it works very well. There are people everywhere who would gladly give a few hours each week to support someone in need, but they have no idea who they are or where they are. Given the opportunity and shown how to help, people blossom.

Women caregivers were my focus in the alternative support groups. I’m sure, however, that some type of plan would work for men caregivers who may need friendship. While I often worked through church groups, I believe that any civic or other group could do the same thing. Nothing says that there must be weekly meetings. We found there was a need for socialization and it suited our caregivers, but bi-monthly or monthly meetings of some type could be fine.

While every volunteer originally committed to be there once a week, take part, and support the caregiver, we found that it never stopped there. Granted, we never had another porch and ramp built, but we had families adopting the caregivers and patients and doing things families would normally do. We met from mid-September to mid-June. During the summer we each took a week to be responsible for a home visit and phone calls. Many women outdid themselves to make their weeks a special time.

Were there problems? I didn’t encounter serious problems. There will always be well-meaning but unreliable volunteers, and a leader must be on top of things and ready to fill in at a moment’s notice. Even that was unusual. Folks seemed to enjoy the groups and feel that they were needed.

Although known PSP cases were scarce here during those years, after the Dudley Moore program aired, patients began turning up in greater numbers. Sadly, now there are enough in our state to form some regular support groups. Time marches on, however, and like old soldiers, we old-timers do fade away. I have retired and while my heart will always be in PSP work, I limit my support to home now.

When caregivers, who are without computers contact me, I monitor the listserv and the Internet and print off pertinent information for them. I write to several caregivers, continuing as long as they choose. When the PSP Advocate comes out, there are calls from new caregivers and I try to help them or direct them to help. There is so much to offer caregivers now. How wonderful to have a Society, literature, listserv, and a newsletter available to them!

Recalling my bleak days of trying to hold the PSP monster at bay in ignorance and isolation, I thank God that I lived to see the PSP Society bloom and flourish. Now I look forward to celebrating that day that PSP is defeated.

I think of my husband, enduring unspeakable indignities from trial and error, as one of the pioneers who helped blaze a trail for those who would come after him and benefit from the knowledge gained in it—and I know it was not in vain.

“My greatest joy was seeing this couple’s last days spent surrounded by loving friends”

### DISCLAIMER

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

## Caregiver Reflects On Her Experience

By Barbara Leitenberg  
Burlington Free Press, Milton, VT  
June 11, 2001

In 1995, John Clements of Milton was told that he was suffering from progressive supranuclear palsy (PSP), a rare neurodegenerative disorder often mistaken for Parkinson's disease. With this diagnosis, Clements' wife, Janice, joined the uncounted ranks of "informal caregivers," the friends and family members who provide over 75 per cent of the long term care in the United States.

Last month, Janice received the Rolfe Stanley Caregiver Award from the Vermont Alzheimer's Association. She was recognized as a caregiver representing many other Vermonters "who silently, patiently, compassionately, lovingly, creatively provide care day after day after day to someone who really needs them. They do this without thought of reward. And they do much more than they probably realize to inspire and influence others."

For five years, John Clements needed increasing care as the disease progressively affected his vision, handwriting, balance, coordination, speech, and swallowing. Until January 2000 when he died, Janice cared for him at home and received an education in the complexities of PSP, Medicare, community services, and both their own personal needs. The most important thing she learned, Janice says, is to stay connected and share your experience with others.

"Many families retreat in the face of a long term illness or frailty, but the support and caring of others is ultimately the thing that will sustain you," Janice says "Don't wait to include others until later when the situation may be more frightening. When people offer help in the beginning, let them do ordinary things that you still can do yourself - like trips to the barbershop or dentist or just visiting for a while. Let them get used to being with a disabled person, and let the person learn to be comfortable with other helpers."

When John's brother, an avid garage sale visitor, asked what he could do, Janice suggested that he take John with him to the sales on weekends. "It was an eagerly anticipated outing for John and a break for me," she says.

Janice urges caregivers to join a support group, talk to family, friends and neighbors, and talk to your clergy. "You can never predict what kinds of unannounced help is available. There will come a time when you can't do it all. No one can do it all," she says.



*John and Janice on a cruise during the early stage of PSP*



*John and Janice mid-PSP*

Currently Janice is still facilitating two support groups that helped her and John. One is for caregivers of people with neurodegenerative disorders. The other is for couples, where caregivers and their afflicted family members meet together for social fun and to share information. She also serves as a member of the Board of Directors of the Society for PSP in Baltimore, helping start support groups all across the United States.

At these group meetings Janice shares the things she has learned, like the value of the UVM Dana Medical Library. For \$3.00 /month, you can receive monthly research updates on any selected disease or condition. The National Library for the Blind offers a free service, mailing taped versions of the books and periodicals in its huge catalog. The Clements found this invaluable as John's vision failed. "John spent many enjoyable hours listening to books on tape," she says.

"If I had to give up all the services we used except for one, I would choose to keep the Adult Day Center," Janice says. ADC is a day program with flexible and week-end hours, run locally by the Visiting Nurses Association. "It's the best value for care for the money, providing activity and stimulation," she says. "John enjoyed the socialization, activities, and the purposeful routine. I had a chance to recharge my batteries and be involved in activities outside home."

As John needed more and more care, Janice found that she had to juggle numerous providers and funding sources. She learned to ask for help. "Call your local agency on aging," she advises. "These people can lead you through all the benefit programs, especially Medicare. VNA staff helped us appeal two Medicare denials. Be sure to get your primary care doctor to be your partner and support you."

"Most of all, we learned to make the most of every day, keep living," Janice says. In the last year of John's life, the Clements went to Hawaii. They traveled with a family member, had wheelchairs available at either end of the trip, and reserved some time at a local adult day center. "We had a wonderful time in a place we both loved," Janice says.



*The whole family except Janice (photographer), late-PSP*

### My Sister Lois

I'm writing this with many mixed emotions... emotions of sadness, joy, loneliness, gratitude, and thankfulness. There were three of us... all sisters four years apart in age. I was the youngest, my sister Lois was the middle child and Thelma was the oldest. We grew up in a family of very modest means, but one that was not lacking in love and faith. We had a devoted mother and father. We all married, had children and dealt with life's ups and downs as most people do. But, this story is about Lois who had her share of life's heartaches. This story is about a sister that we loved dearly... one who fought and lost her battle with PSP on July 8, 2001.

Lois had been a widow since 1975. She raised her three children. Victoria, Vince and Valerie. She had two adorable grandchildren, Micaela and Shannon. When Lois started with this illness, her doctors had originally diagnosed it as Parkinson's disease. It took two more years before the final diagnosis of progressive supranuclear palsy was given. Initially we were relieved when the neurosurgeon gave us the diagnosis, but we had to find everything we could about PSP... we had to know! We searched the Internet, contacted the PSP Society, read the PSP newsletters (which were most helpful) and any other articles we could find. We then began to understand what a devastating disease this was. It was a time of awakening for all of us, but it was also a time for us to come together and to give her all the love and support we could so she wouldn't have to travel this road alone.

Slowly we watched year after year as the disease took over her body. There were many falls, several broken bones and trips to the hospital. There was the slurred speech, choking, and inability to walk, to write, and then to speak. When being at home compromised her safety, her children had to make the decision to admit her to a skilled care facility. Her daughters were not able to care for her anymore, as they couldn't be with her 24 hours a day. Through all of this Lois never lost her faith, her stamina and her spirit. We included her on every decision that needed to be made, no matter what the situation was. It was important for her to be involved in every aspect of her life and the lives of her family. This is critical for people suffering with PSP. It keeps them connected - it helps them to feel that they are still a part of life.

The journey was getting harder for her and for us. We knew it was time to seek out a support group, and luckily one was formed in the very nursing home where Lois resided. This was a tremendous help to Lois and to all of us. She wanted to go to every meeting. This was important to her. We could connect and listen to other people's stories. We knew we weren't alone.

Losing her ability to speak was very difficult for her. We tried several communication aids, but her hands were somewhat contracted and she wasn't able to operate the keys on a computer. The only thing that worked was a homemade alphabet board. It was very simple... just a board with large letters on it. When she could see well, she would point to the letters, and we would then try to form sentences. It wasn't always easy for her or for us, but we so wanted to maintain communication with her, as this was so essential to her. She began to lose sight in her right eye, and wasn't able to see the board. This did not deter her in anyway. She memorized where the letters were located, and would then hold up her fingers, i.e., 1 would be row one, and 2 would be the letter B, etc. And this is how she communicated until her death.

The feeding tube came two years ago when it became evident that she wasn't able to swallow at all anymore. Another difficult decision, but one that Lois herself made. One "fun food" that Lois loved was chocolate, and so we would bring in tiny pieces so she could put it under her lip just to have a taste of something good.

Through these last nine years, Lois also endured the loss of her only son in April 1999 and our mother in January 2001. She had expressed to us many times that she didn't want to die before Mom. God was good... he heard her! We always thought that when the time came Lois would die from complications of pneumonia, as we knew this took many PSP patients, but this wasn't to be. Lois went to sleep on July 7, 2001, and at 4:30 am on July 8th when the nurse went to check on her feeding tube, she was gone. She peacefully slept away. Again, God was good!

Lois has left a legacy to all of us, and especially to her two daughters and granddaughters. This was a difficult and long journey, but it was also a time for our family to come together and to be there for someone we loved very much. Lois taught us how to live, how to cherish what we have and not question what we don't have. She taught us about courage, about faith and love of God. We have all been blessed to have her in our lives, and we will truly miss her. She is our hero!

Written in loving memory of Mary Lois Onorato  
By Peggy Stanton, sister - Pennsylvania  
July 18, 2001



Mary Lois Onorato with her sisters Peggy (left) and Thelma (right) at her son Vincent's vault.

## My PSP Story

By Jan Harrison – Rhode Island

We had known for some time that something was wrong, but we weren't sure what. Then in March, 1997, we learned that my husband had PSP. It didn't even sound like the name of a disease and we certainly had never heard of it. After hearing that it was a degenerative brain disorder, our world seemed to crumble. We had both recently retired and were looking forward to traveling, visiting places that we had never seen.

Instead, we spent our time going to doctors and physical therapists. At times Joe would balk, but I kept telling him that even though there was not cure he had to fight it. And he did try.

Coincidentally, our daughter Kelley, a psychologist, then working in Baltimore, discovered that the Society for PSP was located there. She became involved, sent information to family members, and is now serving on the Board of Directors.

As if things weren't bad enough, in August of '97, Joe fell and broke his leg. While recuperating, he developed an intestinal problem resulting in colostomy surgery. When he came home, needless to say, the task of caring for him was overwhelming. I will be forever grateful to the visiting nurses who came every day and assisted me.

After he was well enough to travel, we proceeded with our previously made plan to move from Florida back to Rhode Island, where we were from originally. For almost three years, I cared for him and sadly watched how he regressed. All the symptoms that we had heard about appeared: difficulty swallowing, talking, focusing, and of course, walking. I think one of the hardest parts was that we could no longer converse.

In August, 2000, Joe fell again while he was trying to get from his bed to his chair. He injured his back. Another trip to the emergency room. This time he did not come home. Now, 8 months later, he is in a long-term care hospital. He has a tracheotomy and a feeding tube. His sisters, brothers, Kelley (who now lives in RI as well) and I visit him often. Our sons, living out of state, visit as often as they can. We communicate with him via a dry-erase board. (He can still write, though not always legibly.) We've been able to bring some joy to his life by organizing sing-a-longs at the hospital on Christmas and St. Patrick's Day. He truly enjoyed the music. (He was once a beautiful singer.) So, we plan to have another one soon. The other patients and hospital staff enjoy them too!

There are very few positive things I can say about his situation except that his family loves him dearly and he knows it. And we are so grateful for the existence of the Society for PSP.

## Feeling Responsible

Janet Edmunson, M.Ed. – Massachusetts  
Wife of Charles, who died of CBGD on May 11, 2000

Feeling responsible for Charles, I was almost ready to call Charles' friends and make them feel guilty for not coming by—until I talked to Mike.

Mike was one of the Hospice volunteers that spent an hour with Charles on various late afternoons between the morning and evening shift of aides. I usually didn't see him, as I was still at work. But the one time I met him I remember noticing

his comforting smile and voice that shared the deep passion of his role as a Hospice volunteer.

One day I arrived home early and bumped into Mike as he was leaving. We chatted at the front door on his way out onto the porch. His words helped me through this anxious time.

While people from Charles' work (especially some of his very closest friends) had visited Charles quite regularly throughout his illness and subsequent retirement, I recently noticed that they weren't coming much at all anymore. My heart ached wondering if Charles recognized their absence and if he felt lonely and abandoned.

To Charles, nothing was more important than relationships. During his first year home on retirement, a number of friends committed to seeing him. Bob, his company's founder, came the most regularly and shared management books with Charles, as well as his infectious laugh. Michelle from the Framingham plant also visited often, dragging one of the other managers or workers with her. While Charles' speech slurred, he clearly came out with his famous "Wow!" when someone said or read something profound, which reinforced the reward each felt in visiting.

As the disease progressed and Charles could no longer talk, I understood that it was difficult for his friends to visit. Even I found it hard to carry on a one-way conversation with Charles. I can imagine how awkward his friends felt.

As Mike was leaving after spending time with Charles, I thanked him for visiting and mentioned that the Hospice volunteers now played an important role as friends for Charles. I told him that most of his work colleagues and friends had stopped coming by.

Mike's eyes tenderly focused on me and he said, "I understand." Then he revealed a personal story that helped me to understand, too.

"I have a very good friend that has MS," he said, leaning on the frame of the open front door. "Prior to my friend's illness, we'd get together with three other buddies quite regularly, to play cards, talk and enjoy each other. We were really close." Then Mike's eyes looked away and I felt them reveal his guilt. He said, "As time went on, my friend's MS progressed, keeping him in bed, unable to do much of anything. We all had a hard time talking to him and understanding him. His other friends stopped visiting. I tried to keep going, but my visits got farther and farther apart. Now I barely can get myself to go once every five weeks or so. I find it too painful to see my friend so helpless."

But then Mike said, looking back at me with his eyebrows furrowed as if a new truth was dawning on him, "While I have such a difficult time visiting my very closest friend with MS, I have no problem being with Charles in his condition. Maybe it's because I don't have that prior close relationship with him, like I have with my friend."

Now my eyes lit up with new awareness. "That explains why many of Mike's friends who were so good at visiting him earlier in the disease haven't been able to come by now," I remarked. I sensed the reality that Charles' friends had probably stopped visiting because it was too painful and difficult for them to see Charles deteriorating so much.

After Mike left, I determined not to make the proactive phone calls to encourage visitors that I had previously committed to do. And I began to celebrate the strength of character those that did visit exhibited—enduring the suffering of seeing Charles so helpless. I believe Charles rewarded their efforts with the sparkle and intensity of his eyes looking directly into theirs—his only way to communicate.

# Support - Our PSP Stories

## Running For A Cause

By Ken Todd

When I got into the 2000 New York City Marathon, I decided to run in honor of my dad, who was fighting PSP. My goal was to raise money for the Society for PSP to help fund research. This experience taught me that it is easy to raise money by following a few simple steps:



- Contact the Society for PSP. They will provide you with fact sheets and credit card donation forms.
- Compose a simple letter describing PSP, your connection to the disease, and how you plan to raise the money.
- Put together a manageable list of family, close friends and colleagues. Send the letter, fact sheet, and credit card form to them. You can enclose a self-addressed stamped envelope to make it easier for the giver.

I was amazed that I was able to raise over \$3,000 in about six weeks just through this relatively small network of close friends and family!

I will be running the NYC Marathon again this year on Sunday, November 4, 2001. While my father passed away this year, my family and I are still committed to help find a cure for this disease. If anyone would like to support my 26.2-mile run this year in memory of my dad and to help others with PSP, please send a check payable to the Society for PSP (or SPSP) to:

Ken Todd  
412 Amsterdam Avenue, #3N  
New York, NY 10024



*Ken Todd and Jen Todd Gray (with their father, Dr. William R. Todd, orthodontist and life long resident of Petoskey, Michigan) believe that when you make your living from a community, it is important to give back with service - and he did."*

## Philadelphia Symposium

Continued from Page 8



*Janice Clements, member of the Society's Board of Directors with Sheryl and Gail Jaffe at the PA Symposium*

The Society for PSP thanks all the special speakers at the PA Symposium.

- Gwyn M. Vernon, MSN, CRNP - Neurology Nurse Practitioner Lankenau Hospital, Wynnewood, PA  
Clinical Faculty  
University of PA School of Graduate Nursing  
The Society for PSP Board Member
- Howard I. Hurtig, MD  
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- Ame Golaszewski, MS, RD, CNSD  
Clinical Nutrition Support Services  
Hospital of the University of Pennsylvania, Philadelphia, PA
- Stephen M. Gollomp, MD  
Clinical Associate Professor of Neurology  
Thomas Jefferson University Hospital  
Private Practitioner, The Lankenau Hospital, Wynnewood, PA
- Millie Bickling, MSW - Licensed Geriatric Social Worker  
Genesis ElderCare
- Janice Clements - Research Administrator (Retired)  
Caregiver  
The Society for PSP Board Member



*Anneliese and Gunnar Hausmann from Westlake, Ohio attend the PA Symposium*

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Wayne Hart - In Memory of James Hestad  
Virginia Hathy  
Leo Hawk - In Memory of Francis Stulpin  
Annie Hayashida - In Memory of Ross Hayashida  
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Walter Hecht - In Memory of Irene Hecht  
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Michael Henderson - In Memory of Kathleen Hodge  
Pam Henderson  
Carlye Henley  
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Patricia Houser - In Memory of Francis Houser  
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Monty Ichinaga - In Memory of Lester Ichinaga  
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Charles Keegan  
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William Kelly  
Randy & Madeleine Kerber - In Memory of Margaret Rose  
Geraldine Kikuta - In Memory of Ross Hayashida  
Toshio Kikuta - In Memory of Ross Hayashida  
James Killian - In Memory of William Parker  
Joan King - In Memory of Thomas E. King  
Philip M. Klauber - In Memory of Delta June Klauber  
Stanley Klotz - In Memory of Thomas P. Brassil  
Barbara Knighton - In Memory of Ted Knighton  
Shirley Knoll - In Memory of Edward Knoll  
Henry & Shirley Koening  
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Ysabel Lacache - In Memory of Edward Knoll  
Amedeo & Maria Lamberti - In Honor of Alda Mocogni  
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Larry Hulsey & Co. - In Memory of Senator Tom Haywood  
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Mark LeDoux  
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William Murfey - In Memory of Betty Joe Mayes Murfey  
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Michael Musko - In Memory of Gertrude V. Musko

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Continued

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Napleton's River Oaks Cad - In Memory of Bessie Miller  
Shelly Newman - In Memory of Rose Newman  
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Wayne & Isabelle Nishimoto - In Memory of Ross Hayashida  
Francis Nizzari  
Mike & Milta Nizzi - In Honor of Alda Mocogni  
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Stephanie Normann - In Memory of Erwin & Pearl Poizner  
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Northwood Plaza - In Memory of Cecil Comer  
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John Platt - In Memory of Jack Jordan  
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The Society for PSP, Woodholme Medical Building, Suite 515, 1838 Greene Tree Road, Baltimore, MD 21208  
1 (800) 457-4777 1 (410) 486-3330

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
- #20 Information About PSP translated in Spanish
- #21 I Have Been Diagnosed With PSP
- #22 Challenges in the Management of PSP

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FOR PHYSICIAN'S ONLY:

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

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*As we went to press, the attack on America occurred. The Society's Board of Directors, staff and volunteers extend their deepest sympathies to those who suffered such great loss. Families who everyday face the strife, struggle and strains of PSP, now face the additional burdens of this tragedy. The Society hopes for the blessings of peace and the restoration of our country and its citizens.*

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