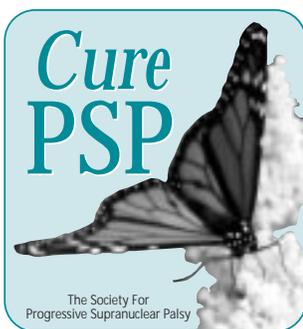


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INSIDE

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Details on Page 9

The Society for Progressive Supranuclear Palsy

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

The Society for Progressive Supranuclear Palsy, Inc. (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 fatal degenerative brain disorder that has no known cause, treatment or cure. The Society provides information, education, support and advocacy to persons with PSP, their families, and caregivers. The Society educates physicians and allied health professionals on PSP and how to improve patient care.

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

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(In memory of Henry and Jane Ogiba)
Assistant to the Editor: Debra Thompson
(In memory of Lois Croft Davis)

TABLE OF CONTENTS

Director's Doings/Chairperson's Corner	3
Support Services Survey	4
Diagnosis and the Epidemiological Project	5
More 2001 PSP Grant Recipients	6-8
Sixth Biennial PSP Symposim	8-9
New Orleans Support Group Meeting/AAO	10
Dysphagia and PSP	11
Home Exercises	12
PSP and the Bladder	13
Talking About End of Life Issues	14
2001 Memorial and Tribute Gifts	16-17
Support Group Listing	18
Support Group News	19-20
PSP Stories	21-23
Helpful Hints	24-26
Report of Gifts	28-30

Director's Doings



We passed the baton!

The Society passed the baton in October, 2001 from George Jankiewicz, Jr. to Liz Brissom as new Chairperson of the Board. George served as Chairman for three years and treasurer for two, even serving as chairman and treasurer one year concurrently. What a feat!

As Executive Director, I take my marching orders from the

Chairman of the Board and for three years, I heard nothing but the finest of marches—John Philip Sousa quality or Johann Strauss. George molded the Society during his term with his profound wisdom, his extensive knowledge and experience in finance and accounting. He has been a visionary, serving with grace and patience.

If you looked at George, you would immediately guess he excelled in basketball. But his tall frame can be equally measured commensurately with his "tall" character. He has put hours into leading, organizing and advising on many issues vital to our young organization's start-up needs. He approached issues with genuine sensitivity and empathy for persons diagnosed with PSP and families even as he faced the passing of his father to progressive supranuclear palsy. As my boss, he listened intently to needs concerning staffing and human resources, another area in which he has considerable knowledge.

He has been a gentle and caring leader, molding various opinions and points of view into a focused effort. He is always there for us and because of his leadership, we have always wanted to be there for him.

Thank you, George for all you have done for the Society and for helping me grow as Executive Director. Our organization has blossomed under your baton. I, too, have gleaned much from your outstanding leadership.

We look forward to you remaining on the Board as a trusted leader and guide to Liz, the new Chairperson and the Board of Directors.

With great respect and admiration,

Ellen Pam Katz
Executive Director

Chairperson's Corner

Liz Brissom
Chairperson, Society for PSP

"Optimism is the faith that leads to achievement. Nothing can be done without hope and confidence."

Helen Keller

As my Chairmanship begins, I would like to reflect a moment on my predecessor, George Jankiewicz. George once asked, "What can we do to make a difference?" I think it is the dedication of so many wonderful people, like George, that I have come to know over the last six years being involved with the Society, that really does make the difference. George has served the Society for many years and has been instrumental in seeing the fruition of the Society's Vision and Strategic Plan for 2000-2003. The torch has now been passed on to me and I am honored to be your new chairperson. I bring with me the same passion and dedication that George inspired in me and all those around him.



We have a very strong Board of Directors that understands the mission and goals of the Society. We have entered into a new decade having commemorated our 10-year anniversary only one year ago. Now it is the "Decade of Hope," and it is this sentiment that I embrace fully, and hope a cure is found for progressive supranuclear palsy. There is still so much to be done and it is gratifying to see so many people come together to share their stories. We are deeply appreciative and touched that actor Dudley Moore stepped forward and revealed he was diagnosed with PSP, and established a research fund. Professional baseball player Denny Neagle too, came forward to see what he could do when he learned his father-in-law was also diagnosed with PSP. Denny began a "Strike Out PSP" fund.

This year will be very busy with two major events coming up, including the Biennial Symposium in May focused on support group leaders, caregivers and those diagnosed with progressive supranuclear palsy. We also are planning a Research Symposium in November inviting researchers to come together to share and discuss the latest findings in their PSP research. All of these initiatives are in line with our goals, which include:

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

I will continue to support the strategies, which were created by the Board of Directors in 1999, and I look forward to further collaboration in creating the Society's future beyond 2003. I want to thank George for his leadership as well as the Board, staff, volunteers, donors, physicians, and you, our supporters, for keeping the mission on the forefront in all of our actions. Let's make this a "Decade of Hope" in finding a cure for PSP!

Thank You!

 The Society for PSP is pleased to announce that it has received a gift of \$200,000 in memory of Willa McNear Budge. The gift was made possible through a bequest from the estate of Hazel Reed Baumeister which is administered by Dr. John Saidy, Mrs. Budge's personal physician who attended her throughout her long battle with PSP. Dr. Saidy and his wife, who were close friends of Willa and her husband, Bill, wished to pay tribute to her by making this bequest in her memory. The gift will establish the Willa McNear Budge Memorial Fund and will be used to fund research as well as outreach and educational programs. Willa McNear Budge lived with her husband William Budge in Hillsborough, CA, a suburb of San Francisco. The Society thanks Dr. and Mrs. Saidy for remembering their friend in such a caring and meaningful way.



A SPECIAL THANKS

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

“High Marks Reported By Donor Survey”

Bonnie Heneson
Communications, Inc.

In September 2001, the Society for PSP surveyed its donors to identify the needs and desires of persons profoundly affected by PSP. The survey was designed to identify future organizational resources to help enable a cure through research and to provide outreach services. Approximately 825 persons (15%) responded from the United States and Canada. The survey was tabulated and analyzed by Bonnie Heneson, a marketing and communications consultant in Owings Mills, MD. The following information is from her analysis.

PATIENT AND FAMILY INFORMATION:

- The majority of responders were spouses of persons diagnosed with PSP with children being the next highest category. About 10% indicated there were other persons in the family with neurological problems, including Parkinson's disease.
- The greatest challenges facing families were:
 - Dealing with medical professionals who do not know about PSP. The Society's information was much more helpful than what is provided by doctors.
 - Lack of public knowledge on the disease
 - Feeling of helplessness and frustration
 - Emotional drain
 - Feeling of isolation

WAYS THE SOCIETY FOR PSP CAN BE MORE HELPFUL:

- Find a cure
- More articles on time frames related to the illness and what to expect
- More support groups
- Educate doctors and the medical community
- Increase public awareness of disease with more media coverage

SATISFACTION WITH THE SOCIETY:

- It was gratifying to see how much the Society for PSP meant to so many persons diagnosed with PSP and families. The Society is truly a lifeline for those struggling with the frustrations, challenges and emotions of caring for PSP patients. The Society for PSP was the only place people could turn.
- Most respondents were highly satisfied with the performance of the Society.
- The newsletter was overwhelmingly the most popular service provided by the Society and received rave reviews. The website, brochures and support groups came in next with the list serve and symposiums to follow. Interest was also showed in knowing more about being a brain donor.

CHARITABLE GIVING:

- The major reason people made a gift or would make a gift to the Society was to continue research efforts to find a cure. The next most popular reason was in

- memory of a loved one, followed by the Society continuing to provide education and support to families, the health community and to the general public.
- Most respondents, depending on their capacity to give, responded favorably to continuing their financial support of the Society. Many wished information on bequests, planned giving and establishing named research funds. Many responders who were retirees and/or on fixed incomes expressed their desire to support the Society to the extent they could. Many responders expressed that they wish they could give more.

VOLUNTEERS:

- The Society received hundreds of responses from persons willing to volunteer, organize events around the country, raise funds, serve on the Board of Directors and help in any way they could. Many were willing to host speakers on PSP research at small get-togethers and fundraising dinners, as well as sporting events – walkathons and runs.

SUMMARY:

In summary, this survey has provided the Society for PSP with information about how donors view the Society and how they wish to help. The work now really begins with the need to follow up on leads, supply requested information, evaluate areas in which forming support groups would be most helpful, tapping into a potentially new volunteer pool for board members, fundraising and other activities.

Perhaps one of the strongest messages that emerged from this survey was the importance of the role of the Society for PSP in educating doctors, informing the public about PSP and, in general, raising the visibility of this disease. It is very clear from these surveys that the Society for PSP is indeed making a difference in the lives of persons diagnosed with PSP and their families and that people are counting on the Society to spearhead research efforts around the country.

PSP EUROPE

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

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The Old Rectory
Wappenham, Nr Towcester, Northamptonshire
NN12 8SQ
Telephone 0044 (0) 1327 860299
E-Mail psp.eur@virgin.net
Website <http://www.pspeur.org>

Diagnosis and the Epidemiological Project Newcastle, UK

David Burn, M.D. and Uma Nath, M.D.

“THE NEED FOR DIAGNOSIS OF PSP”

Physicians as a group are (I hope you will agree) bright, motivated and highly trained. We know that patients with PSP have a characteristic eye movement problem, their illness is difficult to treat and tends to progress. We also know that Parkinson's disease is a disorder without eye movement problems in which patients respond well to treatment. So why are patients with PSP still being misdiagnosed as having Parkinson's disease? Why do patients with PSP see so many specialists before being given the correct diagnosis? Indeed, one might even query what difference a correct diagnosis makes, since patients with PSP often do not respond to treatment.

WHY DOES DIAGNOSIS MATTER?

It matters. Waiting merely a few days for the results of a hospital test can be unnerving; patients with PSP often have this agonizing delay for months and even years. So many, when finally given a correct diagnosis, tell us of the trail from one specialist to another, having test after test, and occasionally even undergoing unnecessary treatments. Nor are practical difficulties the only problem. Hopes are raised and dashed with each test and each visit. Different specialists may provide differing explanations for symptoms. Possible diagnoses, such as dementia or Parkinson's disease,



Uma Nath, M.D. with Irene Litvan, M.D.
at the AAN Meeting in Philadelphia

may be mentioned, each rather worrying. Patients may even feel that their doctor is “out of their depth.” This can be very frightening for the patient and erodes the relationship between patient and doctor. Considerable frustration may be generated.

When so much is uncertain, patients cannot move forward psychologically. They are less able to come to terms with the illness, plan for the future or explain the situation to their families. Everything seems to be “on hold.” Depression is a natural consequence. While this is terrible to experience at a time when the illness itself may be progressing, it is equally terrible for relatives and friends to witness.

We as doctors are only too well aware of these problems. We know that we cannot prevent PSP, cannot cure it or even slow down its course. At the very least we should be aiming to diagnose it accurately early on in the disease so that problems outlined above can be avoided. Patients often feel a sense of relief when meeting a physician who obviously has some experience in dealing with the disorder. We are able to tell them about which symptoms we can treat, whether some of the symptoms are actually nothing to do with PSP, and most importantly, help them to plan ahead realistically. While it is true that progression in PSP is very variable even when the diagnosis is clear, patients and relatives show extraordinary resilience once they know what they are dealing with.

Continued Page 6

Research

WHY IS PSP MISDIAGNOSED SO OFTEN?

The above description shows how difficult the diagnosis may be. PSP can begin in many different ways. There is no laboratory test to confirm the diagnosis. Most physicians are able to identify an advanced case of PSP, as most of the hallmark features are present. However, there is no easy way to diagnose cases early before all the features have developed. Thus, at onset, a time when a clear diagnosis would be most crucial to the patient, it is the most difficult to give. Paradoxically, the more experience of PSP the physician has, the less categorical they are about precise diagnosis, as they know only too well that patients with PSP do not always fit "textbook" descriptions.

THE LINK WITH CORTICO BASAL DEGENERATION (CBD)

PSP is called a "tauopathy" as the brain in sufferers contains this abnormal protein tau and their DNA, when analyzed, often contains the same protein. However, tau is present in the brains of patients with cortico basal degeneration as well. In fact the same type of tau is present in the DNA in both disorders. Even the appearances of the brain are strikingly similar. It is, therefore, possible that PSP and cortico basal degeneration represent different points on a spectrum of the same tauopathy.

OUR RESEARCH AND ITS FINDINGS

We are based in the North-East region of the UK and were given the opportunity by the PSP (Europe) Association to conduct research into PSP in 1998. We wanted to find out how common the disorder is in the UK and the extent to which it was being misdiagnosed.

NATIONAL STUDY

Our first step was to identify a large group of patients with PSP and confirm their diagnosis. We asked neurologists across the UK to forward details of cases to us, and reviewed their medical records where available. This generated a large number of patients with PSP, but missed cases not seen by neurologists; therefore, the study was "biased."

REGIONAL STUDY

We then asked all physicians (not only neurologists) in the North-East of England to forward us cases of PSP ("passive" case identification) as well as allow us to look at all their correspondence and patient databases over two years ("active" case identification). This obviously generated fewer cases than the national study, but the sample was less "biased."

COMMUNITY STUDY

Lastly, we examined all patients with parkinsonism not responding to treatment in one city in the North-East of England (Newcastle upon Tyne) to find cases with PSP. This study was not biased, but was necessarily very small.

Each study was smaller but more detailed than the last. We identified 17 cases of PSP in Newcastle alone. This means there are five cases of PSP per 100,000 population. Thus, across the UK, we should have found over 3000 cases. We found 577 cases in the UK, which meant that nationally we were only identifying one in every five cases. Patients referred to neurologists tended to be younger and more likely to be male than those seen by other physicians. Problems with vision were a common early problem and patients had often seen their local opticians several times (up to five times) asking for stronger spectacles. Eight percent of national cases were seen by eye specialists who had difficulty in diagnosing the disease in all cases. Patients had seen, on average, four physicians before a diagnosis of PSP was made. In Newcastle,

40% of cases were incorrectly diagnosed, three as Parkinson's disease, three as strokes and one as hydrocephalus.

FUTURE DIRECTIONS

We are in the process of publishing data on the clinical symptoms and signs observed in our patients as well as factors influencing the course of the illness and which factors have the strongest influence on quality of life in PSP sufferers. We have also commenced a questionnaire-based study to find out whether there is any familial predisposition to development of PSP. These, like all research in PSP, are ambitious projects, which are only possible with the support of PSP sufferers and their families. The collaboration of patients and researchers in this common cause can only end in success for both. We look forward to apprising you of our future results.

Congratulations on your work, Uma. Uma was selected to give a platform presentation of her research project at last year's American Academy of Neurology Annual Meeting. Reprinted with permission from the PSP Europe Association, PSP Bulletin, Summer 2001, Vol. 8, No. 22

More 2001 Society for PSP Grant Recipients

"Glial Tau Aggregation in PSP and Cultured Cells"

*Funded By The Patton Family Foundation
\$50,000*

Hanna Ksiezak-Reding, Ph.D.
Mount Sinai School of Medicine, New York, NY



This grant proposal is a continuation of our studies supported by The Society for PSP in 1999-2000. The goal of our continued studies is to replicate pathological tau aggregation in brains of PSP patients using glial cell cultures of human origin. Two types of glial cells will be examined, including astrocytes and oligodendrocytes. Tau aggregates induced in glial cells in vitro in our preliminary studies will be compared to tau filaments isolated from glial-specific lesions in PSP brains. In Aim 1, we hypothesize that upregulated tau phosphorylation and tau protein content in cultured cells will lead to aggregation of tau into filaments, which resemble authentic tau filaments of PSP. The similarity between cell culture-derived and authentic tau filaments will be established at biochemical and ultrastructural levels. Furthermore, based on our recent observations, we hypothesize that aggregation of tau in glial cells correlates with upregulation of Akt, a factor involved in cell survival pathways. In Aim 2, we hypothesize that aggregation of tau is linked to the upregulation of Akt. These studies will implicate the Akt survival pathway as a molecular mechanism for tau aggregation in cellular models of glial degeneration and in PSP.

Research

“Analysis of the 17q21 Region in PSP, Tau Gene Analysis in Parkin’s Disease Dementia and in Other Atypical Parkinsonisms”

Funded by
The Eloise H. Troxel Memorial Research Fund
\$36,000

Eduardo Tolosa, M.D., Ph.D.
Neurology Service, Hospital Clinic

Progressive supranuclear palsy (PSP) is the second most common cause of idiopathic parkinsonism. Many of the PSP cases appear to be sporadic, although there are reports showing different families with several members affected, supporting the possibility that genetic factors could be involved in PSP. Recent studies have found an association between a region on chromosome 17 (17q21) and PSP. This region has also been associated with other parkinsonism such as frontotemporal dementia and parkinsonism (FTDP) and Parkinson’s disease. The tau protein is a cytoskeletal protein that is codified in this region. It is known that the tau protein accumulates in the brain of PSP patients constituting its pathological hallmark. Recently, we have reported a Spanish family in which two brothers who presented a clinical picture mimicking atypical PSP had a mutation in the tau gene. Up to now, no mutations have been found in the tau gene of patients with typical PSP. However, it is possible that other genes near the tau gene could be involved in the disease. The main goal of our work is to identify candidate genes responsible for the genetic susceptibility to PSP and search for mutations in these genes. One of these candidate genes is the NIK gene (mitogen-activated protein kinase). The NIK proteins interact with a protein named dynein that is involved in microtubule and cytoskeletal dynamics.

“Characterization of Tau Auto-antibodies in Progressive Supranuclear Palsy”

Funded by *The Erwin & Pearl Poizner Memorial Fund*
\$30,000



James W. Tetrud, M.D.
Clinical Director
The Parkinson’s Institute
Sunnyvale, CA

PSP is characterized by a relatively rapid clinical decline with little or no response to pharmacotherapy. The diagnosis is often delayed by several years and may be missed even by experienced movement disorder specialists. The lack of a reliable clinical marker for this disorder often results in confusion and frustration for patients, their caregivers and treating physicians as well as investigators selecting PSP patients for clinical trials. Thus, the identification of a reliable

biomarker for this disease could represent an important step in understanding the underlying pathophysiology and the study of potential therapeutic agents.

“Screening of Tau Mutation in a Unique PSP Family”

Funded by *The Barbara and Harold Fox Living Trust*
\$14,250

Rong Chen, M.D., Ph.D.
Research Scientist, Basic Research
The Parkinson’s Institute
Sunnyvale, CA

There is more and more evidence supporting a susceptibility factor in the tau gene to the pathogenesis of progressive supranuclear palsy (PSP). But where and what it is still remains unknown. This proposal is to identify the causative mutation in the tau gene in a special family with two siblings having typical clinical and pathological features of PSP. Multiple affected members have been reported in consecutive generations, which suggests an inheritance of autosomal dominant pattern. The pathogenic mutation will be screened by sequencing all the exons and nearby areas of the tau gene. Its impact on RNA transcription expression as well as implication in sporadic PSP will also be studied. Once the mutation is identified, it will greatly improve the clinical diagnosis and genetic counseling for PSP family members. Moreover, it will have tremendous impact on the future research of PSP. Biological study of the gene and its encoding protein involved in the familial forms of disease will provide new insights into the pathogenesis of sporadic PSP, which will subsequently help in exploring new avenues to prevent and/or cure this devastating disease.

“Prehistory of PSP: Bibliographic Search and Copying”

Funded by *Research Donations to the Society*
\$3,000

Professor Adolfo Brusa
Primario Emerito
Ospedalia Galliera (Genoa, Italy)

The Investigator had the opportunity to describe in 1961 a case of a degenerative disease with a complex symptomatology which, three years later, was recognized by Steele, Richardson and Olszewski as a case of progressive supranuclear palsy. After 1961, many cases of this disease have been described and it seems very strange that it was very rare before that date. The Investigator has planned a review of the old neurological literature in order to look for cases which clinically resemble progressive supranuclear palsy. These patients can be possibly found in the parkinsonian and pseudobulbar fields. This research work could be important for a better understanding of the epidemiology of the disease.

Continued Page 27

You Are Invited To Attend

THE SIXTH NATIONAL BIENNIAL SYMPOSIUM ON PROGRESSIVE SUPRANUCLEAR PALSY

An Educational Conference for Persons Diagnosed with PSP, Families and Caregivers

BWI Airport Marriott • Baltimore, MD

Saturday, May 18, 2002

8:45am - 4:15pm

- | | | | |
|-------------|---|-----------|---|
| 8:00-8:45 | Registration, vendor exhibits and continental breakfast | 1:15-2:00 | Family Adjustments to Chronic Disease
Susan Imke, RN, MS
Gerontological Nurse Practitioner
Southwestern Health Services
Fort Worth, Texas |
| 8:45-9:00 | Welcome
Liz Brisson
Chairperson
Board of Directors, The Society for PSP
John C. Steele, M.D, F.R.C.P., Guam
Fellow, American College of Physicians
(In 1963, Dr. J.C. Steele, together with
Dr. J.C. Richardson and Dr. J. Olszewski,
identified PSP as a distinct neurological
disorder) | 2:00-2:30 | Dealing with Functional Mobility Issues in PSP
Heather J. Cianci, PT, GCS
Geriatric Clinical Specialist
The Dan Aaron Parkinson's Rehabilitation
Center at Pennsylvania Hospital
Philadelphia, PA |
| 9:00-9:30 | The Basics of PSP
Paul S. Fishman, M.D, Ph.D
Professor of Neurology
University of Maryland School of Medicine
Baltimore, MD | 2:30-3:00 | Break and Vendors |
| 9:30-10:00 | Updates in Research
Irene Litvan, M.D.
Chief, Cognitive Neuropharmacology Unit
Henry M. Jackson Foundation
Bethesda, MD | 3:00-3:45 | Breakout Session #1
Caregiver Question and Answer panel

Breakout Session #2
"I have been diagnosed with progressive
supranuclear palsy"
A special sharing session for our PSP loved
ones to meet each other.
Susan Imke, RN, MS |
| 10:00-10:30 | Eye Movement Problems With PSP
Mark Walker, M.D.
Assistant Professor, Neurology
Johns Hopkins University School of
Medicine | 3:45-4:15 | Evaluation and Closing Remarks
Liz Brisson
Chairperson
Board of Directors, The Society for PSP |
| 10:30-11:00 | Break
(Light refreshments and vendor exhibits) | Cost: | \$69; \$59 Early Registration By April 23
Limited scholarships available
Must provide own wheelchair |
| 11:00-11:30 | Helpful Hints for Swallowing in PSP
Laura Purcell Verdun, M.A., CCC/SLP
Inova Fairfax Hospital Department of
Rehabilitation
Otolaryngology Associates, PC | | |
| 11:30-12:00 | Question and Answer Session | | |
| 12:00-1:15 | Lunch | | |

*For More Information
Contact the Society's Office*

1-800-457-4777 • 1-410-486-3330

email: spsp@psp.org

Fax: 1-410-486-4283

Register Online At

www.psp.org

Special Events - Join Us For Additional Symposium Activities

Friday, May 17, 2002 SUPPORT GROUP LEADERSHIP WORKSHOP

5:30pm-9:00pm
BWI Airport Marriott

- 5:30-6:00 Welcome
6:00-6:30 Dinner
6:30-9:00 Support Group Leadership Training
Wendy Resnick, RN, MS
Depression and Related Affective
Disorders Association
Baltimore, MD
Program A - Cost \$29.00

BUSINESS EVERYONE NEEDS TO TAKE CARE OF

6:15pm-8:45pm
BWI Airport Marriott

- 6:15-6:30 Welcome
6:30-7:30 Dinner
7:45-8:45 Laurie Frank, Attorney
(Invited)
Program B - Cost \$29.00

Saturday, May 18, 2002 THANK YOU, DUDLEY MOORE, RENA FRUCHTER, BRIAN DALLOW AND MUSIC FOR ALL SEASONS, INC.

6:30pm-8:45pm
BWI Airport Marriott

Relax and spend a musical evening with other PSP families as The Society thanks Rena Fruchter, Brian Dallow and Music for All Seasons for helping to raise funds for PSP research and increasing awareness of PSP both nationally and internationally. Rena and Brian were Dudley Moore's friends and caregivers.

- 6:30-8:00 Welcome, Dinner and Program
8:00-8:45 "Diva Duo"
Melissa Perry and Sharon Rose Derstine,
sopranos; Hugh Kronot, pianist
Courtesy of Music for All Seasons, Inc.
Cost \$50.00

OCTOBER IS PSP AWARENESS MONTH

Learn about organizing special events and fundraisers to help increase PSP awareness in your hometown.

Saturday, May 18 • 5:30-6:15 pm
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Special Events

Caring and Sharing In New Orleans



On Saturday, November 10, 2001, The Society for PSP hosted a meeting of "Caring and Sharing for Persons Diagnosed with PSP, Families and Caregivers" at the Best Western Landmark Hotel in Metairie in the New Orleans area. Nancy Brittingham, PSP Advocate Editor, represented the Society at this meeting. Topics included information about PSP, resources available, a question and answer session and time to meet each other.

The Society would like to recognize and thank the guest speakers at this meeting. These presenters gave of their time and met with each of the program's attendees.

"An Overview of Progressive Supranuclear Palsy"

- Jayaraman Rao, MD
Professor of Neurology, Cell biology and ENT
Dr. Carl Baldrige Chair in Neurology and Neuroscience
Director, Parkinson's Disease and Movement Disorders
Center, LSU School of Medicine

"Swallowing Problems and Progressive Supranuclear Palsy"

- Julia D. Edgar, Ph.D.
Assistant Professor of Speech-Language Pathology
Department of Communication Disorders
School of Allied Health Professions
Louisiana State
University Health
Sciences Center

During the following week, the American Academy of Ophthalmology held its annual meeting at the New Orleans Convention Center. The Society was represented at an informational exhibit during the week, distributing PSP information educating this important group of physicians who may see symptoms of PSP before anyone else.

The Society would also like to thank Brenda Gremillion, New Orleans PSP Support Group leader, for all her help in organizing this meeting.



*Brenda Gremillion and
Nancy Brittingham*

The 105th Annual Meeting of the American Academy of Ophthalmology

New Orleans, Louisiana, November 11-14, 2002



Over 12,000 physicians and health professionals attended the American Academy Of Ophthalmology's 105th Annual Meeting at the Morial Convention Center in New Orleans last November. The American Academy of Ophthalmology (AAO) is the largest national membership association of ophthalmologists, who are the medical eye physicians and surgeons who provide comprehensive eye care. This meeting provides the highest quality of continuing medical education available to ophthalmologists today. There is opportunity to develop, maintain and enhance knowledge and skills in research and clinical advances through the various learning formats. The latest and most advanced products and healthcare services available are housed in several exhibit halls stretching over 300,000 square feet of space.

The Society staffed an informative exhibit at this annual meeting to educate national and international ophthalmologists about the diagnosis of progressive supranuclear palsy and inform them about the services of the Society. Most persons experiencing the problems of PSP begin their search for diagnosis with the ophthalmologists. Physicians attending these types of meetings are given an electronic swipe card with their contact information which is imported into a mailing data base. There was an overwhelming number of ophthalmologists swiping their cards to obtain more information about PSP. The Society office staff immediately began mailing out Physician PSP Information Packets to these ophthalmologists. It is noted that more and more ophthalmologists are aware of progressive supranuclear palsy as compared to previous years and these physicians were appreciative to learn there is an organization they can refer their patients and families to for education and support services.

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PSP Advocate, First Quarter 2002

Dysphagia In Persons With Progressive Supranuclear Palsy “The Typical Diagnostic Process”

Julia D. Edgar, Ph.D.
Assistant Professor of Speech-Language Pathology
Department of Communication Disorders
Louisiana State University Health Sciences Center
New Orleans

THE NORMAL SWALLOW

1. ORAL PREPARATION

Food is placed in the mouth and chewed if it is a solid, sometimes swished if it is a liquid. During chewing the teeth crush the food and it falls back onto the tongue. The tongue gathers the smaller pieces and moves them back onto the teeth. This sequence is repeated over and over until the pieces are sufficiently small and well mixed with saliva. There is no pre-determined length of time for this to occur because it depends on what you are eating. If you are eating steak it will take longer than if you are eating saltine crackers.

2. ORAL TRANSPORT

Now the food is ready to be swallowed, and the tongue gathers the bite, or sip, together into a “bolus” and moves it through the mouth towards the throat. This happens very quickly and takes only about one second.

3. PHARYNGEAL

During the pharyngeal phase the food moves through the throat. Although all phases of the swallow are important, the pharyngeal phase is sometimes considered the most important in terms of safety. Breathing and swallowing share the same pathway in the pharynx. When we swallow we stop breathing and the airway is tightly shut off so that food doesn't enter. When food does fall into the airway we cough and choke. The pharyngeal phase lasts about one second.

4. ESOPHAGEAL

During the esophageal phase the food passes from the bottom of the throat down to the stomach. Muscles in the esophagus and gravity help move the food downward. It will take between 8 and 20 seconds depending on the texture of the food.

Dysphagia, or difficulty swallowing, is a common characteristic of PSP. Dysphagia can be managed so that eating is easier and safer. In fact, the goal of diagnosing and treating dysphagia is to prevent aspiration, malnutrition, and dehydration while maintaining quality of life. Speech-language pathologists (SLPs) work with other health professionals to help patients with swallowing problems. The SLP is often the person who directs the swallowing evaluation.

THE TYPICAL DIAGNOSTIC PROCESS

1. CLINICAL EVALUATION

The clinical evaluation is the first step in the dysphagia diagnostic process. A thorough case history will be obtained. The head and neck are examined to see if there is adequate strength and movement in the muscles of swallow. The SLP

will also observe respiration and check on the strength of the cough reflex. Typically, the patient will be observed eating, so that rate of eating can be observed along with making note of things such as whether there is food left in the mouth, if food falls out of the mouth or there is coughing or choking, etc. If problems are noted, the SLP will recommend an instrumentation assessment of the swallow to obtain more specific information about swallowing function and to make suggestions for treatment.

2. VIDEOFUOROSCOPIC ASSESSMENT

A videofluoroscopic swallowing study (VSS) is also known as a Modified Barium Swallow (MBS), and sometimes even a “Cookie Swallow Test.” It is a moving X-ray of the swallow. Barium is mixed with food and liquid. The barium shows up darker in contrast to the rest of the X-ray so that the speech-language pathologist and radiologist can follow the bolus and watch the swallow. Many believe this test is the “Gold Standard” for examining swallowing disorders because the doctor can evaluate all of the swallowing phases with this test. To complete the test the patient will usually swallow thin and thick liquids, a pudding consistency, and a cookie or cracker. Sometimes other foods are included in the study.

3. FIBEROPTIC ENDOSCOPY

EXAMINATION OF SWALLOWING (FEES)

A FEES study is conducted by slipping a small diameter, flexible tube through the nose. The tube has small fiberoptic wires in it and is attached to a light source and a camera at the other end. No barium is used during this study, and since there is no radiation exposure the test can last longer. With a longer study it is easier for the SLP to observe if the swallow changes if the patient gets tired. It is easier to examine breathing in relation to swallowing with FEES. However, the entire swallow can't be observed. FEES isn't used as often as VSS, but it can provide very valuable information.



Julia D. Edgar, Ph.D. speaking at the New Orleans “Caring and Sharing Meeting”

COMMON SIGNS THAT MAY INDICATE A SWALLOWING PROBLEM

A group of researchers published the results of a study that examined PSP patient responses to a swallowing survey as well as instrumentation swallowing studies. The following table is a summary of the types of problems that these patients reported experiencing. [Litvan, I., Narahari, S., & Sonies, B. (1997). Characterizing swallowing abnormalities in progressive supranuclear palsy. *Neurology*, Vol.48,1654 - 1662.] The top ten problems are listed below.

DOCUMENTED PATIENT COMPLAINTS

# of Subjects	Survey Item Marked as a Problem
20/27 (74%)	Coughing or choking while swallowing
17/27 (63%)	Excessive saliva or mucus in the mouth
15/27 (56%)	Difficulty swallowing
15/27 (56%)	Food falls out of the mouth
13/27 (48%)	Food gets caught in the cheek
12/27 (44%)	Slow eater
12/27 (44%)	Food spreads all over the mouth
11/27 (41%)	Avoids foods like apples, nuts, and cookies

Continued Page 12

Education

Continued from Page 11

Dysphagia

- 10/27 (37%) More difficulty swallowing liquids than solids
- 9/27 (33%) Very dry mouth

DYSPHAGIA HISTORY - *If you notice any of these changes in your eating, please contact your physician.*

1. Has there been a change in appetite?
2. Has there been any weight loss?
3. Has there been a change in food preference?
4. Do you avoid any foods?
5. Does choking occur? If so, on what foods?
6. How long does it take to eat? Is this a change from before?
7. Have you noticed any change in sensation of taste or temperature?
8. Do you have problems with excess mucus or saliva? Any drooling?
9. Do you have any problems with respiration (difficulty breathing)? If so, in what situations?

DYSPHAGIA DOCUMENTED BY VIDEOFLUOROSCOPY (VSS)

The researchers mentioned earlier also looked at VSS results. The problems seen on VSS matched well with what the patients and their caregivers reported on the swallowing survey. It is possible to have problems in the oral phase (poor tongue movement, a slow start to the swallow, more trouble with solids than liquids, and trouble handling saliva, for example). In the pharyngeal phase they noticed food remaining in the pharynx as well as coughing, choking, and aspiration. There were also some problems in the esophageal phase. Certainly, not every patient presented with every problem. But all patients had some problems.

HOW CAN EATING BE SAFER?

There are specific treatments that can be recommended depending on the problems noted during an evaluation. These should be specified after the evaluation is finished. Often the best approach is to teach the patient and the caregiver how to work together at mealtimes. The visual problems that persons with PSP experience can cause problems, too. Some patients have difficulty seeing their plate. Here are some basic things you can do.

1. Place the plate in the patient's line of vision.
2. Eat slowly—take one bite at a time and swallow everything in your mouth before taking another bite.
3. If you notice coughing and choking on certain food, remove them from your diet until you have a chance to see a speech-language pathologist.
4. If you are having trouble eating enough food, see a dietitian for suggestions for increasing calorie intake.

SUMMARY & KEY THINGS TO REMEMBER

1. Swallowing is complex and safe swallowing is critical to maintaining good health and well-being.
2. Persons with progressive nuclear palsy typically have some form of dysphagia.
3. It is important to obtain a complete evaluation so that the safest eating method can be determined.
4. It is a good idea to get a swallowing evaluation early. If your doctor doesn't suggest it, initiate the topic yourself. Ask for a referral.

5. The caregiver and patient should work together as a team to ensure safe eating and adequate nutrition.
6. If you have questions, ask for help. Your doctor, speech-language pathologist, dietitian or nurse can guide you to the appropriate health professional to obtain answers to your questions.
7. There may come a point in time when you can't eat safely. There are other ways to get nutrition. Your physician will help you make the best decision as to how to proceed should this happen.

Keeping Active – What Can I Do At Home?



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

Progressive supranuclear palsy can cause slowness of movement, muscle rigidity and changes in one's posture, walking and endurance. Many individuals have been encouraged to perform exercise on a regular basis to better deal with these issues. Exercise and early intervention by a physical or occupational therapist can improve your ability to perform certain functional activities for a longer period of time. Certain exercise can even help reduce stress and promote relaxation.

With your physician's approval, here are some basic exercises that you can do in your own home to get started. Happy exercising!

RELAXATION EXERCISES

These exercises can decrease muscle tension and improve the ability to perform activities of daily living and other types of exercises.

• DEEP BREATHING - SITTING

Close your eyes and gently place your hands on your abdomen. Slowly breathe in through your nose and feel your hands move out as your abdomen rises. Exhale slowly and fully through your nose. Repeat 10 times.

• RIB CAGE EXPANSION - SITTING

Begin with arms at your sides in a relaxed position. Slowly take in a deep breath through your nose as you lift your arms up above your head and reach for the ceiling. As you exhale, gently bring your arms back down. Repeat 10 times.

STRETCHING EXERCISES

These exercises help to maintain the flexibility of muscles. This way, muscles will not tighten so easily and will work more efficiently.

• HEAD TURNS - SITTING

Slowly turn your head from side to side and look over each shoulder. Hold each turn for 3 deep breathes in and out. Repeat 5 times.

• SHOULDER SHRUGS - SITTING

Slowly shrug your shoulders up and then roll them backward, feeling your shoulder blades pull together. Repeat 10 times.



Education

- **WRIST CIRCLES - SITTING**

Place your arms straight out in front of you and make slow circles in and out with your wrists, ten times in each direction.

- **ARM STRETCH - SITTING**

Hold arms straight out in front of you, move arms to straight out to your sides, and then behind you. Hold this pose for 5 deep breaths in and out. Return arms in front of you always keeping your elbows straight and head upright. Repeat 10 times.

- **ANKLE CIRCLES - SITTING**

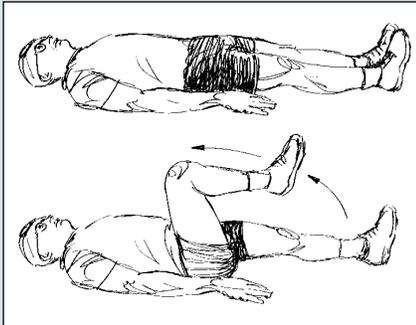
Straighten your knee and make slow circles with your ankle. Repeat 10 times in each direction. Do the same with other ankle.

- **WAND EXERCISE - LYING DOWN ON BED**

While on your back, lift a cane or stick to the ceiling with both hands. While keeping the elbows straight, slowly allow the cane to fall backwards, over your head. Hold this pose for 5 deep breathes in and out. Repeat 10 times.

- **KNEE TO CHEST - LAYING DOWN ON BED**

While on your back, gently hug one knee up toward chest while keeping the other leg flat on the bed. Hold this pose for 5 deep breathes in and out. Repeat with each leg 5 times.



- **TRUNK ROTATION - LYING DOWN ON BED**

While on your back, bend both knees up so that your feet are flat on the bed. Make sure knees and ankles are touching. Slowly allow both knees to fall to one side so that your lower trunk is twisting. Try to keep your head and top trunk flat on the bed. Hold this pose for 5 deep breathes in and out. Now allow legs to fall to the other direction. Perform 5 times in each direction.

STRENGTHENING EXERCISES

These exercises will help to keep muscles strong so that transferring and walking are easier to perform.

- **SHOULDER SHRUGS - SITTING**

Bring your shoulders upwards towards your ears, count to 5 and relax. Repeat 10 times.

- **SHOULDER SQUEEZES - SITTING**

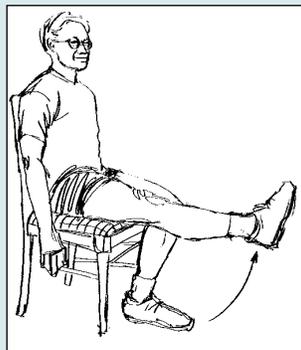
Bend your elbows to 90 degrees and hold them at your sides. Gently pull elbows back and squeeze shoulder blades together. Hold for a count of 5 and relax. Repeat 10 times.

- **SITTING KICKS - SITTING TALL IN A CHAIR**

Slowly kick one leg straight out in front of you. Make sure your knee is straight. Hold this position for 10 seconds. Repeat with each leg 10 times.

- **BRIDGING - LYING DOWN ON BED-**

While on your back, bend your knees up so that your feet are flat on the bed. Slowly lift



your bottom up off of the bed as high as possible. Hold this position for a count of 5 and relax. Repeat 10-20 times.

- **STRAIGHT LEG RAISE - LYING DOWN ON BED**

While on your back, bend one knee up so that your foot is flat on the bed. Keep the other leg straight. Slowly lift the straight leg a few inches up off of the bed. Be sure to keep the knee straight. Hold this for a count of 5 and relax the leg straight down. Repeat with each leg 10 times.

- **HIP SLIDES - LYING DOWN ON BED**

While on your back, slowly slide one leg out to the side as far as you are comfortable. Slide leg back in and repeat on the other leg. Be sure that toes are pointing to the ceiling and one knee is straight the whole time. Perform 10-20 times on each leg.

For more information or help in developing an individualized program, contact your local physical or occupational therapist. Heather can be reached at hjcianci@yahoo.com or 215-829-7275.

PSP and the Bladder

Lawrence I. Golbe, M.D.

Chairman, Society For PSP Medical Advisory Board

Many brain disorders, including all of the parkinsonian disorders, can affect the urinary bladder. The normal nerve circuitry linking the bladder to the spinal cord perceives stretching by a large quantity of urine. These circuits normally set in motion a reflex, not unlike the knee jerk reflex, that stimulates the muscle in the bladder wall. This squeezes the bladder, causing it to empty. It is the job of the normal brain to inhibit this function. When we voluntarily initiate the act of emptying the bladder, we temporarily suspend this inhibitory brain function. Patients with PSP have difficulty inhibiting reflex bladder emptying. As the bladder slowly fills with urine from the kidneys, this produces sudden urinary urges ("urgency") and in many cases, incontinence—a condition sometimes called "irritable bladder." In PSP, degeneration of a small cluster of nerve cells near the lower end of the spinal cord (the "nucleus of Onuf") contributes to the problem.

Urinary urgency and incontinence can be treated in a variety of ways. First, it is wise to check for a bladder infection. The inflammation caused by infection can irritate the bladder lining, fooling its sensory nerves into perceiving that they are being stretched. This stimulates the reflex contraction of the bladder wall muscle. Treating the infection with antibiotics and fluids can correct this problem. There are many possible causes of bladder infections, including enlargement of the prostate in men, which can be treated by medication or surgery, and "dropped bladder" in women, which can be treated with surgery.

The overall disability of PSP can cause a bladder infection by making trips to the bathroom difficult and infrequent, allowing urine to accumulate in the bladder excessively, which permits bacteria in the urethra (the tube from the bladder to the outside) to spread into the bladder and grow. Many people with PSP drink little fluid, either because they cannot swallow easily or because they cannot easily walk to get a drink. This reduces the frequency of urination and the natural cleansing of the urethra by regular flows of urine.

Continued Page 14

Continued from Page 14

PSP and the Bladder

If bladder infection is not the cause of urinary urgency and incontinence, the symptom often responds to drugs that stimulate the muscle at the neck of the bladder. Even when the bladder wall muscle contracts abnormally, the ability of the bladder to empty, and the sensation that it needs to do so, can be inhibited in this way. Two of the more popular drugs are oxybutinin (Ditropan) and tolterodine (Detrol). Both drugs can also cause dry mouth and constipation. The latter is often already a problem in PSP and can be treated by fluids, fiber and stool softeners and in more severe cases, laxatives.

These drugs must not be overused, as they can actually worsen the urinary problem by making it so difficult to empty the bladder that it overfills, weakening the bladder wall muscle. Some drugs used to treat the movement disorder of PSP, such as amantadine and amitriptyline, can share this side effect.

Incontinence during the night is especially common because of the reduced availability of a caregiver to aid the trip to the bathroom and because the recumbent position increases blood flow to the kidneys, producing more urine per hour. Nighttime incontinence can be reduced by avoiding drinking fluids after supper. This must not be accomplished at the cost of reducing the total daily fluid intake and causing dehydration.

If urinary incontinence in PSP fails to respond to these measures, it may be necessary to use an absorbent pad or adult diaper. Advice of a visiting nurse is often useful in choosing between this method and a urinary catheter and for instruction in avoiding skin irritation. For men, a condom ("Texas") catheter is usually preferable to an indwelling ("Foley") catheter because the latter allows bacteria to ascend the urethra and gives them a surface in the bladder on which to grow and cause infection.

Talking About End-Of-Life Issues

by Mark Edinberg, Ph.D.

(From the editor - this article is written directed to children of aged parents, but it is applicable to everyone.)

When I was given this topic to write about, I started to make a list of the issues that I should discuss. The list has a lot of important topics, and I will discuss them. But the one thing I realized in making the list is probably the most important thing I think I have to say: These topics aren't just for the end of life, even though many of them have to do with issues about the end of life. They really should be part of the life fabric of a family, not necessarily the focus of everything a family does, but rather part of how we live our lives fully. Making a will may not be something we do every day, but knowing that it is a responsibility we have and actually doing something about it is.

WILLS

A will is a legal document that makes the specific wishes known as to how an individual wants his or her assets (estate)

to be distributed. It also specifies who will be in charge of distribution of assets and who may control assets for others. Even if you don't have a will, the state you live in has rules about how assets may be divided. Besides taking a lot of time and meaning that YOUR wishes are not being followed, not having a will means that YOUR wishes will not be respected after your (inevitable) death. I have read that a large percentage of people in the United States do not have wills; clearly they are not acting in their own best interest by avoiding this action.

How do you talk about wills? In part it depends on the emotional situation in your family. Obviously, if you haven't talked to your older parents in 5 years, for example, starting the discussion about a will is not the best course of action. Similarly, if there is some mistrust of children by parents (or visa versa) the discussion may look like you are being greedy, wanting to know what you are going to get or trying to start a fight, make others mad, and so forth.

If you live in a family in which wills haven't been discussed, it may just be the "way you work" or it may indicate some degree of distress over the topic or even some family resentments. The rationale for everyone having a will still stands; how to get there may be a tricky path to follow. I know of one case in which a parent had remarried when her daughter was in her 20s and she and her second husband had another daughter. The husband always felt that the first daughter was "not his." The only way the first daughter could find out anything about her parents' plans for their will and estate was to get the second daughter to ask them directly and relay her the information. While not perfect, this method of communication did get the necessary information to all family members without creating dissension between generations.

The key is to be sure that you start the discussion and be clear about your own motivation; you are doing this for the benefit of the entire family.

LIVING WILLS

Living wills, or advance directives, are a legally defined (by state) documents that specify in varying degrees what types of "extraordinary" measures one would want and NOT want to maintain their life. These documents are invaluable when an individual is in a coma or is otherwise unable to communicate what he or she wants for his/her care in dramatic health situations. I think every adult should have one. Otherwise, when someone, be it a parent, spouse, sibling or even an adult child, is in such a situation, decisions cannot be made in accordance with the person's wishes, or, occasionally, in their best interests.

Talking about this document with your parents is relatively easier than perhaps ten years ago, when there was less public awareness of it. The things that hold people back are fearing that somehow or other raising this means they want their parents dead, or that they may be seen as interfering in others' lives. In fact, you are a part of their lives and I assume do not want to be left "holding the bag" with a life or death decision when you have no idea what the parent wants. If you are wondering how to raise this topic, the starting point is that you want your parents' wishes to be upheld and, secondarily, that your parents have some responsibility to the family.

These topics aren't just for the end of life

Education

MEDICAL POWER OF ATTORNEY

Medical power of attorney refers to the power of an individual to make medical decisions for another person who is unable to make such decisions. This is an important part of making advance directives, but, again, is one of those topics that some people would rather avoid. However, even though it is uncomfortable to imagine a loved one not being capable of making medical decisions, it is absolutely better for the rest of the family if such a power is given. Your older relatives may well appreciate that they would be making life easier for their children and grandchildren if they thought about and acted on matters such as this one.

BURIAL PLANS

The average funeral in the United States can easily cost \$5000 (including a burial plot). Many people do not either plan for their funerals or allocate funds for their funerals, although more and more are doing so. This is a tough topic to talk about with your parents, but if you don't, you may be left (again) making decisions that may not meet their wishes. In addition, people are more likely to spend unnecessary funds "just to be sure" they are doing things in the most respectful way, when in fact, the parents would have rather had a simpler funeral and had their funds go directly to their descendants. Again, talking about funeral plans is uncomfortable because they imply that someone will die. Talking about them does not, however, mean that someone wants someone else dead!!! Rather, pre-planning is important for financial and "peace of mind" issues and should be presented that way, e.g. "Mom and dad, we've been thinking about a series of life concerns, such as wills, estates, funerals and things like that. Have you thought about making plans on these matters? We would hope that you do and let us know so that your wishes can be followed and we will have peace of mind that what you want can be done correctly."

ESTATE

A person's estate is everything he or she owns or has direct interest in (e.g. a house in two names). It is a great idea to talk about belongings and personal items in terms of who might want or get them after a person dies. Too often, families fight over sentimental valued items after a death when they could have conceivably had much less tension if discussions had been held before a death. I remember one woman telling me she really liked a portrait of her mother on the mantle, but her sister and she never talked and there was some other family tension. At my urging, she had the discussion with her sister while mother was living, and reported back that her sister said, "I don't even like that portrait, take it." I wonder how easily the sister might have been willing to give up the portrait after the mother's death especially if she felt guilty about issues between herself, her mother, and the sister who eventually got the portrait.

FAMILY HISTORY

There are usually a lot of untied ends in a family's history. Some people call it "unfinished business"; sometimes it takes the form of secrets or issues that have never been explained. Deciding whether or not to pursue these issues at the end of life is a delicate decision. For younger family members, it may be the last time to find out the truth about important aspects

Continued Page 26

Thank You, Carol Marchi



The Society for PSP wishes to thank Carol Marchi for her six years of service on the Board of Directors. Carol Marchi, a native of Massachusetts, transplanted to California to teach high school English as well as many years of working in Adult Education both in the school system and the Catholic Church. For the last ten years, Carol has worked in Outreach and Education for Parkinson's disease and other movement disorders, notably progressive supranuclear palsy and recently retired from the Parkinson's Institute in Sunnyvale, California. Carol brought to the board her special gifts of wisdom, experience, creativeness, dedication and was always an advocate for persons diagnosed with PSP and their families. The Society wishes Carol much happiness in her "retired" life enjoying traveling with her husband, Joe, and enjoying her first grandchild. We will all miss you - (*especially this editor*)!!



Carol Marchi (center) with Sue Dagart, Development Consultant and Dale Ferris, Society Board Member

www.psp.org

The Society for Progressive Supranuclear Palsy is pleased to announce the launching of our new website, <http://www.psp.org>. The website was created under the direction of the website committee chaired by Stephen Hamer, Jackie Allison, the Assistant Director, and Nancy Brittingham, the Editor of the Society, were instrumental in the execution of the website.

The new website will enable an expansion of the Society's ability to reach persons diagnosed with PSP, families, caregivers, researchers and allied health professionals. Immediate access will be available to online giving, registration for events, current news, ordering of PSP materials, special events, and applications for research grants. Persons may also order our newsletter, *The PSP Advocate*, online.

The Society extends their thanks and appreciation to Steve and Carol Poizner for their generous gift that made the development of this site a reality.

In Memory - Memorial gifts given to The Society for PSP during the

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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, phoning and 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:

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Let us post your support group news and announcements in the PSP Advocate. Deadline dates are Feb. 10, May 10, Aug. 10, Nov. 10. Please send your support group news/photos to The PSP Editor at NancyB501@cs.com or to the Society office.

News From Support Groups

Five Years Later

Alice Kitchen
Co-Facilitator of the Missouri/Kansas PSP Support Group

In January 1997, my husband Ron died of PSP (2nd Quarterly PSP Advocate 1999, Vol. 10, No.2). I was fortunate in that Ron and I had benefited from a correct diagnosis early on, information on our national PSP Society, good friends, and thoughtful planning in the early stages of Ron's diagnosis. As Ron's PSP progressed, we had the valuable support of homecare and hospice. As I look back, I don't think I could have held it altogether without these supportive healthcare services. It meant arguing with Ron's insurance carrier, going to their Corporate Trustee's Annual meeting and questioning their policy changes and surrounding myself with advocates to help me make my case for what Ron needed from his insurance carrier.

At times, I felt like I had added several new roles to my life; besides being friend, wife to Ron of 21 years, I was now his medical case manager, his untrained nurse, his voice and his interpreter. Luckily, I had home health care and family support, so Ron had a regular break from me and persons who had different relationships with him. Keeping Ron connected to his friends was one of my most concerted efforts. In retrospect, that was valuable for all of us. Ron's friends still have enormous appreciation for the time they spent with him in his last stages. These men and their wives were a circle of friends then and now. One of our friends voiced what was said by many who were involved in those last few days in less direct statements: "I haven't been afraid of death since I was with Ron in those last days and hours."

Five years later, I still feel like a crusader. Whenever the opportunity seems appropriate to remind family and friends about the value of talking about how we plan to live to the fullest and die with the most comfort, I do. Sometimes I feel like a nag with a gentle but not too subtle message.

Taking care of those wishes, legal decisions and instruction to all who matter is what made Ron's death devoid of last minute distraction and unnecessary agonies.

Even though it has been five years since Ron died, I think of Ron every day through the day but not as often as the first year or two after his death. Some of the hard, sad memories of watching Ron become increasingly incapacitated, unable to make his body do what he wanted, come less frequently now. The bittersweet memories I will always have with me.

One way to put this difficult learning experience to good use for me has been to become a co-facilitator of a PSP support group. Our Missouri/Kansas (MO/KAN) group meets every other month at the local Parkinson Association office. My co-facilitator, Marion Golic, and I can't say we relish doing this but we can say we feel called to because of our own personal experience. That doesn't make it any easier. For us it means being reminded of the difficult times we endured—those times we want to forget. And yet, when family members call and ask basic questions about their loved ones and what they are facing... we know why we do this. So often the support group members have not had anyone to talk to that has been "in their shoes." We all can tell them they are not alone. No matter where we are on the journey, we can relate to what they are experiencing. We can share our experiences, our tears, our laughter, our tips, and offer our support.

Because we can share those experiences, it makes those years not all in vain.

MISSOURI/KANSAS MEETING DATES

Meetings are all on Tuesday at 4 p.m. at the Parkinson Association located at 7808 Foster in Overland Park, KS.

- April 9
 - June 11
 - August 13
 - October 8
 - December 10
- Call Marion Golic, Co-Facilitator for information at 913-381-6972

Support Through Hospice

Ruth Goldstein, Baltimore PSP Support Group

"We don't hasten, we don't prolong," said the petite brunette standing at the head of the oval conference table. Michele Levin, a hospice nurse from Hospice of Baltimore, was addressing the Baltimore PSP Caregivers Support Group's January gathering. It was one of our evening meetings (we alternate between mornings and evenings to give everyone a chance, but evenings are more populated), and 12 or so people were ranged around the big table, ignoring the cookies and pretzels, hanging on every word.

Michele Levin had been invited to shed some light on the sometimes murky subject of hospice care, and how apropos: two of our families had lost their loved ones within the last month—one just a week before our meeting. Would this be too painful a subject? How would we meet their extraordinary needs and still do justice to the speaker and her topic? Not to worry! They both contributed many positive comments about the hospice care they had recently only received, and how beneficial it had been.

Michele began by saying that the two biggest myths about hospice are that it's only for cancer patients and old people. In fact, she said, "About two thirds of our patients have cancer and the other third include an increasing number with neuro-degenerative diseases," like progressive supranuclear palsy. She went on to describe some of the main features of hospice care and to respond to the group's comments and questions.

WHAT IS HOSPICE?

Hospice, Levin told us, is "supportive care for terminally ill patients and their families." That care is delivered by a team that consists of the hospice nurse, who coordinates all aspects of the patient's care, a home health aide, a social worker, the chaplain, volunteers and bereavement counseling for after-care, all under the supervision of the patient's medical doctor.

The hospice philosophy, said Levin, is to provide "comfort rather than cure" for those who receive end-of-life care. Hospice is an extended benefit of Medicare's regular home health services, providing many additional hours of nursing and personal care, as well as increased social and spiritual services, with an emphasis on quality of life.

WHO IS ELIGIBLE FOR HOSPICE?

Hospice is an appropriate consideration for anyone, regardless of age or diagnosis, who has a terminal disease with a six-month prognosis. The six-month time-frame is approximate and can be extended indefinitely if the doctor approves. About 90% of patients receive care from the various members of the team in their home. The other 10% are in-patients in Hospice of Baltimore's 24-bed facility, the Gilchrist Center for Hospice

Continued Page 20

News Support Groups

Baltimore Support Group

Continued from Page 19

Care. A few are in other facilities like nursing homes and assisted living.

WHO PAYS FOR HOSPICE?

Medicare is the main insurer. Medicaid, private insurers and prepaid health plans also contribute. No one is turned away because of inability to pay.

WHEN TO CALL HOSPICE?

The earlier the better, says the hospice nurse, as soon as the goals of care have changed from cure to comfort. Anyone can initiate a referral, including a family member. A specially-trained nurse will visit the patient and perform an assessment, which she will report to the patient's doctor. The primary care physician will usually certify the need for care and supervise the hospice team's activities.

The hour flew by and we thanked Michele for her moving and informative presentation. She had provided so much food for thought and stimulating discussion. She said her goodbyes and we continued with the support group portion of our meeting, reinvigorated by the up-beat message Michele had brought to our group about caring for loved ones nearing the ends of their lives.

WISCONSIN SUPPORT GROUP CELEBRATES FIVE YEARS

The PSP Support Group of Wisconsin recently celebrated five years as an organization. The group started in October of 1996, under the leadership of Barbara Sharkey of Rhinelander. Meetings are held during the months of April through October at St. Michael's Hospital in Stevens Point, Wisconsin. Barbara's husband, Leroy, was diagnosed with PSP but has since died.

"We have shared many experiences and information throughout the five years with friends, relatives and caregivers, including both men and women. One must hear Adam's many funny experiences in caring for his wife Marge to appreciate all the humor caregivers must possess. Usually our group has between 2 to 22 people in attendance. Refreshments are always served. The first meeting of 2002 will be held in April. Watch your mail for the notice.

I am happy to be of service to you." – Barbara Sharkey



Barbara Sharkey (standing center) with members of the Wisconsin Support Group

HOUSTON SUPPORT GROUP NEWS

Silent Fundraiser Raises \$2,000 to Mark PSP Awareness Month

The Houston support group members are dispersed over a sprawling geographical area. Some who live in Houston drive 75 miles or more round trip to monthly meetings. Many members are employed full-time, have teenagers, too, and may also contribute to the care of a family member with PSP. Still others provide either full-time care, or may work full-time and provide care after working hours. Distance and family commitments, therefore, make it impossible for most members to lend the time it requires to help plan and stage special events to mark October PSP Awareness Month. Consequently, the suggestion that the group hold a silent fundraiser was a welcome compromise.

Each member was given two envelopes: a 4x6 opaque security envelope bearing the name of the Society (but no address), and a second letter-size envelope pre-addressed to the group administrator. Each participating member then placed a donation check in the security envelope—along with appropriate acknowledgement information for the Society's reference if the donation was made either in memory or in honor of another individual. The security envelope holding the donation was then mailed to the group administrator in the mailing envelope provided to be forwarded to the Society office at the fundraiser's conclusion.

The donation envelopes were collected over a six-week period and then sent altogether by registered mail to the Society office for tabulation. This procedure meant that everyone who wanted to make a contribution could do so anonymously in any amount, no matter how large or small, and no one in the group, not even the person collecting the contributions, would know who had made donations nor the amount of any individual donation. Our contributions were collectively made in memory of those Houston group members lost to PSP since the establishment of the Houston group in May 2000. The Society reported that our silent fundraiser raised \$2000 to mark October PSP Awareness Month.

The unique Concierge, a multigenerational skilled care community which focuses on special care patients with neurological disorders or dementia, welcomed the Houston support group to the gratis Christmas luncheon it offered to the group as part of its community outreach commitment.

For entertainment at the luncheon, the group held a drawing for gifts contributed by each member who attended the luncheon and for the additional gifts solicited from the community. The latter included one-night hotel accommodations for two at the Doubletree Post Oak, the Hilton Westchase, the Hyatt Regency, the Sofitel, and the Casa del Mar in Galveston. Academy Sporting Goods, Dillard's Department Store, Randall's Food Markets, and Salt Grass Steak Houses provided generous gift cards. Spec's Fine Foods and Spirits donated a holiday gift basket of wines and cheeses.

Every group member who attended appreciated the generosity of the Concierge, grateful for its special gift of a Christmas luncheon—for the food that was so tasty and artfully presented and for the remarkable service that was so attentive it made our members feel like paying guests at a very fine restaurant.



The Christmas Gift

This Christmas our family wanted to do something special that would bring the true meaning of Christmas into play with our traditional family gathering. We exchanged names as usual, but limited our spending on the gift to \$5.00 and asked that the remaining amount of what would have been spent on the gift go into a family "donation bucket" for the medical research for PSP.

When our special family member, Jerry Heizman was diagnosed with PSP, we began to search out any information we could find on this disease. The Society For PSP newsletter has become a great source of helpful information to us.

Please find enclosed our family Christmas letter that was sent out to family members indicating our wishes this Christmas, a picture of two of Jerry's grandchildren, B.J. and Ashley Wanninger, holding the "donation bucket" along with their letters they wrote themselves, as well as our family donation of \$280.

Our family has witnessed first-hand the effects of this disease on the person, caregiver and those that love them. Please accept our donation in honor of Jerry, and his wife and caretaker, Marlene Heizman. We hope that in some small way it will be helpful in the continuation of medical research that may help others who suffer, those that are yet to be diagnosed and maybe, one day, a cure.

Sincerely,

The family members of Jerry and Marlene Heizman
Barry Wanninger, Alice Wanninger, B.J. Wanninger, Ashley Wanninger, Stephen Wanninger, Denise Bruce, Brenda Wanninger, Stephen Wayne Wanninger, Dustin Wanninger, Tanika Wanninger, Pam Heizman, Virginia Hartmann and Alfred "Hup" Hartmann

Our Journey With PSP

Bernice Bowers,

Caregiver & spouse of Kenneth Bowers age 73, dec. 6-23-00

Dear Nancy,

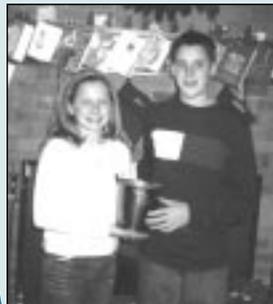
Our journey with Ken's disease may help others to realize the importance of brain donation and receiving a final diagnosis, to say nothing of the benefit it may be to those suffering in the future. We first noticed what we recognized as symptoms about 1988 when Ken complained that when he got up out of a chair, he felt like he was going to keep going forward. Shortly thereafter, he complained of a frequent slight tremor in his leg and arm. I was not too concerned, as neither of those seemed too serious. However, when he began to lag behind in our frequent walks and hikes, and not swinging one arm, we became more concerned. He had a strong heart, good blood pressure and no apparent other health problems. He never smoked, was a firefighter for 30 years, drank only socially, worked out and was a strong athletic man before this disease. However, in retrospect, we have wondered if a severe bout of depression and stress, which he went through in 1981, was connected with this disease or just a mere coincidence. That was the cause of his retirement from the fire department when he was in early 50's.

We started out with a visit to our family doctor (an HMO GP). He diagnosed him with PD, but said it was a mild case. Knowing nothing about the disease, we requested a referral to a neurologist. He turned out to be not a lot more informative. He stated it was a slight case of PD but not bad enough to medicate. He stated meds were worse than the symptoms. We requested another opinion, which the HMO would not approve

We took him to another neurologist on our own. He also stated it was PD and put him on Sinemet. We noticed no cessation in the progression of his disease; in fact it seemed to be progressing very rapidly. They kept increasing the dose of Sinemet and trying Parlodel, and other enhancers but the progression continued. He began falling, freezing steps, stuttering steps, and a dragging footfall – sorts of mobility problems. His voice became very soft, handwriting illegible and impossible after a while. Impotence and incontinence followed. After falls in which he broke his hip and needed a total hip replacement, six months later a shattered femur on same leg, he was never able to walk again unaided. He went into a wheel chair in 1993. I took him to Barrows Neurological Center in Phoenix when they were doing Parkinson's drug trials and he was turned down the first day of trial because they said he did not have Parkinson's. They did MRI, PET, and some other tests, and knew something was wrong, but couldn't make an exact diagnosis. Our home neurologist, who was well respected in his field, was not in agreement with that diagnosis and insisted he did have PD, as he had plenty of PD patients just like that. Later, I wondered how many he misdiagnosed.

Next, we went to Loma Linda where they were doing surgery for PD. When they examined Ken, they diagnosed it as either PSP, MSA, or SND which they explained were all different but hard to differentiate neurological diseases. They advised taking him off all medication for PD as it was not helping and could conceivably cause harm. Difficulty eating and the inability to cover his mouth when coughing or sneezing

Continued Page 22



Ashley & B.J. Wanninger

I would like to make a donation to find a cure PSP. I have found it lttky to be very hard to understand my grandpa and I hope with this donation it could help another person that could have the same future, I can still remember when my grandpa would tess with me and play with me but now it is very hard for him to close, I would like preventing this from happening. My grandpa has scars all over his body because of falling so much because of his disease. I would like to make this donation so no other grandson or granddaughter has to go through what I go through when I see him because I love him dearly. Hope you find a cure, B.S. Wanninger

I have always been my grandpa's little girl. Now that I can barely understand him, the way he looks at me, I can not understand what he is trying to say but he is trying to tell me that he needs something or wants to tell me something. I wish that my grandpa could still do some of the things that he did do in the past. I hope that my grandpa gets better, but know he won't. Maybe this money can help another grandson or granddaughter so they can tell their little girls that they love them.

Always my grandpa's little girl
Ashley, Age-9
I Love My Grandpa

Support - Our PSP Stories

Continued from Page 21

Our Journey

made it very difficult to take him out. His condition was worsening so rapidly that I needed to move to Ohio where I had some family, as he was no longer able to travel. I bought a van equipped with a ramp and drove him from CA to Ohio in his wheelchair, as he was unable to get on a plane. No fun getting him in and out of hotels, motels, restaurants for 5 days, but we made it.

After connecting with a new GP, Ken was examined at Ohio State University and diagnosed as having PSP from a specialist in that field. He was now taking no meds, except BP meds. I connected with the PSP online group and the Society for PSP to learn more about the disease. He followed right down the line with others in their symptoms and problems. It never really occurred to me that we had not reached the final diagnosis. He "fit" with this group of people. There were some differences, but so many similarities. Ken never complained much of pain, even when he had falls. He lost his ability to speak. He could no longer focus his eyes to read or watch TV and became very light sensitive. We had to keep the room dark. He developed aspiration pneumonia from silent aspiration and was hospitalized for 2 or 3 weeks. He began losing weight. He lost 50 pounds before the bout with pneumonia, and they then inserted a peg tube. He never ate again. He received all food, water and meds by peg tube. He became very rigid. In 1995, I began to use a Hoer lift to transfer him from bed to wheelchair, where he would sit the biggest part of the day. We went through all different types of physical therapy early on and again later. Also speech therapy. All helped minimally and temporarily. Nothing lasted. His head was thrust back and he could not move it down. He could not open his eyes without my help and then could only hold them open a short time. He slept a lot during the day in his wheelchair but he never complained. He did gain his weight back on the peg tube, but had to have an indwelling catheter, and had serious bowel problems ranging from diarrhea to bowel impaction.

By the time of his death in 2000, he was rigid, but his mind still appeared to be intact. He knew everyone; it was obvious, and attempted to let you know he understood by a slight squeeze of the hand or a blink. We talked to him a lot, read to him, played music for him. I was his sole caregiver and rarely left the house for the last 5 years of his life. As we looked back over the years, we remembered several tell-tale signs that seemed to lead up to this before the first symptoms he complained of, like his stumbling in our square dances and ballroom dancing. At the time we didn't connect all this.

We had discussed brain donation long before his death. He wanted to do that. To say I was surprised when they concluded from the autopsy that Ken did not have PSP after all but Multiple System Atrophy (MSA) is a gross understatement. I was absolutely stunned. I couldn't even comprehend it for a while. I had identified with all the other caregivers of PSP for so long, and compared all like symptoms there was no doubt in my mind that was his disease. I had spent so many years learning about PSP, and living with it (I thought) that I needed a period of time to adjust. I now am going forward now learning all I can about MSA. It was very important to our children to have an exact diagnosis. It was also important to me.

Submit your PSP stories for publication in the PSP Advocate. Deadline dates are Feb. 10, May 10, Aug. 10, Nov. 10. Please send your stories/photos to The PSP Advocate Editor at NancyB501@cs.com or to the Society office.

Hughie's Story



My father, Hughie Lewis, died September 5, 2001, barely 18 months after being diagnosed with PSP. Although we came to realize that he exhibited many symptoms associated with the early stages of the disease for quite a few years before a neurologist gave a name to it, the period of time in which he was significantly debilitated by PSP was brief. It was nonetheless very painful for my sister and me to see our brawny, athletic father become less able to perform the physical tasks we all take for granted. Our larger-than-life daddy, our very own hero-in-residence, had always seemed invulnerable—at least to us—to the aches and pains we mere mortals suffer.

His story is one of success wrestled from humble beginnings. He spent his early years helping his widowed mother work the family farm, mentoring to a passel of cousins and nephews who idolized him. He played football and relished the role of "B.M.O.C" both in high school and at Wake Forest University, and he served in the U.S. Army and the N.C. National Guard with honor and distinction. Most importantly, both to him and to us, he brought his own brand of gentle sternness and goofy antics to the task of helping our mother raise their two high-spirited daughters. Rising to these challenges had made his spirit as strong as his body. I dare say we expected him to be moving furniture and bossing us around until he was well past his eightieth year. This diagnosis, made when he was just 63, stunned us all.

Because Dad was an intensely proud man, born to a generation that took care of its own and did not complain, we worried that he would neither ask for nor want to accept the help we knew we would eventually have to provide him. But here is where he proved his true mettle: he put his safety and our peace of mind before his pride. I can only imagine how difficult it was for him to stop working when balance problems made his job as a security guard too hazardous; to stop driving when vision and equilibrium problems kept him from judging distances properly; to stop cooking for himself because we worried he might stumble in the kitchen and get burned; and, finally, to use a walker for balance and support, not just at home, but out in public.

I say I can only imagine this because he made these decisions privately, based on the advice of his doctor and the concerns my sister and I expressed, and did not bemoan his fate. Were the changes painful for him? I'm sure they must have been. Did he fear his future? He must have. Was he sometimes discouraged or mortified by the changes in his

Support - Our PSP Stories

body? Almost certainly. But his determination to maintain his mobility and preserve his strength, to postpone further dependency, made him a favorite among the PTs and OTs at his clinic; and his enjoyment of televised football games and a good Southern meal never diminished. Most importantly, he never gave up on living or saw himself as a victim. As his speech became less fluent and a bit slurred, as his features became less animated, as his movements lost their grace and his eyesight its keenness, this father taught his children the most important lesson of all: unflinching courage in the face of desperate odds.

But the full measure of this courage was not to be tested. Daddy died in his sleep, in his own bed in his own home, while he was still able to walk, feed himself, talk, and see. We believe the cause of death was aspiration due to PSP, but it could have been some other natural cause. And while we mourn his passing with a tremendous sense of personal loss, those of us who loved him find comfort in knowing that he was spared further progression of the disease.

His memorial service, held in his hometown of Warsaw, NC, was a testament to the impact our father had had on so many people. Tales of football games won, practical jokes played, sports fans delighted, honors bestowed, goals accomplished, lives touched—they reminded us what an extraordinary man Hughie Lewis was in the prime of his life. I want now to bear witness to what an extraordinary man he was in his final challenge, in facing the uncertainties of PSP with wisdom, hope, and courage.

Through The Eyes Of A Granddaughter

By Lauren Goldberg

Let me tell you a little bit about someone very important to me—my Grandpa Arthur. Grandpa has always been there for me, from the time I was born 13 years ago, to the present day. For years my family and I used to see my grandparents every other week. Grandpa, who is now 73, loved to swim and play with my 9-year-old sister Allison and me all the time. He was always joking around and making us laugh. Grandpa

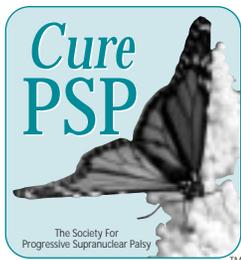
used to come to my house for parties and go to my dance concerts and piano recitals. We loved walking together around his neighborhood on warm summer days.

A couple of years ago Grandpa had a few minor falls. One day when my grandparents were visiting, he stumbled while trying to get up off of our piano bench. I didn't know what was suddenly causing his balance problems, but I was just glad he wasn't hurt. Gradually, I saw his health deteriorating. He started to fall more frequently, his eyes were more tired, and he had much less energy than I had ever remembered. Even though we couldn't do the things we used to do together, I still loved visiting my Grandpa. For a long time Grandpa's doctors couldn't find anything wrong with him. Then some doctors thought he had Parkinson's disease. Only recently was his disease diagnosed correctly as PSP.

Now Grandpa's symptoms are much more severe. He can only keep his eyes open for a very short time, is wheelchair bound, and has trouble sleeping. He needs around the clock assistance doing everyday activities that most of us take for granted. These are just a few of the symptoms that my Grandpa has to suffer with every day. Although he takes many medicines to help ease his symptoms, he still asks whether there is a miracle pill that can cure him. I hope someday soon that his wish will come true.

In early September my grandfather was in a New York City hospital for a few weeks of rehabilitation. On September 11th we were worried about his safety because we couldn't get into the city to see him. A week later, my dad asked me to accompany him to visit Grandpa. At first I was nervous to go into New York City so soon after the attack on the World Trade Center, but then I realized that it was even scarier for Grandpa to be alone in the hospital. It meant so much to Grandpa to have someone by his side to keep him company and to hold his hand.

I've learned through my Grandfather's struggle with PSP how important it is for family members to be supportive. My family, along with my father's siblings, and aunts and uncles pitch in whenever they can. Unfortunately, most of the burden falls on my grandmother and his aide for his day-to-day care. With everything he is going through, my Grandpa still makes us all laugh. PSP has taken away his balance, power to walk, and many other abilities, but it hasn't taken away his sense of humor and the love he has for our family.



"The PSP Butterfly Pin of Hope"

The Society for PSP is pleased to offer 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 second 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. The Society is also thankful to our donors, *Barbara and Jack Kelley*, for the initial and second 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.

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

Helpful Hints

Editor's Note: This information is provided as a service. Please contact your physician to discuss these "Helpful Hints" and the needs of your family and loved one diagnosed with PSP. If you have any hints, medical devices, equipment or services you can recommend to other PSP families, please contact The Editor. The Society DOES NOT ENDORSE any products discussed and neither the Society nor its staff has financial interest in any of these products.

Dear Nancy,

Finally, here is the letter I promised to write. Let me know when you receive it: (It was duly edited by my wife.)

I am 51 years old. I have been diagnosed with PSP. The symptoms first occurred following major surgery. It took doctors and specialists almost a year to diagnose my illness, partly, I believe, due to the "young" age at which the symptoms first appeared. I was 43.

Could trauma have caused the early onset of symptoms, and the disease, to manifest itself? Doctors aren't sure as of yet. However, I'm aware of other cases wherein the symptoms of PSP began in conjunction with a traumatic experience. I hope doctors are looking for a possible connection here.

The thrust of this letter, however, is my lack of ability to speak clearly, and the help I have found. Next to my loss of balance, this loss of my ability to talk clearly and with understanding to family, friends, and doctors has been extremely frustrating. Maybe I've found an answer.

In December of 2000, I attended a conference which featured augmentative communication machines. I was searching for any way to allow me to communicate better. At the conference, I discovered PIAT, the Pennsylvania Institute of Assistive Technology.

To a Pennsylvania resident, and upon completion of an application, PIAT will loan any machine to which they have access, at no cost, for a six-week trial practice time. I urge PSP patients in other states to explore what may be available to them. However, for anyone interested, a phone call to PIAT could be well worth your time. Their telephone numbers are: 215-204-7428 (voice), and 215-750-7428 (TTY). For those out-of-state, PIAT, at the least, may be able to tell you about a similar program in your own state. During the six weeks that I had a machine, I learned how to operate it to see if it would benefit me. In addition, I worked on obtaining funding to assist me in the acquisition of my own machine.

The machine—which I now own—is about the size of a laptop computer. Its main screen has lower case typewriter displayed keys for spelling words not included on the different screens which you can access by the touch of a button. (There is a shift key for upper case letters). The main screen also has commonly used pronouns, verbs, and adverbs. The touch of a key displays the word or letter chosen in a blank area located in the upper center of the screen. By touching this area, what's "typed" is spoken by a preselected male or female voice. The user can also change screens, add screens, or add buttons to suit his or her lifestyle. Plus, one can type communications (sentences and paragraphs) and save them

for later use. One example of how I use the machine is that before my doctor's appointments I enter the information I want to convey to him or his staff into it. Since it is now pre-entered, I merely press the key to play the recorded message and save everyone's time. Before this I would have had to repeat myself several times until they understood me. There is much that I still have to learn in its use, but it has given me a much needed method of communicating. What's also amazing is that this machine can even be connected to a personal computer.

If you, like me, desperately want to communicate better, you owe it to yourself to give augmentative speaking machines a try. There are several companies that offer them. Anyone wishing to have a one-on-one discussion with me can feel free to contact me through my e-mail. My address is: drag-onfly0023@hotmail.com



More Helpful Hints

Ken Hodge

COMMUNICATIONS

If the person with psp (pwpsp) has difficulty writing or speaking, a personal computer (PC) may provide a medium for communicating. You can do the following:

1. If the patient's vision is affected, or you suspect there is a reading difficulty, the small letter size can be changed to a larger font for the monitor.
2. If there is a problem with the hands' fine motor control, the keyboard characters' repetition rate can be reduced to help eliminate unwanted repeated letters as a consequence of inability to just tap the keys.
3. If unwanted letters are typed while attempting to touch type or 'hunt and peck' because more than one finger strikes a key at the same time, an eraser-tipped unsharpened pencil can be used as a stylus to better enable depressing only one key at a time.

MEDICAL EMERGENCY

If a pwpsp has a medical emergency when away from home (e.g. suddenly taken ill, involved in an accident), a medical professional you've never met before may have only moments to make decisions about his/her care. If the pwpsp and/or traveling companion are unable to provide information quickly on PSP-plus medications, physician and family contacts, etc.—not having this information could adversely affect obtaining the needed care. This underscores the need to carry along Advance Directives, Durable Powers of Attorney for Health Care, a medications list, PSP information, etc. as we are frequently advised.

As a back-up measure, my pwpsp and I acquired internationally recognized Medic necklaces which highlight our medical problems and provide a 24-hour toll-free emergency medical information source. To subscribe or for more information, call 1-800-432-5378. (I am not otherwise connected with this organization.)

ORIENTATION

1. A non-ambulatory patient with little or restricted head movement may find a hand-held mirror handy for peering to the side or to the rear, thus expanding the useful field of vision.
2. To reinforce calendar awareness, I found it helpful to place an office-type 'one-day-at-time' wall calendar where it was easily seen by the pwpsp. These are

Helpful Hints

usually about 7"1 x 9" with a background in large letters reading "Today Is." Tear-off pages for each day show the month, year, and day's name in smaller print, and the day's calendar number in 3" high figures. Early in the day, the prior day's page can be removed ceremoniously, revealing what "Today Is!"

3. Now that the day is on display, a useful adjunct is a digital clock with at least 2" high illuminated numbers; the clock may simply be a timepiece or may include an alarm function or be a clock-radio. The illuminated numbers facilitate readability in low light conditions or at night. Not to be overlooked for special circumstances are specialty clocks which project time numbers on the ceiling, or speak the time at a touch of a button.

WHEELCHAIR ADAPTATIONS

Foot and leg problems experienced by pwpsps often are more than can be accommodated with the footrests commonly available on wheelchairs. Feet and legs have a way of slipping off of, or between, the usual footrests, with the potential for injury when the wheelchair is in motion. To address this problem, I made a vertical and a horizontal panel to comprise a solid backpiece and floor, respectively. The panels were cut with a SkilSaw from 3/8" plywood and padded with 1" foam cut from an exercise floormat found in sporting stores and attached with contact cement. The padding was recommended by a physical therapist.

Tabs on the panels enabled them to be held in place when the normally removable footrests were swung forward and locked in place. Conversely, the panels more or less fell out of place for easy removal when the footrests were swung outwards during removal, prior to folding the wheelchair.

Because wheelchair designs differ, some Yankee ingenuity, custom design, and trial and error will be necessary. I worked with corrugated cardboard as patterns for fit checks before cutting the plywood panels. Even so, I had to perform some minor trimming on the panels themselves for best results.

Dear Nancy,

I have found a new product that may be of interest - the "Airlift Toileting System." It is a hydraulic lift system that fits on top of a standard toilet seat (there is also a bedside commode version) that aids a patent in getting on or off a toilet seat. Weight capacity is up to 270 pounds - that is, the mechanism will lower or lift a person of up to that weight. It's very much like a lift chair for the toilet.

This looks promising for my PWVSP mother. Either assisted or unassisted, she can no longer safely sit on or get up from a toilet seat; this is one of the major causes of falls. A lift toilet seat would offload the weight from a caregiver as well. It looks simple to use. I suspect that Hospice or Medicare would pay for it; I don't have retail costs but I suspect that it would be in the \$400 range.

I found out about this from my sister-in-law, who works for a medical supplies company. She is familiar with PSP through my mother, and thought this would be of interest.

Michelle

Daughter of Patty (71/diagnosed 2 years, symptoms 4 years)

ATTENTION CALIFORNIA RESIDENTS

Coast Caregiver Resource Center serves caregivers of adults with degenerative diseases of the brain. A range of services are available, including financial assistance toward additional caregivers, legal advice, home safety advice and counseling. For further information, call 1-800-443-1236.

Glossary Of Terms

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

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

BLEPHAROSPASM - forced closure of the eyelids.

BRADYKINESIA - Literally, "slow movement."

BROMOCRIPTINE - a dopamine receptor agonist.

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

DEMENTIA - a progressive decline in mental functions.

DYSPHAGIA - difficulty with or abnormality of swallowing.

ETIOLOGY - the cause of a disease, or how it is acquired.

FREEZING - inability to move or getting "stuck," as with the feet appearing to be glued to the floor .

GAIT - the manner in which a person walks.

GLOBUS PALLIDUS - a part of the basal ganglia.

LEVODOPA - the chemical precursor of dopamine and the most effective treatment for PD and some try for treatment of PSP.

NEUROTRANSMITTER - a chemical messenger; dopamine is a neurotransmitter.

PATHOGENESIS - the abnormal processes in the body that produce the signs and symptoms of a disease .

PATHOLOGY - the study of a disease process, including what is affected and what it looks like under a microscope.

RIGIDITY - a tightness or increase in muscle tone at rest or throughout the entire range of motion of a limb; it may be felt as a stiffness by the patient.

STRIATUM - part of the basal ganglia circuit; it receives connections from the substantia nigra and contains the dopamine receptors.

SUBSTANTIA NIGRA - meaning "dark substance," the part of the brainstem that produces dopamine.

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!*

Helpful Hints

GIVE A GIFT ONLINE

www.psp.org



Marathon

Shelley Lambrecht and Brett Beard, from Denver, are training for a marathon in honor of Shelley's father, Donald Lambrecht.

If anyone is interested in participating in this San Diego marathon or wishes to make a contribution to The Society for PSP, please call Shelley at 303-561-0662.

"AN AFFIRMATION OF THOSE WHO CARE FOR OTHERS"

by James E. Miller, www.willowgreen.com

I believe in the power and beauty of self-forgetful love.

I believe it shows itself right in our midst, and further that it's showing itself right in our time as you so faithfully provide your caregiving day after day, night after night.

I believe this unassuming selflessness comes to life each time you tenderly do your caring, despite feeling winded or weary; each time you manage countless caregiving details, in addition to all your other ongoing obligations; each time you so freely perform your duties out of love that others would not perform for a much higher price.

I believe your open hearted spirit can be a model for all of us. For you show us the potential of what life can be:

In quietly persevering with another, ordinary days can contain extraordinary moments, moments which will never be forgotten.

In patiently witnessing what another is experiencing, ordinary lives can be enriched and ennobled, lives which will never be the same afterward.

And in lovingly accepting how the other is dealing with all they face, ordinary relationships can be enhanced and enlarged, relationships which are grounded in equality and respect.

I believe that as a caregiver you have much to teach all of us. You teach us that remaining steadfast when another needs us is more than an act of compassion it is a ritual of healing.

You teach us that reaching out when another feels lost or alone is more than a bridge of comfort it is a means of communion.

You teach us that relating to the other as a person who has infinite value is more than an article of faith it is a lived experience of sacredness.

We know these things because you and people like you share yourselves generously, and because of what you do, life is not the same not for you, not for those around you, and especially not for the one who is bathed in your magnanimous care.

REMINDER OCTOBER IS PSP NATIONAL AWARENESS MONTH

October 2002 is designated as our Third Annual PSP Awareness Month. This is the time that we are asking all persons affected by Progressive Supranuclear Palsy to join together nationally and educate others about this devastating disease. Now is the time to start planning your event. Last October, many events were planned around the country and as a bonus, \$18,000 was raised to help support research and the Society's services. Contact the Society office at spsp@psp.org for more information.

Continued from Page 15

Talking About End-Of-Life Issues

of your family. Usually when people have not discussed something from the past, they are uncomfortable, embarrassed or guilty about it. They may also be protecting a family member (even one who is deceased). In general, I think that one can at least raise the possibility of talking about the family history because you are interested in learning the truth out of respect for family members rather than condemning anyone for behavior or poor judgment. It can also take a burden off of an older relative's shoulders by sharing the family secret. They may choose not to tell you about it, but asking them if they want to talk about it is a good way to open the discussion.

WHEN THEY HAVE DEMENTIA

As any of you who are caregivers know, it becomes hard to know how much a person with dementia comprehends what is said to them. So often, the difficulty of coping with the loss of the persona of the other leads us to not try to communicate at all. I still think that if you have something you really want to say to a parent with dementia, you should say it with the hope (but not necessarily the expectation) that they will understand what you are saying. If you have not said "I love you" much, it is probably far better to say it (if you mean it) while they are alive even if they may not understand you. Anything else would follow the same guide.

As a closing note, think about putting several of these issues together. You can always raise the topic by stating "I read something interesting on the Internet, there's an author who says we should talk about wills, estates, advance directives and even funeral plans so everyone knows what their parents want. What do you think about that?"

And, what do you think about that?

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<http://www.ec-online.net>

Mark Edinberg is a psychologist, author, organizational consultant who has been working in the field of Gerontology for 30 years. He has been a professor at the University of Nevada, Reno and the University of Bridgeport, for the last decade, and is in private practice primarily working with older adults and their families.

Research

Continued from Page 7

“Cross-linking of Tau in PSP Neurofibrillary Tangles”

Funded by The Dudley Moore PSP Research Fund
\$50,000

“Cross-linking of Tau in PSP Neurofibrillary Tangles”

Nancy A. Muma, Ph.D.

Professor of Pharmacology

Loyola Univ. Chicago

The studies outlined in this proposal are designed to fill important gaps in our knowledge of the mechanisms involved in the pathological changes in PSP and other tauopathies. The mechanism(s) involved in neurofibrillary tangle formation, specifically those leading to tau polymerization into filaments are unknown. Mutations in the tau gene lead to increased expression of 4R tau or tau that binds poorly to microtubules and neurodegeneration in FTDP or PSP. Increased expression of 4R tau also occurs in PSP and may therefore impact on NFT formation in PSP as in FTDP. However, increased expression of 4R tau in either cells in culture or in transgenic mice does not result in the formation of tau filaments or NFT. Other mechanisms are likely needed for the formation of tau filaments in addition to an increase in 4R tau. Oxidative injury and increases in cross-linking of tau by trans glutaminase are two possibilities for these additional mechanisms that will be examined in the studies proposed herein. By understanding the mechanisms that underlie the cross-linking of tau and the formation of neurofibrillary tangles, we can begin to design rational treatment approaches. The studies proposed in the grant include a first step to treatment by examining the effects of a trans glutaminase inhibitor on the cross-linking of tau protein in cells in culture. If the inhibitor successfully prevents the cross-linking of tau and tau polymer formation in cells, we can test the inhibitor in transgenic mouse models of tauopathy.

A current hypothesis on neuronal cell death in neurodegenerative diseases with neurofibrillary pathology implicates tau as a central player (Trojanowski and Lee 1994; Spillantini et al. 1998; Poorkaj et al. 1998; Hutton et al. 1998; Hong et al. 1998). The neurofibrillary tangles and neuropil threads displace cellular organelle and may interfere with normal neuronal function. Conversely, loss of functional tau protein may also lead to neuronal dysfunction and cell death. Drugs that

inhibit transglutaminase may prevent the sequestration or stabilization of tau into filaments and thereby prevent synaptic loss and cell death, and ultimately may be beneficial in the treatment of PSP and other neurodegenerative diseases with neurofibrillary degeneration.

“Cortical and Striatal Cholinergic Receptor Subtypes in PSP, Alzheimer’s Disease and Dementia with Lewy Bodies”

Funded by
The Eloise H. Troxel Memorial Research Fund
\$46,314

David J. Burn, M.D.

Newcastle General Hospital, UK

Regional Neurosciences Centre

Department of Neurology

Co-applicants: Andrew J. Lees, Margaret A. Piggott

Aim: To specify cortical and basal ganglia muscarinic cholinergic receptor changes in progressive supranuclear palsy (PSP) and to compare these changes with those found in dementia with Lewy bodies (DLB) and Alzheimer’s disease (AD). We will examine the hypotheses that presynaptic muscarinic M2 receptors are significantly reduced in frontal cortex in PSP, with elevation of muscarinic M1 receptors; and that striatal M1 receptors are decreased, reflecting loss of striatopallidal neurons (also bearing D2 receptors), that M2 receptors are decreased reflecting cholinergic interneuron loss, while M4 receptor density on D1 bearing striatopallidal neurons is maintained. This project will explore the equivocal response of PSP patients to cholinotherapy, in contrast to the significant benefits obtained in DLB, by examining these muscarinic subtype changes. These results will provide a scientific rationale for the future development of cholinergic drug treatments for PSP.

GRANT ANNOUNCEMENT:

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

Regular Grant Program to \$50,000 - Deadlines are April 1 and October 1.

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

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.

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



Report Of Gifts - November 16, 2001 thru February 15, 2001

The Society for PSP extends its thanks to our donors who have given so generously to help find the cure for PSP while helping families meet their difficult challenges.

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Lawrence & Barbara Hauri - In memory of
Barbara Hauri
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Gertrude V. Musko
Jeff & Janice Hausman
Richard & Mary Rose Hausman
James & Lynda Hawkinson - In memory of
William Tuomi
John Hayes - In memory of Geraldine Hayes

Robert Hayles - In honor of Nancy Hayles
Sarah Hellebush - In memory of John Hellebush
Richard Hilden
Patricia Hinckley - In honor of Charles Hinckley
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Winifred Hinze - In memory of Robert W. Hinze
Morris & Ruth Hirsch
Kenneth Hodge
Mary Holman - In memory of Rae Arnold
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Lindberg Hornbeck
Eric Huckabee - In memory of Charles T. Bishop
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Imo Pump
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Nicholas Internicola
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Marcia Jackson
Pearl Jackson - In memory of Gen. Clarence Jackson
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Robert Jeffrey - In honor of Jean F. Jeffrey
Bobby Lee Jenks - In honor of Willie Jenks
John & Viviana Jenner - In memory of
Joseph Latragna
Thomas & Karla Jennison -
In memory of Clayton Gute
Tom & Carolyn Jarvis - In memory of Albert Roland
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Harold Johnson
Janice Johnson
Richard & Jean Johnson - In memory of
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Patricia Johnston - In memory of William F. Riley
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Lesley A. Jones - In memory of Elizabeth Jones
Marcia Joseph
Jean Kahr
Stephen & Stephany Kalil - In memory of
Shirley Patryn
Jacqueline Kathe - In memory of Robert Cooney
Virginia Kay - In memory of Eldred Kay
Bruce Keener
William Kelly - In honor of Catherine Kelly
Thomas Keneshea
Karen Kennemer - In memory of
Mary McNicoll Cheslak
Joan Kerssenbrock - In memory of John Clements
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Walter Kleinpeter
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Alfred Berger
Maddy Licata - In honor of Jack Anderson
Patricia Like - In honor of K. Kennemer

Report Of Gifts

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Thomas Maguire
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Kathryn B. Marshall
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Matthews United Methodist - In memory of
Gloria Lloyd
Thomas McCarty - In memory of Billie Jean McCarty
Kelly McClellan
W. J. McClendon
Arlene H. McCutcheon - In memory of John Slavik
John & Estelle McDaniel
Philip McGowan - In memory of
Elizabeth McGowan
John McGrath
David McKinstry -
In memory of Phyllis Johnson
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Charles C. Hinckley
Judith McNicoll
Stanley & Barbara Meisel - In memory of
Alfred Berger
Greg Mendel - In memory of Robert Mendel
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Dottie Barnett
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Norman R. Meyers
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John Harold Brown
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Steve & Lenore Miller - In memory of
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Connie Mitchell
Ron Mocogni
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Dottie Barnett
Dorothy & Joseph Mormando -
In memory of Ted W. Brockmeier
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Betty Jo Mayes Murfey
Sheridon Murphy - In memory of Roylene Murphy
Lew Nadien - In memory of Bonnie Nadien
Sheri & Howard Neff - In memory of Dottie Barnett
Marcella Nelson
Marjorie Neuwirth - In memory of Beatrice Goreff
James & Mabel Nevins
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Thomas Allen Nichols
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Claude O'Connor
Linda O'Hare - In memory of W. E. Ellingsen
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John O'Rorke - In memory of Joanne O'Rorke
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John Coleman

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Janice Penn - In memory of John Slavik
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PLEASE MAKE ALL CHECKS/GIFTS TO "THE SOCIETY FOR PSP."

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- #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.
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As we went to press, Dudley Moore tragically passed away from PSP. Another precious life was taken from us... a gifted man whose talents touched all of us. The Society for Progressive Supranuclear Palsy will strive to keep Dudley Moore's memory alive by acknowledging that he brought his diagnosis before the public so that the world would become aware of PSP. He also established the Dudley Moore PSP Research Fund so that a cure could be found.

Thank you, Dudley. We will miss you.

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