

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

Denny Neagle, Cincinnati Reds Pitcher, "Strikes Out" PSP



INSIDE

*A Decade of
Caring-Part 2*

LA Symposium

AAN 52nd Meeting

Denny Neagle, one of the National League's top pitchers, has stepped up to the mound to strike out against PSP. Denny's father-in-law, Jim Gray, of Lakewood, Colorado was diagnosed two years ago with PSP. Denny has pledged \$100 per strikeout to establish the "Denny Neagle Strike Out PSP Fund". With an average of 150 strikeouts per season, Denny hopes to raise \$15,000 for the Society. Denny has asked Society supporters to also make a matching gift of any amount. Please sign up on page 3 to help Denny com"bat" PSP. Watch out for a "Special Event" in the fall when Denny will present his gift to the Society!

Denny and his wife, Jennifer, who live in Colorado near Jennifer's parents, believe that this gift will raise awareness as well as funds. At each game, TV and radio announcers have been mentioning the Society and PSP's name as Denny

makes strikeouts. His pledge is also printed in each program. Jennifer Neagle expresses that "The hardest thing is seeing my Dad go through this with no known cure. Hopefully, Denny's contribution will help so no one else will have to go through this."

Denny feels that "As professional athletes, we have the ability to make rare diseases visible. Some athletes put their names on a disease or a charity of which they know nothing about or have no connection. In my case, it hits close to home and I can make more people aware of PSP. It's tough on my father-in-law because his mind is still there and he is totally dependent on others. He realizes everything that is happening to him."

Thank you, Denny, for your terrific efforts!

Now is your chance to "step up to the plate" and meet Denny's generous pledge!! Get your friends to "step up to the plate," too!!

The Society for Progressive Supranuclear Palsy

FOUNDERS

Reba and David Saks

HONORARY CHAIRMAN*

John C. Steele, M.D., F.R.C.P. (C)
Fellow, American College of Physicians
Core Director Micronesian Health Studies

MEDICAL ADVISORY BOARD

Lawrence I. Golbe, M.D., Chair
Professor of Neurology
Robert Wood Johnson Medical School
New Brunswick, NJ

Dennis W. Dickson, M.D.
Neuropathology Consultant,
Mayo Clinic
Jacksonville, FL

John H. Growdon, M.D.
Professor of Neurology, Harvard Medical School
Boston, MA

Joseph Jankovic, M.D.
Professor of Neurology, Baylor College of Medicine
Houston, TX

Andrew J. Lees, M.D.
Consultant Neurologist, National Hospital for
Neurology & Neurosurgery, London

Irene Litvan, M.D.
Chief DVHJP Neuropharmacology Unit
Jackson Foundation and Medical Neurology Branch
Bethesda, MD

Demetrius M. Maraganore, M.D.
Associate Professor of Neurology
Mayo Clinic
Rochester, MN

David E. Riley, M.D.
Associate Professor, School of Medicine
Case Western Reserve University
Cleveland, OH

Maria Grazia Spillantini, Ph.D.
William Scholl University Lecturer in Neurology
MRC Brain Repair Centre and Department of Neurology
University of Cambridge, Cambridge, U.K.

Eduardo Tolosa, M.D.
Professor of Neurology
University of Barcelona Hosp Clinico
Barcelona, Spain

David S. Zee, M.D.
Professor of Neurology, Ophthalmology & Otolaryngology
Johns Hopkins University School of Medicine
Baltimore, MD

BOARD OF DIRECTORS

George S. Jankiewicz, Chairman

Carol Marchi, Vice Chairman

John Fiedler, CPA, Treasurer

Kelly Ann Harrison, PH.D., Secretary

Bruce Barnett, PH.D

Elizabeth Brisson

Janice Clements

Dale Ferris

Lawrence I. Golbe, M.D.

Howard Hurtig, M.D.

Daniel Lake

Stanley Levin

Jennifer B. Shattuck

SPSP DIRECTOR

Ellen Pam Katz

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

The Society for Progressive Supranuclear Palsy, Inc. (SPSP) is a nonprofit 501-3(C) organization that exists to promote and fund research into finding the cause and cure for PSP. PSP is a rare, neurological disorder related to Parkinson's disease. SPSP provides information, education, support and advocacy to persons with PSP, their families, and caregivers. SPSP educates physicians and allied health professionals on PSP and how to improve patient care. The Society, Director, and staff are under the administration of the Johns Hopkins School of Medicine, Department of Neurology

1-410-486-3330.

Toll Free: 1 (800) 457-4777, FAX 1 (410) 486-4283

Ellen Pam Katz, Director

SPSP, Inc.

Woodholme Medical Building

Suite 515

1838 Greene Tree Road

Baltimore, MD 21208

email-epkatz@erols.com

SPSP@erols.com

website-www.psp.org

List Serve: requests@hydra.welch.jhu.edu

Subscribe psp your name

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

EDITOR

Nancy Ogiba Brittingham

103301.640@compuserve.com

(757) 838-0777 • FAX (757) 838-6086

(In memory of Henry and Jane Ogiba)

TABLE OF CONTENTS

| | |
|---|------|
| Director's Doings | 3 |
| A Decade of Caring-Part 2 | 4-5 |
| AAN PSP Presentation | 6 |
| PSP Brain Bank | 7-8 |
| Identification of a PSP Gene | 8 |
| LA Symposium | 9-10 |
| AAN 52nd Meeting | 11 |
| Ask a Doctor | 12 |
| Rehabilitation Specialists and PSP | 13 |
| PSP-The Ultimate Test of a Relationship | 14 |
| Not Even a Butterfly | 15 |
| Support Group Information | 16 |
| New from Support Groups | 17 |
| Helpful Hints | 18 |
| Our PSP Stories | 19 |
| Report of Gifts | 21 |

Director's Doings



What a weekend. One of the most exciting aspects of my work with the Society is observing, contributing and being managed by the Board of Directors. Last weekend, May 20-21, I observed a work of art in action by the SPSP.

Through 14 hours of weekend meetings held in Baltimore, the Board of Directors performed their service with the four "E's": energy, enthusiasm, emotion and excellence. They accomplished the vital work of leading, governing, advising and strategizing. Highlights of their action-packed agenda resulted in:

- An intensive and extensive review of SPSP finances which have enjoyed astonishing growth and the ability to fund critical research.
- A view of the work of the bustling Development Committee, whose fervent work has expanded initiatives in major gifts, planned giving and special events, including the Denny Neagle Strike Out Fund and the Dudley Moore Research Fund.
- An expansion of efforts to better organize support groups, including a manual and contact person for support group leaders to seek guidance.

- Infrastructure growth by the approving of new bylaws, a conflict of interest policy and approval of six new board members.

The work of the Board represents hours of meetings held by conference calls, e-mails and other methods by Board members and committee volunteers whose expertise and experience is outstanding.

I loved to watch the repartee, give and take, and the synergy in action. The wordsmithing was outstanding and the logical progression of ideas into action plans were formidable.

If you see a more impressive PSP ADVOCATE, a growing list of research grants, a regional seminar, more fundraising initiatives, REMEMBER those Board members who travel quarterly to Baltimore from locations throughout the United States (and soon, Canada), who serve unselfishly and with dedication and commitment and who share their talents, financial contributions, skills, experience and expertise to form a vibrant upward spiral of accomplishments. Remember them. We need to know from where we draw our strength.

With deep appreciation for their support,

Ellen Katz, Director



DENNY NEAGLE "STRIKE OUT PSP FUND"

I Support # _____ Strikeouts that
Denny Neagle makes in the
Amount of \$ _____
Per Strikeout.

My check totaling \$ _____ is in the
newsletter's enclosed envelope.

Your gift will be recognized in the next PSP Advocate's
"Strike Out PSP" Honor Roll.

1990-2000 A Decade of Caring

PART TWO: BY JOANNE ARMSTRONG
THE SOCIETY FOR PSP

1995-2000: OUR SECOND FIVE YEARS OF GROWTH
(Continued from *The PSP Advocate* 1st Quarterly 2000)

The year 1995 was a pivotal, transitional year for SPSP. Volunteers involved with the daily operation of the Society were living great distances from one another and all had constraints which impacted the time they could devote to the Society. David Saks, the founder, was in failing health and had given up his roles as Executive Director and Newsletter Editor. He moved to Florida struggling to fulfill his vision of his responsibilities as a self-appointed "administrator" of the Society. Beth Ness, the Executive Director in Nebraska, had remarried and her husband was anxious to have her company on the many trips he had planned for his retirement years. Dr. Stephen Reich, SPSP Board Chair in Baltimore, Maryland was grappling with an increasing number of patients and academic/research responsibilities at Johns Hopkins.

Two important factors brought focus to the administrative and future development of the Society. First, in mid-1995, the Society moved to shared office space in the Johns Hopkins Hospital Outpatient Center and hired its first staff member. This person was responsible for distributing materials and answering the 800 phone number which had previously been answered wherever the executive director resided. The second factor was Margaret and Claude Vannoy's contribution of \$50,000 later in 1995. This event was truly a catalyst; the first major gift to the Society! It enabled the Society to more than double the funds available for research funding in that year. It also motivated the SPSP Board's decision to initiate a search for a part time Executive Director. The Society for PSP entered the calendar year 1996 with new energy, and a sharpened focus....

1996

- Donations total \$96,000.
- Three \$10,000 research grants and two \$2,000 Summer Fellowships are awarded.
- Five presentations directly related to PSP are presented at the American Academy of Neurology meeting.
- Eleven original research presentations on PSP are included in the 1996 presentations at the 4th International Congress of Movement Disorders.
- Ellen Katz is hired as an Executive Director, to serve 28 hours a week, and to work mostly from her office in her home due to the difficulty in physically placing her with the secretary in the 75 square feet available to SPSP at Johns Hopkins Outpatient Center.
- 3,000 issues of the PSP Advocate are sent quarterly.

1997

- Donations total \$653,140.
- Research grants offered are raised to \$20,000 from the \$10,000 previously offered. Nine projects have been funded in the past three years, a total of \$100,000 distributed.
- SPSP receives its first major gift designated for research — \$10,000 to establish the Jerome and Dorothy Blonder Research Fund.



Stephen G. Reich, M.D., Ellen Katz, Joanne Armstrong and John C. Steele, M.D., F.R.C.P.(C)

- Jay Troxel gives a \$400,000 donation to support research over a period of 5-7 years. Additionally, an Eloise Troxel grant is to be given each year at the \$50,000 level.
- The Fourth Biennial Symposium for PERSONS WITH PSP and Caregivers is presented at a hotel in Baltimore, MD. 240 persons attend.
- Support groups grow to 13 around the nation.
- SPSP establishes a website: www.psp.org
- The Society has a presence at meetings of the American Academy of Neurology and the American Ophthalmological Association.
- Seven presentations of original research on PSP are given at the annual meeting of the American Academy of Neurology.
- The PSP Advocate begins to publish for the medical community a list of periodical/journal articles relating to PSP.
- A feature article on PSP appears on the first page of the "Baltimore Sun" newspaper.
- "Climb for a Cause" is launched, as Roger Brisson seeks pledges for his climb of Mt. Aconcagua in Chile. He plans to ascend the highest mountain in the Western hemisphere, 22,860 feet.
- The SPSP office receives 6,500 phone calls; 3000 informational packets are mailed to inquirers.
- The Executive Director's position is expanded to fulltime; additional employees are hired.

1998

- Donations total \$603,372.
- Nine SPSP research grants are awarded, totaling \$209,000.
- Corporate and Foundation gifts are received.
- The revised SPSP bylaws state that there will no longer be membership dues.

Our Second Five Years of Growth

Continued from Page 4

- First annual campaign raises \$60,000.
- SPSP's Board of Directors institutes a Development Committee which would seek to ensure funding to support the mission of SPSP.
- SPSP outgrows the 110 square feet of space at Johns Hopkins Outpatient Center and moves into the Woodholme Medical Building, Suite 515, 1838 Greene Tree Road, Baltimore, MD 21208. Gifts from Mr. and Mrs. William Budge and Mr. Jay Troxell are used to furnish the space.
- SPSP staff expands to 7; the responsibility of SPSP Advocate Editor becomes a paid position. Nancy Brittingham had been doing the ever-expanding job voluntarily for 3 years.
- John B. Ricker, Jr. in memory of his wife, Jane Darling Ricker, underwrites the cost of publishing and mailing the quarterly editions of the PSP Advocate to 9,000 recipients.
- Roger Brisson raises over \$70,000 from 700 donors for the "Margaret Parker Research Fund". Although health complications force him to stop before the summit, the "Climb for a Cause" flag makes it to the top of Mt. Aconcagua with other climbers.
- A Listserv is developed: requests@hydra.welch.jhu.edu
Subscribe psp your name.
- In November, the Los Angeles Support Group sponsors the First Regional Symposium on PSP.
- Seventeen presentations of original research are presented at the 5th International Congress of Movement Disorders.
- SPSP has a presence at the American Academy of Neurology, American Psychiatric Association, and the Movement Disorders Society.
- The "Eloise H. Troxel Memorial Fund" supports the SPSP Brain Donation Program at the Mayo Clinic Jacksonville, Jacksonville, FL 32224.
- SPSP receives a bequest of \$125,000 from the estate of Frank W. Weymouth.
- The family of Ruth Lindenbaum sponsors the first New York Support Group meeting and generously funds the publication of the updated educational pamphlet "PSP Some Answers".
- SPSP receives 5,700 phone calls on its 800 number.

1999

- Donations total \$713,821.
- Annual campaign yields \$80,000.
- \$260,929 is awarded to ten investigators at prestigious research institutions around the country and Europe. The Society and The Office of Rare Disorders, (The National Institutes of Health) jointly sponsor the First International Brainstorming Conference on PSP March 18-19, 1999 at the NIH. Seventy-eight researchers from all scientific disciplines attend to focus on the cause, cure and management of PSP.
- SPSP Board of Directors embarks on a year-long collaboration by the Board, staff and volunteers to formulate a Strategic Plan for the years 2000-2003.
- A relationship is established with PSP France.
- A portion of the profit from each copy sold of Susan Baggette's children's book *Jonathan and Papa* is donated to SPSP. Jonathan's grandfather has PSP.
- The Fifth Biennial PSP Symposium for Persons with PSP, Families and Caregivers is held November 12-13 at BWI Marriott, Baltimore, Maryland. More than 300

persons attend.

- Ellen Katz, Director of SPSP, is appointed to the Board of Directors of the National Organization for Rare Disorders.
- Dudley Moore, actor, composer and pianist announces that he is receiving treatment for PSP.
- Music for All Seasons creates the "Dudley Moore Research Fund for PSP" in November 1999.
- Dudley Moore's interview with Barbara Walters on ABC's 20/20 brings news of PSP and the "Dudley Moore Research Fund" to millions of homes. Over 20 local ABC affiliates air stories about local persons with PSP.

2000

- Cincinnati Reds pitcher Denny Neagle announces that his father-in-law suffers from PSP. He plans to donate \$100 to SPSP for each strikeout he pitches during the baseball season.
- The Los Angeles PSP Support Group works with the Society and organizes the Second Regional Symposium for Persons with PSP, Families and Caregivers. It is held at the Jules Stein Auditorium, UCLA, Los Angeles. Over 110 persons attend.
- The Society for PSP has an exhibit and distributes materials at the 52nd American Academy of Neurology in San Diego, CA.
- Ellen Katz, Director of the Society for PSP, takes an active role on the Board of NORD (National Organization for Rare Disorders). She is involved with approving new membership applications and in planning NORD'S role in promoting advocacy for persons with rare diseases campaign in Washington, D.C.

As we reach our tenth year, we are proud of the phenomenal upward spiral growth that has enabled the Society to increasingly reach out to persons affected by PSP. With a dedicated Board of Directors, volunteers and staff, our future as an organization is filled with optimism and hope that we can conquer PSP while caring for its victims. We face the future with you, our supporters, knowing you share our commitment.



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

Research Presentations on PSP at 52nd Annual Meeting of the American Academy of Neurology San Diego, April 29 - May 6, 2000

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

The meeting of the American Academy of Neurology is the world's leading venue for presentation of research in clinical neurology each year. The submissions are 300-400 word "abstracts" without the detail necessary for a true "peer review" process. However, the abstracts are reviewed by a committee of experts for acceptability. Although the findings sometimes change before final submission of a full research paper to a journal, these abstracts do provide a good window into up-and-coming research developments.

- ◆ In a project supported by a Troxel Memorial Fellowship from the SPSP, Dr. Irene Litvan and colleagues from Bethesda, Maryland performed a placebo-controlled trial of donepezil (Aricept) in 21 patients with PSP. Aricept is mildly effective for the mental symptoms of Alzheimer's disease, an action that depends on its inhibiting the breakdown of acetylcholine, a brain chemical necessary to mental function. There is an acetylcholine deficit in PSP as well. Unfortunately, this trial found that Aricept actually worsened the movement problem in PSP. There was a very mild improvement in memory. The authors conclude that Aricept should not be used in PSP.
- ◆ Corticobasal degeneration (CBD) is similar to PSP in many ways. The symptoms, mode of progression, and microscopic brain changes can be difficult to distinguish from those of PSP, even by experts. Dr. Massimo Tabaton and colleagues from several centers in Italy have now found an important similarity at the genetic level, too. There is a version of the "tau" gene that is more frequently found in patients with PSP than in healthy people. This study found that version to be similarly increased in frequency in CBD as well. The tau gene codes for the production of tau protein, which accumulates in abnormal clumps in brain cells in PSP and CBD. (It also accumulates in Alzheimer's disease, but that variation in the tau gene is absent in Alzheimer's.) But this new study suggests that another gene, or chemical exposure, acts on the mutant tau gene or protein in PSP but not in CBD. It directs research attention in PSP to factors that modify tau.
- ◆ It has been previously reported by Dr. Joseph Higgins of the New York State Department of Health in Albany and colleagues that a certain combination of genetic variations in the tau gene is strongly associated with PSP. Now, Dr. Higgins has expanded and strengthened this finding in a larger group of patients. This study, supported by a grant from the SPSP, found that only one of the 52 patients with PSP failed to show the abnormal gene. That man had a relatively old onset age of 74, whereas the average for PSP is in the mid-60's. Of the 54

people without PSP, only one third of them had the same combination of genetic variations. This result suggests that a change in, or very close to, the tau gene is a necessary but not sufficient factor for the development of PSP. Further studies will have to identify other necessary factors.

- ◆ Problems in controlling the urinary bladder are common in people with advanced PSP. The reasons for this have been unclear, as many areas of the brain are involved in bladder control. Now, Dr. Tomaso Scaravilli and colleagues from Italy and the United Kingdom have performed detailed microscopical analysis of the spinal cords of three people who had PSP. They found that "Onuf's nucleus," a tiny area at the base of the spinal cord that helps control the bladder, was missing over half of its cells compared to people without PSP of the same age. Moreover, the same type changes that occur in the brain in PSP were present in Onuf's nucleus. This finding may help design drug treatment for bladder difficulties in PSP.
- ◆ In a previous issue of The PSP Advocate, we reported that a group of researchers from Newcastle-upon-Tyne, Bristol and London, United Kingdom found that the prevalence of PSP was about 6.5 cases per 100,000 population, several times higher than previously measured by a less sensitive technique. These researchers, led by Dr. Una Nath, presented their findings at the AAN, emphasizing that they have made progress toward creating a registry of all PSP cases in the United Kingdom. This study was supported by our sister organization, the PSP (Europe) Association of the UK.



Joseph Higgins, M.D., New York State Department of Health in Albany, discusses his Poster Presentation about PSP.

The SPSP Brain Bank: A Look Back On The First Two Years

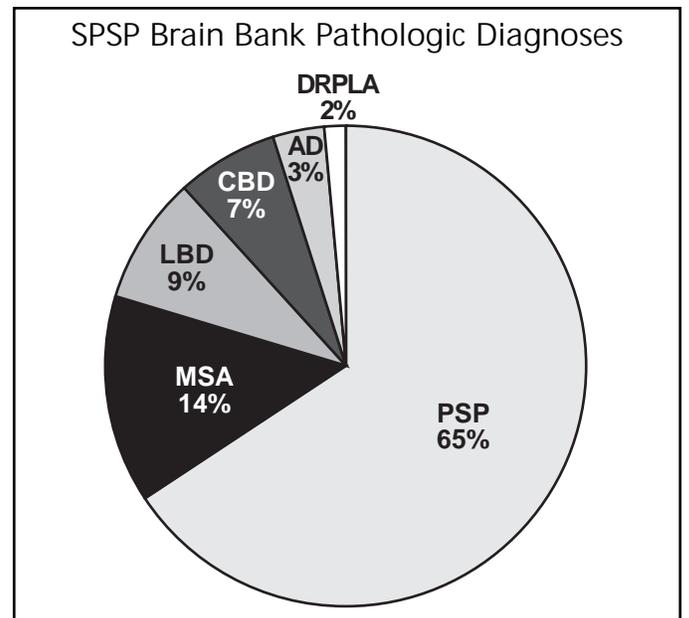
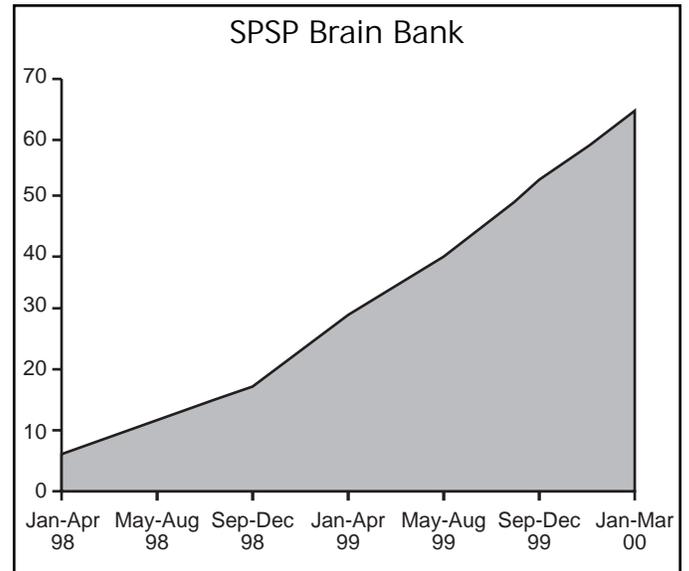
By Dennis W. Dickson, M.D.

The "Eloise H. Troxel Memorial Fund" supports the Society for Progressive Supranuclear Palsy Brain Bank at Mayo Clinic, Jacksonville. Since its initiation in 1998, the SPSP brain bank has received 66 brains from 31 states throughout the USA. Given the prominent involvement of Dr. Larry Golbe in the SPSP and his location at Robert Wood Johnson Medical Center in New Jersey, it is perhaps not surprising that New Jersey leads all states in the number of donors (with 13). The other states with 3 or more donations are Georgia, Colorado, California, Minnesota and Texas. The average age at death of the victim with PSP was 69.8 ± 7.4 years with an age range of 57 to 89 years. There were 35 men and 31 women consistent with the idea that men and women are equally susceptible to PSP.

Not all cases submitted to the PSP brain bank had a pathologic diagnosis of PSP. PSP was correctly diagnosed in 65% of the cases. The disorders most likely to be clinically mistaken for PSP were multiple system atrophy (14%), Lewy body disease (9%) and corticobasal degeneration (7%). Surprisingly, several cases of Alzheimer's disease (3%) were also incorrectly diagnosed with PSP. These statistics emphasize the importance of postmortem confirmation in complicated disorders such as PSP, where the clinician is less often correct than in more common conditions, such as Alzheimer's disease, where reported diagnostic accuracy approaches or exceeds 90%. As experimental therapeutics are increasingly developed and used to treat PSP, it will be important to know that the individuals who respond favorably to new drugs actually have PSP.

The purpose of the brain bank is not only diagnosis, but also research. Of the 66 brains that have been donated, part of the brain was frozen in 51 cases. For the other brains, only fixed or preserved tissue samples were available. All the tissue has been banked and has been and will continue to be distributed to scientists who are interested in doing research on PSP. Research opportunities are much greater with frozen tissue than in cases where only fixed tissue is available. Nevertheless, the brain bank has processed tissue blocks on most of the other cases and this fixed material, as well as tissue embedded in paraffin wax, is also available for morphologic research.

The average postmortem delay for the autopsies is longer than one would ideally want for molecular and biochemical studies on postmortem brain tissue (17 ± 4.3 hours; with a range of 2 to 24 hours.) Ideally the postmortem delay would be less than 12 hours, and the shorter the delay, the better. The delays in getting autopsies on PSP illustrate the importance of advance planning. If the patient with PSP and his or her family are considering this donation, it is advised to make arrangements with a funeral home well in advance and to identify a pathologist or pathologist assistant willing to perform the brain harvest. This can be a difficult process if the patient does not live in a major population center. Nevertheless, almost all community hospitals have a



pathology department that can assist with these studies. Unfortunately, given the increasingly profit-oriented nature of modern medicine, some pathologists will be reluctant to take the time and effort to assist in brain harvest. They may also charge for the service. It may take some effort to find a willing pathologist. We have been pleasantly surprised by the generosity of a number of local pathologists and medical examiners in helping with this endeavor. While it may seem uncomfortable, and it is certainly not an easy topic to discuss, dealing with the logistic issues in advance will make the process run smoothly and shorten the time between death and tissue harvest. This will translate into better quality tissue for research studies.

Continued Page 8

Brain Bank

Continued from Page 7

While the brain bank has spent its formative years acquiring tissue, some research with the brain bank material has already been accomplished. For example, brain samples have been used to study a genetic risk factor for PSP and to study the biochemical profile of tau protein in brain tissue. Histologic sections have been used for immunocytochemical studies of neuronal and glial abnormalities. Future studies will hopefully make further use of this valuable resource. If the brain bank is to be optimally useful, the tissue that has been collected to date will be consumed in the research studies and replaced by new tissue from other donors. The brain bank will serve no purpose if the tissue is not actually expended in meaningful studies. The SPSP can further this use by encouraging research on human tissue samples in its annual call for research proposals. While in no way belittling the research that is based upon study of cultured cells or animal models, these simpler systems eventually need to be validated with human postmortem tissue and ultimately with studies of living patients with PSP. The SPSP can facilitate both of these objectives.

For further information about the SPSP Brain Bank contact

Dennis W. Dickson, MD
Professor of Pathology (Neuropathology)
Mayo Clinic Jacksonville
Jacksonville, FL 32224
(904) 953-7137 - phone
(904) 953-7117 - facsimile
dickson.dennis@mayo.edu

Society for Progressive Supranuclear Palsy Brain Donation Program

For Diagnosis and Research on PSP
Society for PSP Brain Bank
Supported by the

Eloise H. Troxel Memorial Fund
Mayo Clinic Jacksonville • Jacksonville, FL 32224

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

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

To obtain informational packets about brain tissue donations please contact the Society for PSP.

Phone (800) 457-4777 / E-mail: SPSP@erols.com
SPSP, Inc. Woodholme Medical Building, Suite 515
1838 Greene Tree Road, Baltimore, MD 21208

“Identification Of a PSP Gene”

By Parvoneh Navas, Ph.D.
Acting Assistant Professor of Medicine
University of Washington, Seattle, WA

The tau gene, which produces six variations of the tau protein in the human brain, is in some way involved in the onset or progression of progressive supranuclear palsy (PSP). This was initially discovered when certain DNA “fingerprints” in the tau gene region (on chromosome 17) were found in greater numbers of individuals with PSP than in healthy persons. Individuals with PSP also have a different complement of tau protein variants. This leads us to believe that the tau gene is regulated differently in individuals with PSP. Variations (“fingerprints”) in parts of the tau gene that regulate protein production might cause or contribute to PSP. Funding from the Society for PSP allowed us to examine the DNA sequence of the entire human tau gene and the tau gene of a distantly related species. By comparing these sequences, we identified greater than 100 DNA regions within and around the tau gene that may regulate the production of tau proteins and which are the same in various species. We examined these gene regions in PSP subjects and healthy subjects to identify “fingerprints” that are more commonly shared by individuals with PSP. We identified more than 70 new “fingerprints” in the tau gene and have examined 96 individuals with PSP and 86 unaffected persons for differences in “fingerprint” patterns. We are now looking at the effects of these more common PSP fingerprints on tau protein production. This SPSP funded project has advanced our knowledge of the tau gene itself, which is in some way involved in PSP. It has also allowed us to identify regions in the tau gene that may be critical to protein regulation and to begin to identify differences in these regions that might contribute to altered tau protein production in PSP.

This is Dr. Navas’s lay language abstract describing the work she has completed during the year of her PSP grant funding from the Society. The final title of the paper she generated as a result of this research is: “Analysis and Comparison of the Human and Mouse Genomic Sequences Encompassing the Microtubule Associated Protein Tau.” Authors: P. Poorkaj, A. Kas, Y. Zhou, Q. Pham, M. Stone, M. Olson, and G.D. Schellenberg. VA Puget Sound Health Care System, University of Washington, Seattle, WA, Parvoneh Navas, Ph.D.

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.

Special Event - LA Symposium

Los Angeles Regional PSP Symposium For Persons with PSP, Families, Caregivers and Allied Health Professionals

On Saturday, April 29 of this year, 110 attendees gathered together at the impressive Jules Stein Eye Institute, UCLA School of Medicine, Los Angeles, CA to learn all they could about PSP from the medical and allied health care experts. They soon discovered that it was more than a fact finding mission. It turned into a day of not only information gathering, but of caring and support. Families and persons with PSP learned they are not alone and isolated as they met each other and shared stories and challenges.

The Los Angeles PSP Support Group recognized the need for education and support and got to work organizing their second regional symposium for The Society for PSP. The Society thanks Carolyn Cheek of Torrance, CA for her tremendous efforts in coordinating this event. Special thanks also go to others for their assistance in planning such a successful day: Paul Wicorek, Wendell Higbee, Penny Roberts, May Toll, Carolyn and Bill Griffith, Norma Simon, Pat Kreuger, Rhoda Cocca and Jenny Feiger.

The program included:

INTRODUCTORY REMARKS FROM CAROLYN CHEEK

DIAGNOSIS OF PROGRESSIVE SUPRANUCLEAR PALSY

Neal Hermanowitz, M.D., Director of the C. Irvine Movement Disorder Center

CURRENT AND FUTURE STRATEGIES FOR THE THERAPY OF PSP

Jeffrey Bronstein, M.D., Assistant Prof., UCLA Dept. Neurology, Director, UCLA Movement Disorder Programs

FAMILY ADJUSTMENTS IN CHRONIC NEUROLOGICAL DISEASE

Susan Imke, R.N., M.S., Director of Education CTC, National Parkinson's Foundation

THE GIFT OF BRAIN TISSUE TO RESEARCH

Dennis W. Dickson, M.D., Neuropathology Consultant, Mayo Clinic, Jacksonville, FL

THE SOCIETY FOR PSP AND YOU

Carol Marchi, Vice Chairman, The Society's Board of Directors
Outreach Coordinator,
Parkinson's Institute, Sunnyvale, CA
Nancy Brittingham,
Editor for the Society for PSP



Carolyn Cheek, Paul Wicorek, Wendell Higbee (all members of the LA Support Group) and Susan Imke, Symposium Presenter, Director of Education CTC, National Parkinson's Foundation



Carol Marchi, Vice Chairman of the Society's Board of Directors and Pat Kreuger (LA Support Group)

There were two breakout sessions at the end of the program. "Living Well with PSP" was a session for caregivers with a question and answer caregiver panel. This session was facilitated by Carol Marchi. Susan Imke facilitated "How Do I Feel?," bringing together 22 persons with PSP to express their frustrations and, yes, even their joys of each day as they struggle to meet the overwhelming difficulties of PSP.

Continued Page 10

Special Events - LA Symposium

Continued From Page 9

The Society for PSP would like to recognize our special volunteer, Karen Kennemer from Houston, Texas, for her countless hours of work in researching, contacting and promoting corporate support for the Symposium. Twenty vendors participated in one of three ways: through an exhibit of their product with information for distribution at the symposium, product brochure information inserted into each attendees symposium infopak or product brochure/catalogs displayed on the Corporate Symposium information table at the event. A special thanks goes to Ceri Williams of LA, Society volunteer, for organizing and coordinating the vendor information table display throughout the event.

The Society is striving to support symposias throughout the United States, Canada, and the world. If there are any persons interested in organizing and coordinating a symposium in your area, please contact the Society. We will work together organizing and supporting this event. Just look what the Los Angeles Support Group did! You can, too!

The Society for PSP would like to thank the following Los Angeles PSP Symposium Corporate Supporters.

CAREGIVING SUPPORT

Care Trust Publications 800-565-1533
In-Sight Books 800-658-9262
Making Life Easier 608-824-0402
Today's Caregiver Magazine 800-829-2734

COMMUNICATION AIDS

Crestwood Communication Aids 414-352-5678
Luminaud 800-255-3408
Saltillo Corporation 800-382-8622
ZYGO Industries 800-234-6006

HOME CARE PRODUCTS

Dolomite Home Care Products 877-558-7055

HOME HEALTH CARE

Apria Healthcare Group 714-427-2000

LONG TERM CARE INSURANCE

Conseco Senior Health: Long Term Care Insurance
800-772-6881

MEDICAL AND INDEPENDENT LIVING CATALOGS

MOMS Catalog 800-232-7443
North Coast Medical 800-821-9319
Sammons Preston 800-323-5547

MOBILITY AIDS

Healthcraft Products 888-619-9942
In-Step Mobility Products 800-558-7837
Orthotic Mobility Systems 888-667-4046
Shirley Walker Company 800-848-9255

ORAL HYGIENE PRODUCTS

Laclede 888-BIOTENE
Trademark Medical 800-325-9044

OTHER

The Brookfield Reader 888-389-2741



*Lunch on the lawn.
A special time of sharing for all attendees.*



Carolyn and Bill Griffith pick up informational product brochures and catalogs sponsored by corporate support for the Symposium.



Susan Imke facilitates the "How I Feel" Breakout Session for persons with PSP while families and caregivers attend the "Caregivers Panel" facilitated by Carol Marchi.



Ceri Williams and Carolyn Cheek, Society volunteers, recognizing the Corporate Support Sponsors.

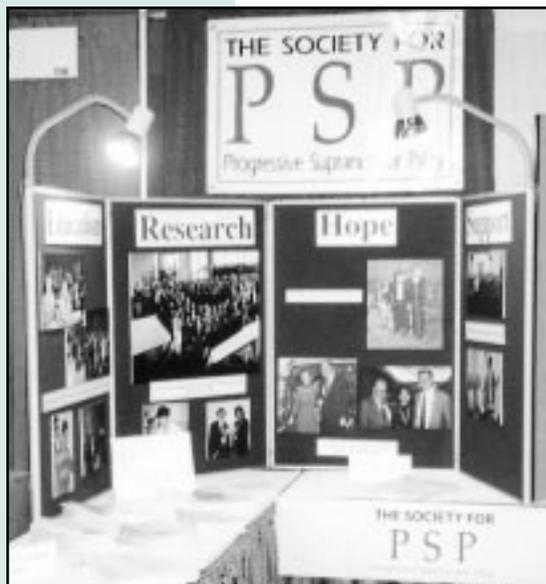
Special Events

The American Academy of Neurology 52nd Annual Meeting

The 52nd Annual Meeting of the American Academy of Neurology was held in San Diego, CA, April 29-May 6, 2000 at the San Diego Convention Center. This year's scientific program hosted 83 platform sessions as well as six poster sessions highlighting 1,200 presentations of neuroscientific research. Summaries of PSP presentations at the Academy are described on page 6. The Academy also hosts Industry and Association Exhibitors for three days of the meeting.

Volunteers and staff of The Society for PSP, with their newly created exhibit, attended the Academy meeting. Neurologists visited the booth area and collected informational packets about PSP and the Society. Numerous national and international neurologists added their names to the mailing list. Positive comments were made when neurologists learned about the Society's existence. Physicians were grateful to take information back to their PSP families and to refer them to the Society for PSP.

PSP volunteers in the San Diego area were present at the exhibit helping to distribute information and speak with the visiting neurologists. A special thanks to Jeanne McRay, Anna Garcia and Charlotte Meloche. The Society would like to also thank special volunteer Gail Strickland for her time in setting up and staffing the booth as well as helping to organize and plan details facilitating the Society's presence at this prestigious meeting.



The Society for PSP's informational exhibit at the 52nd Annual Meeting of the Academy of Neurology



Society Volunteers Charlotte Meloche & Anna Garcia distribute information at the Academy meeting



Gail Strickland, San Diego PSP Volunteer



Niall Quinn, M.D. & San Diego APD Volunteer, Ronnie Griffith



San Diego PSP Volunteer, Jeanne McRay, distributes information to neurologists.



David S. Zee, M.D. (member of the PSP Society's Medical Advisory Board) visits the PSP booth attended by Nancy Brittingham (Society Editor)

Liz Brisson



Congratulations and thank you to Liz Brisson, Chairperson, Development Committee and Board Member. Liz recently received a \$1,000 grant from her employer, New England Financial, which was awarded to The Society for PSP on her behalf. This grant will be designated to the "Margaret Parker Research Fund" which Liz and her husband, Roger, established in 1997 to honor her aunt who has since passed away from PSP. New England Financial associates who volunteer for non-profit organizations are eligible to win a cash grant. The CARE Grant (Community Action Recognition Grant) program provides up to twenty \$1,000 grants to non-profit organizations where associates volunteer their personal time and effort. Grant winners are selected by a committee according to the level of effort and impact of an associate's contribution, length of service and the organization's needs. This is the second time Liz has been awarded this grant.

1999 SYMPOSIUM VIDEO TAPES AVAILABLE

If you did not attend the National PSP Symposium in Baltimore, MD, held in November, these tapes are the best way to learn from the experts about care, treatment, research and caregiver issues. 3 tape-set, \$75, \$7 shipping and handling, USA, and \$10 outside USA. Order on page 31 of this newsletter, Item No. 10. You may also call in an order with your credit card. 1-800-457-4777.

Ask A Doctor Does PSP Cause Dementia?

By Irene Litvan, M.D.
Chief DVHJP Neuropharmacology Unit
Jackson Foundation and Medical Branch
Bethesda, MD

The answer depends on how you define dementia. Dementia can be defined as a set of one or more deficits in thinking that progress over time. PSP patients do not suffer from a dementia like that of Alzheimer's disease.

People with Alzheimer's disease have severe problems in memory and later develop problems using language and navigating their way around their environment. PSP, however, includes problems in "executive" function. This category of mental action includes planning, problem-solving, reasoning, concept-formation, and social thought. All are problems that PSP patients may experience at early stages of their disease. These aspects of thought reside in the frontal lobes of the brain. If the definition of dementia includes the presence of executive cognitive deficits that worsen over time, then we can say that PSP does cause dementia.

Frontal lobe executive defects are not exclusive to PSP. They also occur in other parkinsonian disorders such as Parkinson's disease (PD) and multiple system atrophy (MSA). Certain cognitive deficits due to frontal lobe dysfunction; such as concreteness of thought, diminished verbal fluency, and difficulty with placing events in their correct sequence, however, are more severely affected in PSP than in most patients with PD and MSA.

The memory impairment observed in PSP patients is thought to be related to their inability to organize how to search through their memory and is likely due to their frontal lobe dysfunction. Retrieval of older information is more impaired than new learning but that is also true for patients with PD and MSA. PSP patients, unlike those with Alzheimer's disease, can benefit from cues when searching their memory. Since the memory impairment observed in patients with parkinsonian disorders like PSP is less severe and distinct from that seen in patients with Alzheimer's disease (which is characterized by more rapid forgetting and less benefit from cueing), it must be because the abnormalities found in the hippocampus (a brain structure shaped like a seahorse that is critical for new learning and memory) in PSP are not severe enough to interfere with learning.

The most common and severe behavioral change in PSP is apathy (91%), which is only occasionally accompanied by depression (18%). The apathy of PSP patients is characterized by decreased spontaneity (91%), initiation of conversation (86%), and interest (64%) in what is going on around them. In practice, PSP patients' apathy is often mistaken for a depressive disorder and they are frequently but unsuccessfully treated with antidepressants.

Disinhibition and impulsive behavior occur in one-third of PSP patients and is manifested by acting impulsively without considering the social or personal consequences of that behavior (e.g., crossing the road without considering traffic; getting up without assistance in spite of their poor balance). PSP patients may occasionally be tactless with their remarks. Disinhibition is less evident in patients with other parkinsonian disorders, and is seen in only 12% of patients with PD (compared to 33% of PSP patients).

Support & Education

Continued from Page 12

PSP patients not only have slowed movement but are very slow in processing ongoing information. In contrast to patients with lesions (due to strokes, tumors, or head injuries) confined to the frontal lobes, in contrast to patients with PSP, while also demonstrating executive cognitive deficits, are not slow. Thus, PSP not only causes motor problems but also causes executive cognitive deficits and problems in social behavior. Whether these deficits can be considered a form of dementia or not remains controversial among clinicians and researchers, but for the family member or friend, the cognitive and behavioral changes resulting from PSP are significant and disturbing and can become an impediment to continuing relationships and maintaining normal functional activities.

Especially in the earlier stages of PSP, we focus on the motor, eye, speech and swallowing problems. This focus may distract us from the subtle cognitive and behavioral disturbances. However, if detailed neuropsychological evaluations are performed, all patients with PSP will be shown to suffer from some form of cognitive or behavioral impairment (even if it is not described as a "dementia") during the course of their disorder.

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

Rehabilitation Specialists and PSP

By Fran Roggen, Physical Therapist
Masters Degree in Exercise Physiology

Progressive supranuclear palsy is a rare, degenerative brain disease related to Parkinson's disease. It strikes middle-aged adults and the elderly, slightly more men than women. Its cause remains a mystery and there is no cure. Early symptoms include falling, difficulty walking, imbalance and slow movement similar to Parkinson's disease. People with PSP experience vision problems such as double and blurred vision as well as difficulty with speech and swallowing. In advanced stages, persons with PSP are bedridden or in wheelchairs and require full-time care.

Rehabilitation specialists can be very helpful when learning to cope with the mobility problems progressive supranuclear palsy causes. There are three traditional therapies: Physical Therapy (PT), Occupational Therapy (OT) and Speech/ Language Pathology (SLP).

People often ask what the differences between these types of therapists. A physical therapist is trained to work with patients with neurological disorders. The physical therapist evaluates the patient's balance, strength, ROM (RANGE OF MOTION), posture and muscle tone. Functional mobility is also evaluated including rolling over in bed, coming to sit from lying down, moving from sit to stand and back, walking, sitting comfortably, walking on different surfaces and climbing stairs. Once areas of difficulty are noted, the therapist works with the patient and caregiver to establish goals for mobility and function. Patients are seen 2 to 5 times per week depending on the patient's needs. Movement, exercise, and patient/caregiver education are the most common types of treatment.

To facilitate mobility, it is very important that an appropriate wheelchair is selected when the person with PSP needs to use a wheelchair. The right type and fit of a wheelchair can make a huge difference in the ability to propel oneself independently. Having the best posture available with a properly fitted wheelchair can also help to normalize muscle tone and coordination of arms and legs. Depending on where you live, either OT or PT can fit a person for an appropriate wheelchair.

Occupational therapists work with mobility as it relates to activities of daily living, such as bathing, dressing and self-feeding. They also work to improve fine motor coordination such as writing. When needed, OTs can choose appropriate assistive devices that may enable a person to do an activity independently. The client is evaluated and goals are set similarly to PT.

Both OT and PT teach caregivers to assist the client properly to allow the client to do as much for himself/herself as possible, and to make it easier for the caregiver to do such activities as transferring the client out of bed and into a chair. This may include techniques to change muscle tone or to improve posture by good positioning in a chair. Proper fitting of a wheelchair should also be assessed to be sure that the client is comfortable, in the optimum position for swallowing, and is sitting to promote the best posture possible to aide in normalizing muscle tone.

Speech and language pathologists work with swallowing issues and with communication. The SLP can aide in finding the best position for the head and neck to promote safe swallowing. They also assess whether the consistency of food is safe or if a different consistency, pureed for example, might be safer. Compensatory techniques for speech can be taught, or if the client is unable to speak, he/she can be assessed for some other form of communication, such as a communication board.

Therapists frequently overlap in areas of concern. For example, OT can work on feeding techniques to get the food to the mouth, the SLP works with swallowing, and the PT works with posture and position to allow optimum use of arms and hands and optimum position of back, neck and head for swallowing.

With your neurologist discuss the benefits of rehabilitation specialists for you or your loved one. When looking for these rehab specialists, the ideal scenario is to find a team including OT, PT, and SLP that specializes in and have experience working with people with neurological disorders. If this is not available, find individual therapists who specialize in working with people with neurological disorders. These therapists can be found in a variety of settings, including hospitals, rehab centers, outpatient rehab clinics, and home health agencies. The home health therapist comes to the home to treat people. This is certainly better for those who have great difficulty getting out of the house.

Medicare covers the cost of all three therapies. Other insurance companies may or may not cover the different therapies. Please check with your insurance company to find out what your plan covers. To be reimbursed for therapy, most insurance companies require a physician referral or prescription for therapy. Talk to your physician about your needs, both for the person with PSP and for education for the caregiver. The physician should be able to connect you with the appropriate agency. If not, you can call the different therapy clinics and home health agencies to find out about them, then choose the one with which you and your physician feel most comfortable.

PSP, The Ultimate Test of a Relationship

Susan Hunt
Consultant in grief, loss and pain management

"In sickness and in health", "Honor your father and your mother", "Love your brother as you would love yourself"; these aren't only Biblical instructions, they are guidelines that have been part of our culture(s) for generations. We accept them, believe in them, try to follow them, because we firmly believe that they are morally right for us. And then our loved one is diagnosed with a devastating, destructive, long-term illness: PSP. The unbelievable has happened and his/her future and ours are irrevocably altered.

Shock, denial, terror are usually our initial reactions, and most probably the reaction of our loved one as well. We want to encourage them, help them, support them, and meanwhile, we, ourselves, have had the rug pulled out from under us. As we learn more and more about this terrible disease, begin to understand at least some of what may be ahead, we are overwhelmed, terrified, and so is our loved one.

How do you provide support to someone you love when you yourself are devastated by the situation? Somewhere along the way, early in the process, you decide that you will be strong and caring and supportive. Your grief is "not important" in the light of what your loved one is going through.

Your loved one, meanwhile decides that she/he will be brave and stoic, not showing his/her feelings, not complaining. She/he determines to keep as much as possible of his/her suffering inside, out of sight, so as not to "make it worse" for those around him/her.

And so, you begin the journey - one individual whose life has totally changed, trying to be courageous (and usually succeeding), surrounded by family and friends whose lives have also changed and who are also, most of the time, being brave and encouraging.

As devastating as the first few months are, coming gradually to terms with the unbelievable diagnosis, visiting doctors, learning about PSP, accommodating to the initial changes created by the disease, it's usually somewhere down the road that the effects of "being stoic", keeping painful feelings to ourselves, begins to take its toll.

The walls people build to "protect" others from seeing their pain unfortunately results in the creation of a distance, a destruction of closeness and intimacy. The result, then, is that people lose the opportunity to really share deeply in each other's experiences. We lose the relationship long before one of us dies.

How lonely that is, for everyone! Loved ones are constantly cheerful and encouraging; the individual living with PSP is courageous and uncomplaining for years and years. Neither side really knows what the other is going through. Both parties feel increasingly isolated and alone. What a loss, for both parties.

As the months and years pass, unless these repressive communication patterns are changed, the barriers between the individuals involved increase. Walls, chasms, develop between individuals. Interaction becomes increasingly difficult, and warm, spontaneous expressions of love and support become painful and awkward. There is too much pain behind

the wall and both individuals are afraid it will break through.

Complicating this, of course, is the often-increasing difficulty of the individual with PSP to speak and communicate. If the walls to communication have been built and maintained over the years, finding creative ways to communicate becomes difficult and more frustrating.

At one point or another (probably at many points) in the long process of PSP, each individual involved with the disease will become tired, frustrated, angry, discouraged; will wish the "nightmare" was over. And then, very often, they feel guilty for having such feelings. There is a fear that talking about genuine feelings will "make the situation worse", and so, the individuals remain silent.

We CAN, of course, make a situation worse, if we communicate our feelings AT each other, but we don't have to do this. There are ways to openly and honestly communicate feelings that can bring all involved closer together. There are ways to openly and honestly communicate feelings, even painful "ugly" ones, so that the result is more closeness and understanding. Open, honest, loving communication can add tenderness and meaning to an otherwise dreadful situation.

COMMUNICATING FEELINGS:

Recognize that this kind of communication is a learning process. Most of us have spent our lives learning how to hide our negative, "bad" feelings. We aren't supposed to have them. They are "wrong", somehow. No one will want to hear them. People will think we are weak, selfish or foolish if we tell them how we really feel.

Recognize as well, that you are, after all, human. The feelings, good and "bad", are normal reactions to what is happening, and they are only feelings. Expressing them honestly to those we love increases understanding and intimacy. You walk through this experience truly together, rather than remaining aloof and separate.

It takes time, practice, and self-acceptance to learn how to communicate our feelings successfully and to develop the confidence in our skills that will allow for open communication. But the rewards are tremendous. Honestly, deeply connecting with those we love and interact with every day strengthens understanding and enriches relationships. This is equally as important to those living with the disease in their bodies as it is to those who love and support those individuals.

The following is an exercise designed to support the development of interactive communication skills for individuals, family members and friends living with PSP.

1. The first step for each individual is to gently acknowledge, within themselves, the feelings they are holding and accept the feelings, regardless of how "wrong" or "silly" they seem, as normal and OK. Discard any feelings of self-judgment and just explore the genuine feelings.

Take some time, alone, to be with yourself and identify the feelings. Write them down (without judging them!). If you have difficulty writing, think about these feelings. No one else will see them at this point, but before you can work with them, they must be identified. Look at the list, reviewing and exploring each feeling, the reasons for the feeling, the words and possible actions associated

Continued Page 20

Not Even A Butterfly

By Mary Miano

"Not even a butterfly!" I can still hear my mother's voice resounding in my ear, as I think back to my brother trying to sneak a rabbit in the house under his thin windbreaker. Bad enough the kid was skinny and the bulging jacket had two long ears showing up above the zipper! We lived in an apartment in NYC and my mother convinced us that it would be cruel to leave an animal alone all day confining it indoors. My brother had a turtle and I had two goldfish. One day my parents succumbed and bought me a parakeet. That was fun until my sister-in-law was visiting one weekend and stepped on him while I was out. Tears abounded as I was told he flew out the window.

Well, I never had a pet with fur until I turned 50! I gave in to my roommate's pleading for "us" to get a cat! I told her if she wanted a cat she could get one, but all of a sudden, this "us" thing got me nervous! So, in June 1990, we acquired James, an orange tabby with white paws and chest. He was six weeks old and as big as my hand when we got him. By September, my roommate was strongly suggesting that we had to get another one, because it wasn't fair to James to be left alone all day long while we both had to work. I was on my way to Europe and didn't have time to argue with her. The first Saturday after my return, she coerced me into the car and off we went to the pet shop. I was looking around, when suddenly a kitten that was standing on her back paws across the shop captured my eyes. She had a mushroom tummy with black spots. I just started to walk toward her when the sales person stepped in front of me and led the way. I wasn't really serious, but just curious to take a closer look at her. She was so cute. The next thing I knew this silver gray tabby-Abyssinian was in my arms with both her paws around my neck, and she snuggled! On the way to the register, my roommate managed to talk me into buying her. So, now we each had one! Her name just flowed from my heart: Samantha Spots! Sam for short!

Ten years later, so much has happened! I have experienced several losses: the death of my mother, the death of my roommate, having to go on long term disability for PSP! My cats have been there for me through thick and thin. They have "licked" me back to life so many times! When I am down, they come to cheer me. When I need some extra TLC, they are at my side. A friend of mine was up to visit me about two years ago with her dog, Peanut. She lives nearby and was out for her walk. I marveled at how well-behaved Peanut was. I commented to my friend, who began to tell me that she had to put the dog up for adoption, due to her long and erratic work schedule. Before I even realized it, I heard myself saying: "Maybe I could take her for a week to see if she and the cats would get along!" Well, it has been more than a week and she is still with us! Dogs do need a lot more care than cats, but I have found that they also are more company. However, I do have to "take my hat off" to Peanut and again give thanks for her because she keeps me walking, whether I like it or not! I am now home with my three very best friends in the entire world! They are here to comfort me and make me

smile daily! They give me a good reason to come home! They have been my therapists and call me to be still! They are the most efficient alarm cats and dog, and dutifully wake me up at five a.m. daily! They allow me to groom them, which is very therapeutic for me.

While I was working as director of a retreat center, we had two cats and a dog on the property. They were also part of our team, as they ministered to many a retreatant that was having a difficult time and just couldn't open up with others. I had many comments about the animals on our staff who touched people in their own way, and also brought about an inner healing that was unique to each of them.

From the retreat center, I later took a job as a medical social worker in a convalescent home. Monthly, we had "pet therapy" for our residents. It was amazing to watch those residents who were least responsive petting, smiling and even speaking to the pets who were brought in. Once again, I thought to myself: how very special these little furry creatures are as ministers of comfort to the lonely, the sick and the elderly. Animals can do anything from conquering loneliness to helping us to relax. They are often de-stressors. Just by petting them helps to slow down our heart rate. They are also an aid to boosting our immune system. They give us an example to love unconditionally! I find it awesome to be taken into their level of trust. So, to the Creator of these creatures, I say thanks. To my own mom, I can say with a smile that goes from east to west: "Mom, you were so right! Butterflies are meant to be free!" But God gave us cats and dogs as comforters. For those of us who can take them and share our abundance with them, there are many blessings and things to be learned. Some of us can appreciate them only from a distance. Maybe some of our readers would like to comment on the role of animals in their lives. To me, they have been a blessing!

Mary Miano has her Master's Degree in Religious Education. She has lived in the religious community for 27 years working in education, social services, and as director of a retreat center. She has been on disability due to her PSP condition since 1996.



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. Please contact:

ARIZONA

Gale Kittle, RN, MPH Coordinator
Kristina Watts, Asst. Coord.
Muhhamad Ali Parkinson Research Center
500 W. Thomas Rd. Suite 720
Phoenix, AZ 85013
602-406-4931 or
800-273-8182

Rena Valdes-Birch
20 South Buena Vista #115
Gilbert, Arizona 85296
480-632-1791

ARKANSAS

Patsy Cunningham
PO Box 5554
Fort Smith, AR 72913
501-484-0407 e-mail
patphillip@msn.com

CALIFORNIA

Carolyn Cheek
23009 Nadine Circle, Unit A
Torrance, CA 90505
310-534-8623

Nancy Frederick
1131 Eden Avenue
San Jose, CA 95117
408-243-9987

Dr. & Mrs. Robert Daft
527 Grovesnor Court
Sacramento, CA 95864
916-481-3411

Mary Miano
2298 Via Puerta, Apt. N
Laguna Hills, CA 92653
949-855-3972

Lila Kirkpatrick
310 La Herran Dr.
Santa Clara, CA 95051
408-244-5958

Betty Scoggins
2272 London Ave.
Redding CA 96001-2115
530-241-6663

CANADA

Sandi Jones & Janice Stober
4211 Yonge St., Suite 316
Toronto, CA ONT M2P, 2A9
416-227-9700

COLORADO

Dr. Lauren Seeberger &
Kim Martin
Movement Disorder Center
Colorado Neurology Inst.
701 E. Hampden, #501
Englewood, CO 80110
303-788-4600

CONNECTICUT

Frank Cadwell
384 Rt. 148
Killingworth, CT 06419
860-663-1659

FLORIDA

John Arnold
523 Adams Avenue
Cape Canaveral, FL 32920
407-784-5660

Paula John
5383 Lake Arrowhead Trail
Sarasota, FL 34231-7374
941-927-3955

Bud Branson
449 Gould Rd.
Quincy, FL 32351
850-627-6216

Shirley Vlahakis
1067 Island Manor Drive
West Palm Beach, FL 33413
561-969-9553

Virgie Saltzman
23 Lafitte Drive
Nokomis, FL 34275
941-484-7259

GEORGIA

Kathy Thomas
3305 Francine Drive
Decatur, GA 30033
770-939-2612

ILLINOIS

Bea Irminger
One West Onwentsia Rd.
Lake Forest, IL 60045
847-234-1928

IOWA

Esther Cooling
1917 "B" Ave., NE
Cedar Rapids, IA 52402
319-362-4752

LOUISIANA

Mary Schumann
1021 Wilson Drive
New Orleans, LA 70119
504-484-7840

Brenda Gremillion
10 Bistineau Ct.
Kenner, LA 70065
504-467-6658

MAINE

Faye Ryan
HCR 74, Box 88A
Whiting, ME 04691
207-259-2152

MARYLAND

Society for PSP
Woodholme Medical Building, Suite
515
1838 Greene Tree Rd.
Baltimore, MD 21208
1-800-457-4777

MASSACHUSETTS

Patti Ryan
1000 Paradise Road
Swampscott, MA 01907
781-599-1000-W
781-595-4431-H
781-599-1024-fax

MICHIGAN

Carol Ann Klank
4100 Longleaf
Commerce Township, MI 48382
248-363-9064

MINNESOTA

Charlotte Triplet
2440 Carvell Ave., N.
Golden Valley, MN 55427
612-546-1694

Margaret Prod-Homme, RN
UMMS, Neurology Dept.
Box 295

420 Delaware St., SE
Minneapolis, MN 55455
612-624-1404 e-mail
PRODOOL@marbon.tc.UNM.edu

MISSISSIPPI

Mr. Denver Flanagan
2108 Monaco St.
Jackson, MS 39204
601-372-1784

MISSOURI

Pat Lynn
1427 Tanglewood Road
Jackson, MO 63755
573-243-3964

Amy Mandleman
8 Bavarian Court
St. Louis, MO 63146-5301
314-432-5461

NEW JERSEY

Mary Gualandi
131 Ticonderoga Drive
Toms River, NJ 08755
732-505-1739

NEW YORK

Marcy Todd
2 South Court
Port Washington, NY 11050
516-883-7455

Mary Connolly
5077 Foster Road
Canadaigua, NY 14424
716-394-5306

OHIO

Bernice Bowers
7617 Ashler Ct.
Canal Winchester, OH 43110
614-833-2588

Debbie Mills
Parkinsons Center
P.O. Box 670525
University of Cincinnati
Cincinnati, OH 45267
513-558-7312

PENNSYLVANIA

Jane Wright
PA Hospital, Neurology Dept.
330 S. 9th St.
Philadelphia, PA 19107
215-829-7273

Ruth Nulph, R.N.
5115 McCandless Rd.
Butler, PA 16001
724-287-8600

George Weaver
RD #1, 245C
Mill Hall, PA 17751
570-726-6164

Daniel K. Lake
220 Broadmoor Drive
Willow Street, PA 17584
717-464-4057-H
717-397-9037-W

e-mail- dansr@desupernet.net

RHODE ISLAND

Kelley Harrison, Ph.D.
72 Dana St., Apt. 3
Providence, RI 02906
401-621-8566

e-mail kharris9871@aol.com

SOUTH CAROLINA

Doris McCray
613 5th Ave., South
Myrtle Beach, SC 29577
843-445-1647

TEXAS-NEW MEXICO

Karen Kennemer
2235 Cedar Falls Drive
Kingwood, TX 77339
281-358-2282 e-mail
KMK1224@aol.com

VERMONT

Janice Clements
649 Everest Road
Milton, VT 05468
802-893-1263

VIRGINIA

Allen Rohfling
332 Whiting Lane
Virginia Beach, VA 23456
757-426-5281

Kathy Sands
9603 Symphony Meadow Lane
Vienna, VA 22182-4421
703-242-9322

WASHINGTON

Fran McMahon
7148 191st Ave., SW
Rochester, WA 98579
360-273-9496
e-mail franmcdoll@aol.com

Roberta Hunt
Rt. #1, Box 60A
WallaWalla, WA 99362
509-529-1364

WISCONSIN

Barbara Sharkey
5066 Evergreen Court
Rhineland, WI 54501
715-362-1777

News From Support Groups

OHIO SUPPORT GROUP

The Ohio Support group met at the home of Bernice Bowers in Canal Winchester on April 24, 2000 for a pot luck and afternoon of fellowship. Those present included Alan Willis from Dayton, Sheila Anderson and Vivian Enochs from Washington Courthouse, Pat Beekman from Berea, Madge Fosdick from New Paris, Dorothy Hamler from Groveport, and a newcomer to our group Catherine Harvey from Newark. Pat Beekman and Catherine had met at the Baltimore symposium, where Pat told Cathy of our Ohio support group and we were delighted to include her in our numbers.

We shared some PSP experiences, solutions, funny stories, and laughter. Alan's wife Pat was in the hospital with pneumonia but he was still able to come for awhile. We are all wishing her the best. There are still a few men here in Ohio who seemed reluctant or unable to join in our group, but we always let them know of our meetings. So far Alan is our token male, and he is not complaining. The food was all very delicious, and bountiful. We could have fed two more support groups. A few pictures were passed around and Pat shared with us a lovely poem her daughter had written about her father Ed, who passed away 2-21-2000. Pat also brought and gave us each a canvas "PSP Decade of Caring" tote bag that she brought from the symposium.

No new date was set for the next get together, but we intend to make them about every two months since most drive quite a distance to get here. Canal Winchester is pretty central.

Thanks for letting me be of service.
Bernice Bowers

TOM'S RIVER, NEW JERSEY

Our support group tries to meet once a month (weather permitting) at Mary's home in Tom's River, NJ. We usually have between 10-20 people in attendance, of which 2-4 are patients. The warm and friendly atmosphere of our setting lends to the free interchange of helpful hints between caregivers and patients as well as humorous occurrences in our daily lives. We also exchange scientific findings occurring in the genomics and neurological fields that are of particular interest. It is important from a spiritual and psychological standpoint to provide a positive view of the rapidly evolving scientific landscape to our patients and caregivers so as not to lose hope, as can frequently occur with this insidious disease. We seem to have the good fortune of being able to provide information to at least one new member at our meetings. Sometimes we will see them again and other times not. The genuine caring and love that abounds between our members makes our meetings so special and for at least those 2 hours, we realize that we are not battling PSP alone.

Best wishes,
Philip Gratz

CANADAIGUA, NEW YORK

Mary Connolly writes that their meetings are held in the third floor conference room at the Wood Library on Main Street, Canadaigua, NY. Their attendance averages 12-14 people including speakers. Meetings are held the last Tuesday of each month 6:30-8:00 pm. Coffee and refreshments are

served. A social worker facilitates the meetings which have always had a speaker. There have been suggestions that some meeting be reserved for general discussion and sharing among attendees.

In an effort to expand our information between support groups, we are asking support group leaders to forward updates, photographs, meeting dates, speakers, special events, etc. for publication in this new PSP Advocate feature. Please note the deadline dates.

| | |
|--------------------|------------|
| 3rd Quarterly | July 20 |
| 4th Quarterly | October 20 |
| 1st Quarterly 2001 | January 20 |

Please forward Support Group News to the Editor at 103301.640@compuserve.com or 6 Bramston Drive, Hampton, Virginia 23666.

**The next meeting of the
Texas PSP Network is
July 15, 2000 at 2:00 PM
at the City of Houston
Metropolitan Multi-Service Center,
1475 West Gray, Houston.
Call Karen Kennemer at 281-358-2282.**

Going for the Grants!

The Society has engaged the services of Una Martone, a grant proposal consultant, to tap corporate and foundation resources. The grant proposal the Society will submit seeks to fund the Outreach and Educational Program outlined in the Society's strategic plan. We are in need of your contacts to help ensure the success of our grant proposal efforts. Please call Ellen Katz at 1-800-457-4777 for the names of foundations or corporations where we can submit this grant. Let us know if you sit on a board of a foundation or corporation or have access to anyone who does.

This program will fund an Outreach and Educational Coordinator who will establish and support our support groups, organize regional and national symposium throughout the country and plan a program of education and awareness for patients, families, caregivers and medical professionals.

What an opportunity to tap into a new pool of resources with your help!! This is important work—call today!!

Support - Helpful Hints

Dear Nancy,

I thought you might want to include this "helpful hint" for PSP persons. Melodie just wrote to Bell Atlantic and received a form back which I have signed so Hal can use free directory assistance and operator assisted local calls. Now, he will be able to call any of our children, for example, by just picking up the phone and dialing 211. The operator will put his call through without any additional charge. This is a great benefit for those patients who can still speak clearly but can't see well enough or have the fine motor skills to dial a telephone number. The form came from Bell Atlantic-Virginia, Inc., 5415 Airport Road, 1st Floor, Roanoke, VA 24012. The telephone number for more information or questions is (703) 954-6222. The one page form is easy to complete and can be signed by a spouse or other family member on behalf of the person making the request. A physician's signature is not necessary.

I have also ordered a 674-page one volume directory that costs \$30 from the National Organization for Rare Disorders (NORD). It lists societies, organizations, foundations and other non-profit groups throughout the country and contains a variety of medical subjects and diseases. One can be purchased by writing to NORD, P.O. Box 8923, New Fairfield, CT 06812-8923 or calling toll-free, (800) 999-6673. I have found several societies to contact for their information about visual diseases and disorders.
Susan B.

Dear Nancy,

My mother is about 5 years into her PSP disease since diagnosis. Prior to that, we experienced the unusual onset of PSP symptoms (not knowing PSP at the time) such as rigidity, slowness of movement and personality changes but the most serious was her falling. She was always so bruised and there were the two incidents where she had broken bones which resulted in casts.

As I think about watching my father attempt "remedies" as the stages of this disease always change and progress, I recall two of them which I would like to share.

1. An armless office chair with wheels worked well to transport her throughout the house. During the day she remained in her lift chair and watched TV. When it was time to eat or if she needed the bathroom, he would help her into the office chair and then push her to their destination. It wheeled up nicely to the dining room table and overall was less cumbersome than the wheelchair.
2. As eating became very difficult for her, we discovered through one of her therapists, that it might help her to use a mirror to watch herself as she fed herself. It made an improvement. We used an 8 x 10 mirror and leaned it against the phone book or anything we could find. We propped it behind her plate so she could watch her utensil and better direct it to her mouth.

We continue to tackle the challenges of the never-ending progression of PSP.

Susan in PA

Here is a recipe that my loved one with PSP enjoys and seems really easy for him to eat.

APPLESAUCE GELATIN SQUARES

2 packages gelatin 4 cups boiling water
2 cups cold water 1 jar (46 oz) applesauce

Dissolve gelatin in boiling water. Stir in cold water and applesauce. Pour into a 13 by 9 pan coated with cooking spray. Refrigerate. (Sugar Free can be used as well)

Barb

SUGGESTED READING:

These books have been recommended by families living with PSP. If you have any suggestions, please contact the Editor.

The Comfort of Home: An Illustrated Step by Step Guide for Caregivers

Care Trust Publications, Inc. (800) 656-1533
\$23, plus \$3.50 shipping and handling

Author Maria Mayer and Nursing colleague Paula Derr have done an excellent job of presenting the multiple aspects of caregiving using a comprehensive and reader-friendly format. The book is catalogued to enable a quick reference when problems occur. Key teaching points and checklists are highlighted, making this a good teaching reference for health-care professionals as well help for family caregivers. Focus is also placed on the physical aspects of giving care.

Dressing Tips and Clothing Resources for Making Life Easier

Shelley P. Schwarz
Price 22.95

Paperback, 3rd ed., 109 pages

ISBN: 1891854003

Publisher: Schwarz, Shelley Peterman

www.makinglifeeasier.com

This book offers hundreds of tips and techniques to help one dress. Information is available on modifying garments to make them easier to put on and take off. An individual will learn new ways to dress oneself or ways for the caregiver to dress another person. Also available is a resource section locating more than 100 businesses that offer specially designed or adapted clothing for people with disabilities and special needs.

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

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

Nancy Brittingham, Editor

PSP Advocate

Woodholme Medical Building

Suite 515

1838 Greene Tree Road

Baltimore, MD 21208

Fax: 757-838-6086

email: 103301.640@compuserve.com

GRANT ANNOUNCEMENT:

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

Deadline, October 1.

Regular Grant Program to \$20,000 - Deadlines are April 1 and October .

For information contact: Dr. Lawrence I. Golbe, Chairman of the Medical Advisory Board at golbe@umdnj.edu or

Fax 732-235-7041.

“Ordinary Into Extraordinary”

by Nancy Sanford
Daughter of Len and Dot Azzarano

This is as fine a love story as you will ever hear. Two fine young people from different ethnic backgrounds—one Polish and the other Italian-met and married 50 years ago this July. Their lives exemplify the “ordinary” as well as the “extraordinary.”

They lived what appeared to be an “ordinary” life. Dad was a teacher and attended school at night to earn a higher degree in education. Mom cared for all of us acting as a full time mom and full time secretary for dad. She typed his letters for school, deciphered his awful handwriting and corrected his grammar. What was “extraordinary” about all of this is that dad achieved his doctorate of education and mom fulfilled other roles without missing a beat. She even held a job outside of the home.

As time went on, my mom and dad did all the “ordinary” raising of the three of us. They both worked for the School District of Philadelphia. In the summers though, they took us on vacations, camping, fishing, etc. They showed us all the “extraordinary” things in life—the beauty of nature and the joy of the outdoors. Through their example, they taught us in many small ways the importance of education, honesty, accountability and hard work.

As middle age years progressed, they were able to rediscover each other on their many vacations. The vacation that I remember them telling us about was their trip to Italy where they met new friends and renewed their wedding vows in a beautiful cathedral. We spent hours looking through photo albums that have been carefully preserved with all their



memorable trips together. In 1995, they retired and moved to a heavenly location in South Carolina called Callawassie Island. It was there that they were soon challenged by medical problems. Dad’s several-year old hip replacement began to fail; Mom had developed, what was thought to be Parkinson’s disease. With a little help from all of the children, Dad had his overdue hip repair done. Mom was taken to a specialist in Philadelphia to pursue a second opinion. It was at this time that she was diagnosed with progressive supranuclear palsy.

This is the time that this “ordinary” couple has turned “extraordinary.” Dad, the “tool man,”

begins to adapt their home to meet his wife’s needs. He reads and educates himself on how best to care for her. He has even learned to become a decent chef, although he can never match Mom’s gourmet style. Mom is one of the most courageous people we have ever known. She struggles with the day-to-day physical challenges with rarely a complaint or bitter word. She continues to exercise and attend enrichment classes with Dad. In the cool evenings, they enjoy quiet moments on their back porch watching the birds and fishing.

I know this small tribute could never touch all the “extraordinary” things about our parents. Yet, we want to honor them on their 50th anniversary. As we read this to our parents, we want them to know how much we love and admire them, as I am sure is the same for so many other families affected by PSP. We will all be spending the week of July 30th with them and join them in their celebration of their 50th. They have taught us so many things, but their love and courage have showed us how they make an “ordinary” life into an “extraordinary” life!!

Bravest Woman

Dear Nancy,

I would like to tell you about the bravest woman I ever knew. Her name was Jean Moore and she was my mother. In the early 1990s, she began having some health problems that we knew were not normal, namely vision and balance troubles. These got progressively worse and, unfortunately, the doctors could not figure out what was wrong with her. After a few years, a neurologist from Oak Ridge, TN, about 20 miles from our hometown of Kingston, TN, sent her to the University of Alabama in Birmingham for a consultation with a neurologist down there. We were relieved that we finally might get a diagnosis for Mom, and some treatment that would help her. That day she did receive a diagnosis; the doctor knew immediately what was wrong with her, but the prognosis was not what we wanted to hear. We had wanted a cure, a magic pill or something for my 60-year-old mother to take to make her well. What we got was the news that she had PSP, and that there was nothing that could be done to cure her. Dad says that Mom rode back from Alabama quietly that day, never crying, just quiet. I know that it was so disappointing to her to find out that she would not get better. She did not get better. Each year she just got

Continued Page 20



Roane Newspapers/FILE PHOTO
The Kingstonettes in 1978 Included, from left, Polly Cole Russell, Jean Moore and Margaret Stewart.

Support - Our PSP Stories

Bravest Woman

Continued from Page 20

worse, until August 3rd, 1999 when she passed away, no longer able to fight the horrible disease.

She was a wonderful mother and a wonderful singer and a wonderful Christian. She was an incredible grandmother to her nine grandchildren. She had a beautiful smile and a beautiful voice. It was heartbreaking to hear her speech get worse and worse through the years, first becoming slurred and eventually becoming unintelligible, to eventually coming to the point that she barely tried to talk because it was of little use. It was so sad when she wanted to tell us something and we would have to have her repeat it many times hoping to understand some word or syllable that would enable us to tell what she was wanting to say, only having to give up and say that we were sorry but we just couldn't understand. But she never cried. She was always so brave. A few days before she died, she told me she loved me in as plain a voice as I had heard come from her lips in many, many months, and I will never forget those three little words she mumbled. She knew how much I needed to hear her say it.

Mealtimes became progressively harder and harder through the years. She chose early on while she was still able to talk that she never wanted a feeding tube, and we respected her wish. Her swallowing got progressively worse and worse, plus her neck was so stiff that she was permanently looking towards the ceiling. My brother says that she was looking towards heaven, and mom would smile when he said that. Mealtimes became a lesson of frustration and creativity. Early on, foods that were more difficult to swallow were avoided. Thickeners were added to liquids. Food were mashed, then pureed. Eventually, mealtimes would sometimes take over an hour, and we wouldn't be able to get down near the food she needed. Choking fits were common. Every swallow she took, she had to trust that someone would help her get "unchoked". Dad, my niece, and I would shed many a tear while we fed her, but she didn't cry. The last days we weren't able to get anything at all down her.

Many changes took place in the home. Mom never liked furniture rearranged, or her things gone through, but we had to make room for potty chairs, lift chairs, wheelchairs, and eventually the hospital bed, suction machine, oxygen tanks. She had to sit and watch all her possessions that she had placed throughout the 40 years she had lived in her house moved, and moved again with each additional piece of equipment. She just sat and watched; she couldn't talk. But she didn't cry, We did though. There are so many ways my mom was so brave. The pain and suffering she had to endure was tremendous, but she was so sweet to care for. I don't know how she did it. She was always able to find something to laugh about. I remember when we took her to the doctor once, and my dad took a wrong turn and was rolling her into the wrong doctor's office. She couldn't say anything, but my, how she got tickled and laughed and laughed. Even the doctor peeked out into the waiting room to see what was going on. One day when Dad was still able to take her to the doctor by himself, he decided to go to the fruit market, and naturally left her in the car. She accidentally hit the automatic door locks, so when he came to get back in, he couldn't. It took him a very long time until he could get her to push the right button so he could get back in the car. She always got a chuckle out of that story when he told it. Needless to say, he never left the car again until he rolled the window down a bit or took the keys with him.

Fortunately, we were able to keep mom at home, and that's where she died, surrounded by her family. We still miss her, but I know she's up in heaven singing her heart out. I also know she's saving a place for the family who meant as much to her, as she meant to us. I always knew that my parents were special, but Mom's illness just showed me over and over again the strength of their bond together. My dad took such good care of Mom, and recently had to live through his 49th wedding anniversary without his beloved.

Your newsletter was a source of much-needed strength and information throughout Mom's illness. We knew so little about the disease and your newsletter was welcomed each time we received it in the mail. Thank you so much. If any of your readers would like to contact me, my email address is lipperts@icx.net, and my mailing address is: 2881 Kingston Hwy. Kingston, TN 37763.

Beverly Lippert, Loving daughter of Jeannine Moore

PSP, The Ultimate Test of a Relationship

Continued from Page 14

with the feeling(s). Remind yourself that the feelings are not "wrong" and begin to explore how you might put words together in a way that says clearly what the feeling is, without assigning blame (self or otherwise) or shame. Can you say gently, "I know neither of us can do anything about this, but I just need to say I am TIRED!" or, "I am frightened," or feel helpless or hopeless, etc.

2. If/when you do begin to communicate in this way with your loved one(s), be prepared to hear his/her response and then perhaps begin to explore how both of you are feeling. This may lead to tears and other expressions of emotion. Allow the tears, the emotional expression. Touch each other or hug each other, if it feels appropriate. Don't be in a hurry. Allow plenty of time to just be with this process, talking back and forth, lovingly and honestly.
3. Ask your loved one to tell you what he/she needs from you. Then really LISTEN to thier response. Talk honestly about whether or not you can provide what he/she needs and if not, why. Explore this gently together.
4. Tell your loved one, gently, what you need from him/her and explore this together.
Both 3 & 4 must be "possible" needs, realistic in the present situation.
5. Explore, together, how you can both bring some lightness into the situation. Is there also some way to find beauty and meaning in your relationship, regardless of the devastation of the disease?
6. Reaffirm the love and caring that you share.
7. Repeat this exercise on a regular basis. You may find that different things come up each time. We change. Our needs and feelings change. Once this closeness has been established, it is important to maintain it.

Individuals living with PSP, from whatever perspective, have been presented with a tremendous, terrible challenge. Responding to the challenge is difficult and painful. Be as loving and patient with yourself as you are with others, as you try to find a way to remain connected with those you love.

Regular Report of Gifts

February 16 thru April 30, 2000

PSP PARTNERS - \$10,000 AND OVER

Jay Troxel

GOLD BENEFACTOR - \$1000 AND OVER

Bruce Barnett

Wayne Berger in honor of Alfred Berger

Margaret Brown in memory of John Harold Brown

Ruth Dittmer in memory of Tom Dittmer

C. Rae Franey in memory of Shirley Stephens

Judith & Richard Gilmore in memory of Charlotte B. Wernick

Carol Hutchinson

Shirley Jackson

Frederick Koallick

Lucy MacAnaney in memory of Paul MacAnaney

William Murfey in memory of Betty Jo Mayes Murfey

Mari Anne Pisarri in memory of Jim Pisarri

Helen Rossini in memory of Harry Rossini

Dr. & Mrs. Shearer in honor of Marilyn Henery

Eleanor Singer in memory of William Singer

Eleanor Stewart in memory of Louise M. Stewart

U.S. Aggregates Inc. in memory of Pat Shane

GOLD PATRON \$500 - \$999

Janice Clements in memory of John Clements

Friends and Relatives in memory of M. Jean Pomnichowski

Frances Green

Thomas Huber

Husband Alex And Children Paul, Sharon and Kathy
in memory of M. Jean Pomnichowski

Ralph Glendinning in memory of Halbert E. Payne

Carol Marchi in honor of Ellen Katz & George Jankiewicz

Mr. & Mrs. E. Moloney in memory of Martin J. Murphy

Era Murphy in memory of Martin J. Murphy

Alex Pomnichowski in memory of Jean Pomnichowski

Rhea Solomon in memory of Rollo Solomon

Lane Stokes

United Way of Tri-State

John & Marie Zimmerman in honor of John G. Zimmerman

SILVER SPONSOR \$250 - \$499

Larry Aronofsky in memory of William Aronofsky

Geraldine Brosman in memory of Gilbert Brosman

Mrs. Gene Carolan in memory of Gene Carolan

Chesapeake Group

Richard Clift in memory of Miriam Clift

The Concord Madrigals in memory of Olivia Nields

Eric Erickson in memory of Joan Margaret Erickson

Elsie Garland

James A. Gatton

James Caldwell HS in memory of Cyril Goss

William Ketcham in honor of Thomas Amory

Michael Kirby in memory of Don & Bea Heck

Helen Kirkley in memory of Robert E. Kirkley

LaCleda Inc

Nancy Levy in memory of Ellen Biderman

Miriam Malone in honor of Tom Connolly

Shaw Mudge in memory of Halbert E. Payne

Prebon Yamane Inc in memory of Teresa Homa

Michael & Polly Rabalais

Dr. Stephen Reich

John & Judith Remondi in memory of Joan Cullen

Ruth J. Roberts in memory of Ruth Aldridge

Sheboygan Paper Box Company in memory of Lee Liebl

Sam Smolkin

Amy Todd in memory of Ruth Lindenbaum

Lorreean Tracy in memory of Jack Tracy, M.D.

United Way of Tri-State

DONATIONS - PATRONS \$100 AND OVER

Mikeal & Constance Adams in memory of Roscoe K. Crane

H.A. Aldridge in memory of Ruth Aldridge

Dieter Ambros in memory of Delbert Boyce

Thomas Amory

Anesta Corp. in memory of Jean Pomnichowski

Apria Healthcare

Susan Arbuckle

Joanne Armstrong

Peter Babits in memory of Mary Babits

Mary Ann Barber in memory of Charles Barber

Donald & Vicki Barrigar in honor of Vicki Barrigar

Georganne Beers in memory of Bob Holland

Ann & Glenn Behnke in honor of Glenn Behnke

Antonio & Alberta Benivegna

Emmy Bennett in memory of Ruby M. Bennett

Jean Bernhardt in memory of Helen J. Emerson

Blue Rill Day Camp in memory of Anne DeRogatis

Sarah Boze in memory of William R. Boze

Mrs. Nan Breece & Jim & Beth in memory of Dale Breece

Margaret Briggs in memory of Jean Lewis Johnson

Robert Brooks in memory of Halbert E. Payne

Wallace & Doris Bruce

Peter & Marilou Buffum in memory of Ida Massari

Calvin Burnes in memory of Halbert E. Payne

Dorothy Butterworth

Patrick & Shirley Carroll in memory of Ray DeBono

Mary Jane Cheever in memory of Olivia Nields

Timothy Cheslak in memory of Mary McNicoll Cheslak

Michael & Lucrecia Chiechi

Robert Ciesla in memory of Lee Liebl

Rick & Laurelyn Claybrook in memory of Audre McGranahan

Cindy Colafella in memory of Marjorie Mirliani

Bernard & Judith Connolly in honor of Thomas Connolly

Conseco Senior Health

Construction Specification Institute in memory of John Hamilton

Crestwood Company

Cutting Edge Supply in memory of Pat Shane

Vicki DeCourley in honor of Helen H. Parard

Maria DeBono in memory of Ray DeBono

William & Ann Degnan in memory of Delbert Boyce

Kathryn Cobb DeGraw in memory of Helen Cobb Drake

Dolomite Home Care Products

Marsha & Larry Donahue in memory of Florence Butts

William & Barbara Dordelman in memory of Halbert E. Payne

Roslyn & Anthony Dorman in memory of Charles P. Wachsmuth

Barbara Dressler in memory of Lee Liebl

Bill Dugger in memory of Betty Lou Smith

Judy Dunn in memory of John Lawther

Charles & Janet Edmunson in honor of Mickey Khera

Emerson Investment Management, Inc. in memory of

John Clements

Employees of Lake Worth Drainage District in memory of

Sherwood W. Butz

Roberta Evans in memory of R. Preston Evans

V. Annette Evans in memory of Myrtice Gafford

William & Jean Eveleth in memory of Jack Litten

Mary Everett in memory of Lee Liebl

Kenneth & Letty Jane Farmer in memory of Ida Massari

Warren & Elizabeth Farrington in honor of Betty Farrington

Feirich/Mager/Green/Ryan - Attorneys at law in memory of

Bill F. Green

Denver Flanagan in honor of Mary Flanagan

Susan Foster in memory of Florence Butts

Margaret Fowler in memory of Charles Fowler

Jeffrey & Jean Fox in honor of Elbert Harris

Donna Frederick in honor of Kerry Branson

Friends from Filene's Basement of Nancy Gordon in memory of

Olivia Nields

Friends/Family of Margie Alice Abel in memory of

Margie Alice Abel

Charles & Marjorie Fuhr

Albert Gammall

Henry & Rosemary Garcia in memory of Bob Holland

Report of Gifts

DONATIONS - PATRONS \$100 AND OVER continued

Judy Geller in honor of Annabelle Geller
Margaret Gillenwater in memory of William Gillenwater
Helene Glazer in memory of Teresa Homa
Jeanne Graham in honor of Diane Oselett
Frances Green in memory of Bill F. Green
Capt. James Hamburg
Robert Hauer
Ross Hayashida
James Healey in memory of Dr. Vernon Mikkelson
Emily Bulian Helmes in honor of Adele Bulian Davis
Robert Henry III in memory of Beatrice Freedman
Josephine Hesla
Hillcrest Friends in memory of M. Jean Pomnichowski
Ward & Dorothy Hodge in memory of Jean Pomnichowski
JoAnne Hodgson in memory of LaVerne E. Johnson
Edward Holland in memory of Bob Holland
Lisa & Alan Hope
ID Care Inc. in memory of Mary Longo
In Sight Books Inc.
James Infanti in memory of Beatrice Freedman
International Council of Shopping Centers in memory of Edward Gdovin
International Paper Employees in memory of James Starks
David & Kym Ionta in memory of Anna C. Ionta
Jay & Lucy James
Judges & Staff - Jackson County Courthouse in memory of Bill F. Green
Pauline Jurrens
Patricia H. Kazmaier in memory of Olivia Niels
Henry Kemp
Richard Kissinger in memory of Johana A. Kissinger
Robert Klovensky in memory of Charles P. Wachsmuth
Norman & Linda Konczal in memory of Sally Shollack
Lucille Konrade in memory of Leon Konrade
N. Kosmetatos in memory of Anastasios Thomas Mantis
B. Raj Kothari
Susan & P. Kumer in memory of Marcella Gewirth
Kathryn & Dillian Lafferty in honor of Kathryn Keener
Cheri McCay Langmeyer in memory of Albert Langmeyer
Mary Langmeyer in memory of Albert Langmeyer
Chris Larkin
Ethel Latham in memory of Cecil R. Latham
Gary Latter in memory of Ed Wiley
J. T. Lazar in honor of Mary Darby Lazar
Walter & Peggy Lee in memory of Lisby Lucius Wade
Joseph Leto in honor of Evangeline Leto
Jeffrey & Caroline Liebl in memory of Lee Liebl
Robert Liebl in memory of Lee Liebl
Thomas Liebl in memory of Lee Liebl
Thomas & Joan Litle in memory of Olivia Niels
Andrea LoPinto in honor of John LoPinto
W. Ralph & Esther Lowe in memory of Olivia Niels
Victor Lyon in honor of Georgia Lyon
Kevin Malloy
Manning Selvage & Lee in memory of Irene Hanzak
Jeanette Marmor in memory of Philip P. Vicino
Lois Martin in honor of Bob & Carolyn Cheek
Nita Curl Martin
David & Judi McCaughey in memory of Mary McNicoll Cheslak
McFaddens & Hill Auto Hock in memory of Sally Shollack
Eugene & Joy McHale in honor of Tom McHale
George & Pamela McKellar in memory of Julia Maude McKellar
Jan & Michael Meisel in honor of Alfred Berger
Mary & William Michels in memory of Halbert E. Payne
Richard S. Mickel in memory of Ruth Aldridge
Gail & Wayne Miller
Thomas Moran
Patricia Moreland in memory of Anne M. Levins
MSI, Inc. in memory of Betty Lou Smith
E. J. Nicholson in memory of Pat Shane
North Coast Medical Inc
Helen O'Donnell-Smith in memory of Thomas H. Collins
Kathleen & Mike O'Halloran in memory of Betty O'Donnell
Eric Olson in memory of Lee Liebl

Jonathan Painter in memory of Jack Litten
Parkinson Foundation of Canada
Rajni Paun
D. W. Pennington in memory of Lisby Lucius Wade
Loretta Phillips in memory of Delbert Phillips
Laurel Pieper
Pitney Bowes
John & Judith Powell
Eugene & Irene Prather
Bernard & Robyrtta Rappoport
Harvey Raschke in memory of Doris Raschke
Kari Reiber in memory of Olivia Niels
Joyce Reisman
Barbara Reynolds in honor of Delbert Phillips
Jacqueline Riley
William Riley
James & Betsy Rill in memory of John Lawther
Diane Roscetti in honor of Eilene Harrington
Esther Roscoe in memory of James Starks
Elaine & Bernie Rothman in honor of Annabelle Geller
Saltillo Corporation
W. R. Sandwith
Mario Santacaterina in honor of John Santacaterina
Roger & Nancy Saylor in memory of Shirley Stephens
Peter & Mary Schaefer in honor of Beverly Schaefer
Toni Scheper in honor of Howard Dodge
Othmar Schroeder in honor of Sally Schroeder
Candice & Dave Schuchardt in honor of William Hector & Pat Lynn
Richard Schutte in honor of Mary B. Schutte
Richard & Jeanne Scroggins in memory of Halbert E. Payne
Audrey Scruggs in memory of William Scruggs
Marvin Seidman in memory of Seena Seidman
Shirley Serby in memory of Kenneth Serby
Douglas Sheeley, Jr. in memory of Douglas V. Sheeley, Sr.
Pearl Sherman
April Shinkle in memory of Hazel Shinkle
Dean & Kristen Shollack in memory of Sally Shollack
Dorothy Simmons in memory of Joyce E. Day
Storme Smithers in honor of Mickey Smithers
Ben & Margaret Smolenski
Frank Spampinato in memory of Ida Massari
James & Margaret Stanton in memory of Lee Liebl
William Sterling
Stephen Stone in honor of Suzanne Stone
John Sword in memory of Charles Cooling
Sylvia Tansey
Margaret Tauer in memory of Francis James Tauer
Jo Ann Tavarez in memory of Nan Scelzi
The Jean Pomnichowski Revocable Trust in memory of Jean Pomnichowski
Bryan Thornton
Ned & Maryon Titus
Mary M. Torre
Trademark Medical
Beverly Travis & Lynn Sheehan & E. C. Travis & Co. in memory of Betty Lou Smith
Lawrence Tull in memory of Delores Tull
United Way of Tri-State
Ruth Urso in memory of Paul Urso
Richard Vollrath in memory of Lee Liebl
Walter Vollrath in memory of Lee Liebl
William & Phyllis Warfel in memory of Jack Litten
Joan Weeks in memory of George R. Weeks, M.D.
Weiss, Jensen, Ellis & Howard in memory of John A. Bender, Sr.
Jane Werner
Harry & Priscilla Wheeler in honor of Priscilla D. Wheeler
Lloyd & Arlene Wilcox in memory of Gladys Faust
Kathleen & Wayne Williams in memory of Jack Drinkwater
George & Jane Wilson
Cathy Witte in memory of Harry Witte
Andrew & Anne Wood in memory of Olivia Niels
Virginia G. Woodbury
Raymond & Louisa Yount in memory of Olivia Niels
ZBR Publications in memory of Olivia Niels
John & Marie Zimmerman

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

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

Send me copies of:

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

Mail to: _____

Fax to : _____ Email to: _____

FOR PHYSICIANS ONLY:

- #2 Video "The Diagnosis of PSP" (Recommended for clinicians and faculty) \$30 +4 shipping in US and \$7 outside
- Medical Professional Packet (Grant Award Information/PSP Rating Scale/copies of all other info.)
- I no longer wish to receive the PSP Advocate and by sending this will save expenses for the Society.
- My new address is: _____

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

Name _____

Address _____

City _____ State _____ Zip _____ Country _____

Fax _____ Email _____

Person w/PSP Family Physician Other _____

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

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

Name _____

Address _____

Phone/Fax/email _____

Check/Charge to: Visa Mastercard American Express

Card number _____ Expiration Date _____ Signature _____

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

You Can Help By Becoming A Volunteer

VOLUNTEER PROFILE

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

Spouse or Significant Other's Name: _____

Home Address: _____

Home Telephone Number: _____ Fax: _____

E-Mail Address: _____

Business: _____ Title: _____

Business Address: _____

Business Telephone Number: _____ Fax: _____

Your occupation and job responsibilities: _____

Board Memberships & Professional Organizations: _____

Social Affiliations/Clubs & Organizations: _____

Personal Interests/Hobbies: _____

Areas of Experience or Expertise:

- | | | |
|---|---|---|
| <input type="checkbox"/> Budget/Fiscal | <input type="checkbox"/> Fundraising: | <input type="checkbox"/> Board of Directors |
| <input type="checkbox"/> Legal | <input type="checkbox"/> Special Events | <input type="checkbox"/> Computer Technology |
| <input type="checkbox"/> Accounting | <input type="checkbox"/> Foundations | <input type="checkbox"/> Web site/Internet |
| <input type="checkbox"/> Investing | <input type="checkbox"/> Corporations | <input type="checkbox"/> Newsletter |
| <input type="checkbox"/> Government Affairs | <input type="checkbox"/> Writing | <input type="checkbox"/> Lead a Support Group |
| <input type="checkbox"/> Personnel | <input type="checkbox"/> Media | <input type="checkbox"/> Social Services |
| <input type="checkbox"/> Research/Marketing | <input type="checkbox"/> Graphic Arts | <input type="checkbox"/> Allied Health Professional |
| <input type="checkbox"/> Non-Profit Mgmt. | <input type="checkbox"/> Meeting Planning | <input type="checkbox"/> Counseling/Social Work |
| <input type="checkbox"/> Public Speaking | | <input type="checkbox"/> Other (specify) _____ |

THE SOCIETY FOR
PSP
Progressive Supranuclear Palsy

Woodholme
Medical Building
Suite 515
1838 Greene Tree Rd.
Baltimore, MD 21208

1990-2000
A Decade of Caring

Address Service Requested

NON-PROFIT ORG.
U.S. POSTAGE
PAID
HAMPTON, VA
PERMIT NO. 799