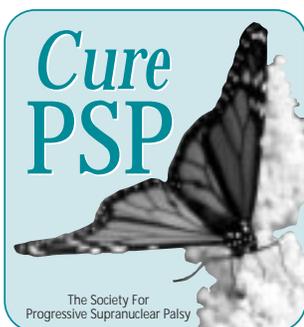


Woodholme
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email:
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www.psp.org

INSIDE

**GENETIC
MUTATION
ASSOCIATED
WITH PSP**

**CARING FOR THE
CAREGIVER**



FACE TO FACE, COAST TO COAST

The Society brings families together

"Now I don't feel so alone." "There's a lot more help out there than I thought." "I've made so many connections here." These were just a few comments spoken by participants at the October 12, 2002 California Regional Symposium for Persons Diagnosed with PSP, Families and Caregivers held at the Doubletree Hotel in Los Angeles. Expertise was shared, questions were answered and new friends were made at this gathering of families, caregivers and clinicians. Over 75 people came together from the states of California, Washington and Nevada to share their experiences and learn more about PSP.

Carolyn Cheek, Los Angeles/Orange County Support Group Leader, opened the day with a warm welcome and acknowledgment of her fellow support group members whose dedication and tireless efforts greatly contributed to the success of the symposium. Dr. James Sutton, Medical Director of The Encephalologic Medical Group, then set the stage with his well-received lecture on understanding PSP. This was followed by an excellent presentation on psychological and behavioral changes in PSP given by Dr. Neal Hermanowicz, Director of Movement Disorders at the University of California, Irvine. Dr. Michael Jakowec and Dr. Giselle Petzinger concluded a terrific morning by effectively communicating current trends in research, a topic always on the minds and hearts of those living with PSP.

After enjoying a bountiful lunch buffet, participants geared up for the second half of the day which included presentations by the Society's Executive Director, Ellen Katz, and John Parker, Attorney at Law. Carolyn Cheek was given a special award in recognition of her outstanding service as a volunteer and family advocate. Mary Miano, Carolyn Griffith and Ceri Williams were also honored for their service as support group leaders and their invaluable efforts as part of the symposium committee.

Afternoon sessions concluded with two breakout options: a caregiver's panel entitled, "Living with PSP," moderated by Jessica Quintilian, Director of Outreach & Education,

PSP WALL OF HOPE



A PSP Wall Of Hope was on display at the California Regional Symposium.

Continued Page 5

The Society for Progressive Supranuclear Palsy

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

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

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Put "Subscribe psp your name" in body of email

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

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(In memory of Henry and Jane Ogiba)

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(In memory of Lois Croft Davis)

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Director's Doings



Has the Society for PSP touched you in 2002?

The message of the work of the Society came to me quite clearly a few weeks ago. My mother recently broke her hip and needed occupational and physical therapy to be rendered in a local Baltimore nursing home. Suddenly, our family was thrust into the world of

"Medicare," long term care and

into the new world of life in a nursing home. My mother went with the idea that she would be rehabilitated and be able to return to living independently. That has not happened and she needs assisted care. However, she can move to an environment requiring less skilled care.

While at the nursing home, I came into contact with the one PSP patient there (out of 150 beds). I knew her family as they assist with organizing and maintaining our Baltimore support group. This lovely lady was approaching the end stages of PSP and had a full time companion with her.

I visited her daily to say hello and saw that she was failing every day. My strongest image of her was in the dining room as she sat with other residents—most of them with some type of dementia, stroke or physical disability. I saw first-hand how much minute-to-minute care a PSP person at this stage requires—more so than any other resident that I observed. As I compared her to the other patients, I realized then that PSP was the most debilitating.

Every person with PSP that I have met during my years with the Society has been an inspiration of courage and strength to me. As I watched the nursing home staff and the family attending to every need, I was reminded of all the devoted and hardworking PSP caregivers as they unselfishly care for their loved one with PSP. All of you are also an inspiration of courage and strength! Caregiving for a person with PSP is a full time job! What can the rest of us be doing to help? We can be spreading the message to persons outside the world of PSP of how disabling and cruel progressive supranuclear palsy is.

Every PSP family can be doing this by giving out the Society's information to friends and family and to the general community. We need to educate everyone about PSP. After all, it can happen to anyone and we know the incidence of the disease will increase as we age. We project 40,000 will have the disease within 20 years, up from the 20,000 we estimate currently.

We can't wait. Take action now—educate, inform and advocate for persons with PSP through the Society and your local resources.

Warm regards,

Ellen Pam Katz
Executive Director

Chairperson's Corner

Liz Brisson
Chairperson, Society for PSP

"Such to me is the new image of aging: growth in self and service for all mankind." Ethel Percy Audrus

I have just returned from a visit to the Society's National Headquarters in Baltimore and was energized by the commitment of excellence emitted from the staff. Why is this important for me to share with you? Because these individuals are dedicated and committed to the mission of the Society. For them, this is more than just a job, it is about building relationships with each and every one of you. Whether or not you actually speak with them personally, they know you through your stories, donations and inquiries. These individuals are proud of what they do and it shows in the quality of work that goes out of the office. These are an extremely caring group of women who are passionate about what they do and I know that Aysha, Kate, Joyce, Adrienne, Jessica, Jackie, Alice, Nancy and Ellen have touched you along the way.



I am personally excited about the last quarter of this year and the initiatives that the Society has planned. In particular, the Society's 2002 International PSP Research Symposium to be held in Miami, FL in November which will also coincide with the year-end Society Board Meeting. The Society for PSP is sponsoring this conference which will provide a forum for the world's leading PSP researchers to discuss and evaluate their PSP research results. By sharing their knowledge and identifying new areas of focus for PSP research, they will plan future areas of PSP research in their dedicated mission to find the cause and cure. Highlights of the research symposium will be published in a future PSP Advocate.

Another important focus for the Society is evaluating and updating the three-year strategic plan for 2004-2006. A dynamic Steering Committee has been selected to focus on the original four goals which are:

- To establish a strong national presence and increase education of PSP, to persons with PSP, their families, carepartners, physicians, and allied professions.
- To continue to generate and increase yearly ongoing revenue for current operating expenditures, special projects and future funding through establishing a Development Program.
- To strengthen and broaden an effective Volunteer Leadership Program.
- To promote and increase progressive supranuclear palsy research.

We will look at areas of expansion as well as the need for creating additional goals. A kick-off meeting is being planned for late December or early January. In the meantime, I would welcome you to contact me if you have any suggestions for the committee to consider. My email address is lbrisson@nef.com Looking forward to a productive close to 2002. Wishing you and your family a very peaceful Holiday Season.

The Society for PSP

Meet Adrienne Bantum

A Special Member of the Society Support Staff

October 2002 will make the fifth anniversary of Adrienne Bantum's employment with the Society for PSP. She joined the staff when it consisted of the Executive Director and a secretary working out of a small area in a room at Johns Hopkins Hospital. Because of the lack of space, much of Adrienne's work as book-keeper and grants administrator had to be done from her home.

Adrienne said she wakes up every morning and thinks about how fortunate she is to be working with such talented and dedicated co-workers. She is now one of eight full time Society employees housed in the Society's own office in Woodholme Medical Building in Baltimore. Adrienne says, "This is a testament in itself of how much the Society has grown." Some of Adrienne's job responsibilities include paying the bills, working with vendors, tracking income, depositing funds, and administrat-

ing grants. She works with the Assistant Director on financial matters. She has played a vital role in the technological conversion to eTapestry that took place in the office this year. "I have watched the Society grow from a seedling into a full fledged flower," she says.

Adrienne was raised in New York City but came to Baltimore to attend college with two of her sisters. She began her employment career as a teller at First National Bank in Owings Mills, Maryland. This is where she met her husband, Raymond. Raymond and his company were clients of the bank and he would come in often and they would strike up conversations. One day phone numbers were exchanged. Now, they have been married for 17 years and have two sons, Ryan (12 yrs.) and Troy (10 yrs.)

Adrienne was promoted to head teller and moved to the corporate bank office where she stayed for 5 years. At this time, she decided she needed a change and worked in the accounting department for an additional 5 years. Adrienne took a new job opportunity to put her accounting skills to work in the technology department. "This opened a whole new area of experience for me. I learned about the other side of accounting and invoicing involving software programs, as well as the back end where the actual programming takes place. I learned to write programs and to troubleshoot for possible problems."

In 1994, Adrienne decided to stay home with her children and says it was the best part of her life. She volunteered at her children's school assisting in the library, and going on field trips, and served on several PTA committees. She was den leader of a Cub Scout troop, venturing out on camping trips and hikes.

Adrienne's husband, Raymond, was a technology manager at Clifton Gunderson and assisted with computer technology at the



Adrienne, Troy, Ryan and Raymond

Society office. In 1997, he was working in the Society office when Ellen Katz, Executive Director, mentioned to him that she was looking for an employee to work part time doing data entry. Adrienne took the opportunity and began her new job with the Society in a part-time capacity. "It was not my intention to return to work full time," Adrienne said, "The job sort of grew on me or maybe I grew into the job. When talking on the phone to family members or someone who has PSP, sometimes it is very difficult for me to hear what they and their loved ones are going through. I wish I could do so much more for them. But, it is rewarding to know that I may have helped someone by just talking and listening. Sometimes we both shed tears as they shared their stories with me."

Adrienne said that she is happiest when with her family—her husband, sons, mom, brothers and sisters, nephews and nieces. "I enjoy it when we get together and have dinner and watch a movie or just talk to relax after a long week," she says. The Society for PSP is proud to have you, Adrienne, as part of the Society "family." You are a valuable member! Thank you for all your

continued efforts in helping the Society fulfill its mission to be of service to the PSP community.



A SPECIAL THANKS

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

Special Events

Continued from Page 1

California Regional Symposium



Ceri Williams and Carolyn Cheek at the California Symposium.

and a special "Music and Joy" session for persons diagnosed with PSP, led by Ellen Katz and Carolyn Cheek, complete with keyboards and tambourines. Panelists Carolyn Griffith, Pennie Parrott and May Toll evoked the most heartfelt emotions of the day with their candid and poignant portrayals of real life with PSP. From these devoted

caregivers, the audience learned tips for dealing with communication, walking and swallowing difficulties, as well as ways to keep activities like reading and meal times as enjoyable as possible for their loved ones. The afternoon brought both laughter and tears as these panelists shared the emotions and struggles that they have experienced as caregivers. The opportunity to question "someone who has been there" was such a vital part of the day for families and caregivers in the audience.

This close-knit connection achieved during the breakout sessions was continued at the "Visions and Opportunities" session presented by Dr. Zeba Vanek, Assistant Professor of Neurology and Director of the Spasticity Clinic at UCLA. Dr. Vanek artfully encapsulated a condensed version of the day's program with wonderful graphics, effective teaching methods and a focus on PSP research, making this presentation a highlight of the symposium for those who stayed for the evening session. Participants also had the opportunity to learn about the Society for PSP, where we are heading as an organization and how families can help. The Society wishes to thank each of the individual and corporate sponsors who supported the California Regional Symposium. If you would like to attend an event like this one, be sure to watch our website for a list of educational and awareness events around the country! Next month, the Society visits sunny Miami, Florida for an Afternoon of Caring and Sharing on Sunday, November 10, 2002. November activities in Miami include the 2002



Carolyn Cheek and the Los Angeles/Orange County Support Group were instrumental in organizing the California Symposium.

International PSP Research Symposium. The Society is sponsoring this exciting conference that will bring together the top international scientists in PSP research. They will discuss the findings of their completed Society supported research grants and determine future PSP research direction. The Movement Disorder Society Conference also takes place in Miami and the Society will participate with an exhibit as we continue to raise awareness about progressive supranuclear palsy.

Thank You

The Society for PSP thanks our Corporate Sponsors for their support of the October 12, 2002 California Regional Symposium for Persons Diagnosed with PSP, Families and Caregivers. Please be sure to mention your thanks when you contact these companies for information on their products which aid in the daily life activities of those diagnosed with PSP and their caregivers.

Advanced Respiratory
800-426-4224

www.thevest.com

AliMed

800-225-2610

www.alimed.com

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www.allergan.com

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www.laclede.com

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www.bookvalet.com

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www.calmoseptine.com

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www.comfortcape.com

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www.insightbooks.com

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www.janssenpharmaceutica.com

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www.liftvestusa.com

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www.luminaud.com

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www.mobilityinc.net

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Saltillo Corporation

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www.simplythick.com

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800-848-9255

Today's Caregiver Magazine

800-829-2734

www.caregiver.com

Trademark Medical

800-325-9044

www.trademarkmedical.com

U-Step Walking Stabilizer

800-558-7837

www.ustep.com

This insert is to correct the telephone number that appeared incorrectly in the last PSP Advocate.

The correct telephone number for Mobility, Inc. is 866-456-8121. This company's Medicare-approved Mobility Air Toileting System is a lift-and-lower commode device available in several models including one for the bedside. www.mobilityinc.net.

Special Events

PSP OCTOBER AWARENESS MONTH ACTIVITIES



PSP AWARENESS BENEFIT
Ruby River Steakhouse
Ogden, Utah
Super PSP Event Planner-Tracie Sansavera

**3RD ANNUAL
PSP AWARENESS DINNER**
Minnesota Support Group
Super PSP Event Planner-Charlotte Tripet

PSP AWARENESS WALKATHON
Sponsored by the Beta Club,
Collinwood Middle School, Tennessee
Super PSP Event Planner-Sherri Cyle Collie

LEISURE STROLLER OR EXERCISER!
The 2nd Regional PSP Awareness Walk
Carroll County Farm Museum,
Westminster, Maryland
Super PSP Event Planners-
Jodi Da Roja and
Provident Bank.

PSP HARVEST FESTIVAL & HAYRIDE
Canandaigua, New York
Super PSP Event Planner-Marcy Bay

PSP SWIM-A-THON
Foley, Alabama
Super PSP Event Planners-
Carrie Wilson and Linda Webster

"JEANS DAY"
Latham & Watkins
San Diego, California
Super PSP Event Planner-Nadine Hylander

**SPAGHETTI DINNER TO BENEFIT
PSP AWARENESS**
Houston, Texas
Super PSP Event Planner-Jane Ellen Nickey

**PSP SUPPORT GROUP SILENT
ANONYMOUS FUNDRAISER**
Houston, Texas
Donations collected first week in November
Super PSP Event Planner-Karen Kennemer

ANNOUNCEMENT

If you have any medical equipment or supplies that you would like to donate to another PSP family, please contact Jessica Quintilian, Director of Outreach and Education at 1-800-457-4777 or outreach@psp.com

GRANT ANNOUNCEMENT:

The Society for PSP announces its Regular Grant Program up to \$50,000 supported by the Erwin and Pearl Poizner Memorial PSP Research Fund, The Dudley Moore PSP Research Fund, The Eloise H. Troxel Memorial PSP Research Fund and other designated funds.
Deadlines: April 1 and October 1
The Society also announces the Annual Eloise H. Troxel Memorial Fellowships, each of \$50,000 for research in PSP.
Deadline: October 1
For information contact: Dr. Lawrence I. Golbe, Chairman of the Medical Advisory Board at golbe@umdnj.edu or Fax 732-235-7041.

PSP EUROPE

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

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

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.

Ways You Can Give

SPECIAL GIVING OPPORTUNITIES

There are many different ways you can give to The Society for PSP. All gifts are tax deductible and can benefit both the donor and the Society for PSP.

OUTRIGHT GIFTS OF CASH OR SECURITIES

- ◆ A Supporting Gift
- ◆ A Memorial or Tribute gift to memorialize, recognize or honor a loved one
- ◆ A Sustaining Gift (pledge from one to five years)

PLANNED GIFTS

Planned Gifts or Deferred Gifts are gifts that can be established now through an estate plan. The Society for PSP would not receive the full value of the gift until some time in the future. There are a number of planned giving options, and your financial advisor can help you decide what is best for you and your family. The future of The Society for PSP can be ensured by your planned gift.

Benefits of a Planned Gift to the Donor

- ◆ Everyone can afford to make a planned gift, not just the wealthy
- ◆ May allow the donor to make a significantly larger gift than normally possible
- ◆ The gift can come from assets
- ◆ Offer tax advantages

TYPES OF PLANNED GIFTS

BEQUESTS are the most popular deferred giving vehicle. A provision is made in a donor's will, where a charitable organization receives cash and/or other assets at the time of the donor's death. Bequests may be used to establish memorials in honor of the donor, family members or others.

To make a bequest of cash or property to The Society for Progressive Supranuclear Palsy, your will or codicil should state:

"I give and bequeath to The Society for Progressive Supranuclear Palsy, a non-profit corporation organized under the laws of the State of Maryland, and having its main office at Woodholme Medical Building, Suite 515, 1838 Greene Tree Road, Baltimore, MD 21208, the sum of \$_____ or _____% of the residue, rest and remainder of my estate to be used for the general purposes and mission of the organization."

GIFTS OF LIFE INSURANCE are primarily given two ways:

- ◆ Transfer of ownership of an existing policy to the charitable organization
- ◆ Purchase of a contract by the donor, where the institution is named the beneficiary

CHARITABLE REMAINDER TRUSTS are used by donors to transfer assets to a trust, which then goes to the charitable organization after the death of the last beneficiary. The donor retains a fixed or variable income for life.

CHARITABLE LEAD TRUSTS are established by a donor transferring assets to a trust which provides income to a non-profit organization for a period of years. At the end of that period, the trust assets revert either to the donor (grantor) or

to someone else the donor designates (non-grantor).

Contact The Society for PSP's Executive Director, Ellen Katz, at 1-800-457-4777 and/or your financial advisor for further information on the best ways for you to give.

RESEARCH GIVING OPPORTUNITIES

ESTABLISH A NAMED PSP SUSTAINING (ONGOING) RESEARCH FUND

Many PSP grants may be funded by establishing a Sustained Research Fund. This fund will allow the Society to annually fund various research projects. Grants range from \$20,000-\$50,000 depending on the grant requirements.

ESTABLISH A PSP RESEARCH GRANT

This is a one-time gift. Size of grants (\$20,000-\$50,000) will vary by investigator.

SUPPORT A SCIENTIFIC RESEARCH CONFERENCE

The Society brings together prominent researchers to share their PSP research findings. These conferences serve as a venue for further research and, ultimately a cure for PSP. The cost to plan, coordinate and implement a conference is \$75,000.

Donors supporting PSP Sustaining Funds, PSP Research Grants and PSP Scientific Conferences can name the project in honor of, or in memory of, a loved one.

- ◆ Donors will be recognized as Special Donors
- ◆ Donors will receive recognition on the Society's Wall of Hope at its National Headquarters
- ◆ Donors will be recognized in all scientific publications of research supported by the grant.

OUTREACH AND EDUCATION

SUPPORT THE OUTREACH AND EDUCATION PROGRAM FOR ONE YEAR - \$50,000

By sponsoring the Outreach & Education program, more and more families can be touched by our educational, informational and support services, including support groups.

ESTABLISH AN EDUCATIONAL AND OUTREACH FUND (MAY BE ANNUAL OR SUSTAINING)

The fund will support development and printing of helpful materials for caregivers, marketing and communication materials to help raise awareness, and support group manuals for leaders and participants.

*The Society appreciates that
Douglas and Barbara Bloom
dedicated the California
Symposium in memory of
Sophie Shapiro.*

Ways You Can Give

AWARENESS & EDUCATION

SPONSOR A REGIONAL MEETING OF PERSONS WITH PSP AND THEIR FAMILIES (\$5,000/EVENT)

The Society brings its educational and networking activities to families in communities throughout the country. Usually one hundred people attend an all-day seminar. You can remember a loved one by dedicating this event.

In addition to unrestricted gifts, there are many tax deductible, specific giving opportunities available to our major donors. Please note that any of these gifts can be made in memory, or in honor of, a loved one.

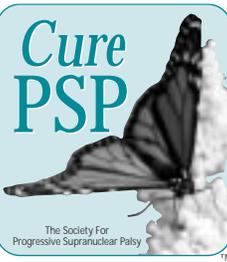
-  Support the establishment of a Development Office for one year at \$60,000
-  Dedicate a room in the Society's National Headquarters
-  Fund the production and publication of a support group manual for leaders and participants at \$10,000
-  Support PSP education and information at meetings and symposiums through sponsoring guest speakers at \$5,000 (\$1,000 per speaker)
-  Support The Society for PSP's presence at meetings and exhibits at medical conferences at \$5,000 per conference

GIVE A GIFT ONLINE

www.psp.org



"The PSP Butterfly Pin of Hope"



The Society for PSP is pleased to offer the "PSP Butterfly Pin of Hope." The beautiful monarch butterfly signifies HOPE and represents the Society's determination to find the cause and cure for PSP. Because of a special gift to the Society, the second offering of the "PSP Butterfly Pin of Hope" will be free of charge. Anyone wishing to order this handsomely designed pin, please fill out and mail/fax the order form below or email the Society office at SPSP@psp.org. A limit of two pins per family while supplies last. The Society is also thankful to our donors, *Barbara and Jack Kelley*, for the initial and second offering of the "PSP Butterfly Pin of Hope" given in memory of Henry and Jane Ogiba, beloved parents of Barbara Kelley and Nancy Brittingham, *The PSP Advocate* editor.

ORDER FORM:

Name _____
Street _____
City, State Zip _____
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Email _____

- one pin two pins

Return form to:
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or email: SPSP@psp.org
Fax: 1 (410) 486-4283

SIXTH NATIONAL BIENNIAL PSP SYMPOSIUM VIDEOTAPE ORDER FORM

The Sixth Biennial PSP Symposium May 17-18, 2002 Baltimore, MD Video Tapes-3 pack \$75 plus \$7 shipping in US and \$10 outside the US

Please make checks payable to The Society for PSP. Mail to:

The Society for PSP, Woodholme Medical Building, Suite 515, 1838 Greene Tree Road, Baltimore, MD 21208.

Please send me _____ set/sets. Total amount including shipping \$ _____.

YOU CAN ORDER THE VIDEOTAPES ON LINE AT WWW.PSP.ORG

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Name _____ Signature _____
Acct# _____ Exp. Date _____

Genetic Mutation Associated with PSP Found

Lawrence I. Golbe, MD
Chair, Society Medical Advisory Board

A specific mutation in "tau" protein has been found in one patient with typical PSP, according to a paper in the October 2002 issue of the prestigious journal *Annals of Neurology*. The finding could have important implications for all PSP sufferers.

The research team was led by Society grantees Dr. Parvoneh Poorkaj of the University of Washington and Dr. Nancy Muma of Chicago's Loyola University. They systematically searched for mutations in the tau protein in 96 patients with PSP and a similar number of individuals without PSP ("controls"). That is, they looked for a disruption in the order of amino acid "beads" in the tau protein strand. They found no mutations in the controls, but in one patient with the disease, the fifth amino acid, arginine, was replaced by a different amino acid, leucine. (Normal tau is made from 352 to 441 amino acids of 20 types strung together in a specific order like the letters of this sentence.)

Such a finding is sometimes explained by random variations among healthy individuals determined by ethnically-related genetic differences. But the researchers concluded that this particular variant, dubbed R5L (leucine [L] replacing arginine [R] at the fifth position) probably did cause PSP in this patient. They cite five reasons for this: 1) The fifth position is not one that tends to vary among populations, 2) the substitution of arginine for leucine would be expected to change the function of the tau protein, 3) the fifth position is in an area



Lawrence I. Golbe, MD

of tau that may, under some conditions, interact with the "microtubule binding domains" (the area that comes in either three or four copies) on the same tau molecule, thereby giving the fifth position some influence over the microtubules, which are important to maintaining the structure of the brain cells, 4) the mutation was absent in a large number of control individuals, and 5) most importantly, a similar mutation wherein histidine replaces arginine at the same site in tau in a patient from Japan with frontotemporal dementia (a condition very similar to PSP) was announced a few months ago.

Intriguingly, the brain of the patient with the R5L mutation did not show the preponderance of four-repeat tau that is extremely common, if not universal, in the brains of patients with PSP. (As described in a previous issue of *The PSP Advocate*, tau protein comes in roughly equal amounts of ~~two forms~~ ^{two forms} in the normal human brain. One form has three copies of the segment that binds tau to microtubules and the other has four such copies. In PSP, most of the tau is of the four-repeat kind. In some other tau-related brain disorders, most of the tau is three-repeat and in others, the normal, even ratio is present.) This suggests that the ~~presence of~~ ^{presence of} four-repeat tau causes the tau to misbehave so as to lead to death of the brain cells, while in this patient, the misbehavior of tau was caused by a different problem, the R5L mutation.

This insight in what sorts of abnormalities disrupt the normal function of tau could give researchers hints as to what sort of drugs might mitigate that effect. This could potentially prevent or halt the progr Recently developed animal "models" of PSP flies offer a convenient way to test drugs for such properties and such tests are, in fact, presently under way. Stay tuned to *The PSP Advocate* for updates!

An Update on the The Society for Progressive Supranuclear Palsy Brain Bank

Dennis W. Dickson, MD
Mayo Clinic

The goal of the Eloise H. Troxel Memorial Society for Progressive Supranuclear Palsy Brain Bank is to provide neuropathologic characterization of brains of patients with antemortem diagnosis of progressive supranuclear palsy. The Brain Bank provides not only diagnostic service, but is also a link to basic research on PSP.

Since its inception, the Society Brain Bank has received over 200 brains. Accompanying the brains is clinical information provided by the physician-of-record and a Society questionnaire filled out by the next-of-kin. Clinical and genetic features of 180 pathologically-confirmed cases of PSP were compared with misdiagnosed cases. Of the 180 cases studied, 137 cases had PSP and 43 had other pathologic diagnoses. Corticobasal degeneration (CBD), multiple system atrophy (MSA) and Lewy body disease (LBD) accounted for 70% of the misdiagnosed cases. History of tremor, psychosis, dementia and asymmetric findings were more frequent in misdiagnosed cases. Pathologic evaluation of clinically diagnosed PSP remains important for definitive diagnosis, and CBD, MSA and LBD are the disorders most likely to be misdiagnosed as PSP.

Society for Progressive Supranuclear Palsy Brain Donation Program

For Diagnosis of and Research on PSP

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

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

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

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

Phone: (800) 457-4777, (410) 486-3330 / E-mail: SPSP@psp.org
The Society for PSP, Woodholme Medical Building, Suite 515
1838 Greene Tree Road, Baltimore, MD 21208

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

Resolving Problems in Nursing Homes

One of the most difficult decisions a family has to make is placing a loved one in a nursing home. Family members often experience feelings of guilt and anxiety because they are no longer able to care for their loved one. But realize that you are still a caregiver even though your loved one is in a nursing home. Regular visits, phone calls, your participation with them in nursing home activities helps keep them mentally engaged... just be there!

Your role has NOT diminished and it may be more important than ever!! The environment has changed for your loved one but not his or her right to make choices about daily life. Occasionally, quality of life goals are not met at a facility. What does a resident and family do to resolve the problem?

Be familiar with the rights of residents. In 1987, the U.S. Congress enacted the Nursing Home Reform Law. The law requires nursing homes to protect and promote the rights of each resident, placing strong emphasis on self-determination and individual dignity. Nursing homes must meet the residents' rights requirement to qualify for Medicare or Medicaid and post these rights. The Nursing Home Reform Act grants specific rights:

- The right to be fully informed about all services available and their fee, availability of nursing home's rules and regulations, the contact numbers for the state licensure office and advocacy groups, availability of state survey reports, assistance if they have an impairment
- The right to participate in their own care including participating in their treatment plan, care and discharge, accept or refuse medication, accept or refuse physical restraints, may view medical report
- The right to make independent choices such as selecting own physician, participate in activities, participate/organize a resident council
- The right to equal access to quality care for all individuals whether they are private pay or receive benefits from Medicare or Medicaid
- The right to privacy and confidentiality regarding medical, personal and financial affairs
- The right to dignity, freedom, and respect to the fullest measure of consideration and respect
- The right to self-determination
- The right to manage their own financial affairs
- The right to be given 30 days notification about a proposed transfer/discharge with information about resident's right to appeal
- The right of access and visitation
- The right to receive notification of relocation or change in roommates
- The right to make complaints and grievances without fear of reprisal or discrimination

When a problem occurs, address it as soon as possible. It is best to follow the chain of command.

WORKING WITHIN THE NURSING HOME

1. Go directly to the individuals involved.

Stay calm and state your complaint in a non-confrontational manner. Sometimes it may be just a misunderstanding or miscommunication. Sometimes, the staff may not be aware that something is a problem. Find out directly from them why the situation occurred and what needs to be done to correct it. Some problems may occur and it may be a more complex problem and out of the staff's control. Management may have limited resources for quality care and services. There may be situations that occur due to lack of knowledge and skill. Document the date, time, specifics of the problem and actions you and the staff are taking to resolve the problem. Documentation of everything is necessary if you must pursue your complaint further.

2. Staff Supervisors

If the immediate staff member did not resolve the problem, contact the person's supervisor. For example, if a certified nurse's aide was directly involved, go to the charge nurse. If the charge nurse was directly involved, go to the Director of Nursing. Tell them the specifics about what happened, when, and what efforts have been made to solve the problem. Be specific so they can better

investigate the problem. Again, document date, time, name of supervisor, and how they responded to your complaint.

3. Facility's Grievance Process

If the staff/supervisor have not responded properly, speak to the administrator of the facility. Every facility is required by Medicaid regulations and/or state licensure regulations to have a formal grievance process. Obtain the information about their grievance procedure and submit a formal/written complaint. Keep copies of everything submitted. Again, document the date, time, name of administrator, and his/her comments about the situation.

4. Contact the owner of the nursing home

Still no resolution? Contact the owner or governing body of the nursing home. It is best to submit your complaint in writing and ask for a written response. Owners care about their business and will take your concerns seriously because the resident is the "customer" and they want to make sure you are satisfied. Contacting the owner may make the nursing home take your concern more seriously. In some cases, the problem may be the direct fault of the owner or governing body, such as not supplying adequate finances to insure competent care. Your contact with the owner will not solve your problem but may be helpful information for the state or federal inspectors.

5. Resident and Family Councils

A Resident Council is an independent organized group of persons residing in the nursing home and sometimes family and friends. This group meets on a regular basis to plan projects and activities, make suggestions and discuss concerns.



Education

Councils vary in their effectiveness, but by working with other residents and family members, you may bring more attention to your problem.

OBTAINING OUTSIDE HELP

1. Long Term Care Ombudsman

Contact an Ombudsman (om-budzman). In the US, this word has come to mean an advocate or helper. An ombudsman promotes and protects the rights of long-term care residents by working with the residents and their families to achieve quality of life and quality care. Based on both federal and state law, ombudsmen have the power to intervene on behalf of nursing home "consumers" who are experiencing problems in a nursing home. The ombudsman investigates the problem and strives to work with the staff to improve quality life and care. Complaints are kept confidential if requested. Ombudsmen also will investigate if others at the nursing home have similar complaints.

◆ For the number of your state or local long-term care ombudsman-call the toll-free Eldercare Locator at 1-800-677-1116 or www.aoa.dhhs.gov/elderpge/locator.htm

2. State Survey Agency

File a complaint with your state survey agency. State government offices called state survey agencies annually monitor and evaluate the care that these facilities provide. They determine whether or not nursing homes meet state licensing requirements and federal Medicare and Medicaid quality and safety standards. If conditions are putting residents in immediate danger, the survey agency is required to investigate the problem within two days. If a resident has been harmed, the investigation is required to occur within ten days. Otherwise, other problems are to be investigated "in a timely manner." If your state survey agency has not satisfactorily resolved the problem, file a complaint with the Centers for Medicare and Medicaid Services.

◆ Information about state long-term care ombudsman programs and state survey agencies in all states and territories is located at www.medicare.gov

◆ Addresses and phone numbers for Centers for Medicare and Medicaid Services Regional Administrator for each state is located at www.cms.hhs.gov 877-267-2323

◆ Contact your state Medicaid Fraud Control Unit usually housed in the state attorney general's office www.naag.org

Quality care should not be a demand—it is the resident's right. Be proactive in resolving problems. Join a citizen advocacy group in your area. If there is not one, consider organizing one and work together for change!

◆ For contact information of nursing home citizen advocacy groups in your area, contact the National Citizen's Coalition for Nursing Home Reform. www.nccnhr.org 202-332-2949

Myofascial Release

A form of massage therapy used successfully on many people.

Amy Mandlman

Speech and Language Pathologist

Member of the Society Board of Directors

In my first article, September, 2002, I discussed many types of alternative medicines that a person may use to complement his or her conventional medical regime. In this issue, I would like to introduce another modality called Myofascial Release.

Myofascial Release (MFR) is an extremely mild and gentle form of stretching that has a profound effect upon the body. MFR helps to improve circulation, promote tissue healing, improve posture, relieve muscle spasms and tension that cause pain, loosen tight areas of your body, free impinged structures of the muscular and nervous systems, and engender profound relaxation.

Fascia is a part of the connective tissue system within the entire body. It exists as a single continuous sheath—a three-dimensional web—that extends from the top of the head to the tips of the toes. It encases and permeates every other tissue and organ of the body, including nerves, blood vessels, muscles and bones down to the cellular level. It holds organs and muscles together to help them keep their shape.

Restrictions occur when there is a malfunction of the fascia system. This could be due to injury, trauma, inflammation, poor posture, disease, surgery, and/or excess strain. When these occur, they can cause fascia to harden and scar. This tension can cause specific pain sensitive areas, but this pain may affect other areas of the body as well. This is because of the complete integration of fascia with all the other systems of the body. As a result, some clients may have extremely unusual pain symptoms that appear to be unrelated to the original or primary complaint.

Release means setting free or letting go of something. To obtain MFR, a practitioner holds his hands in positions on your body for a minimum of 90-120 seconds (gentle sustained pressure over time). A release occurs when softening begins to occur in the tissue below the practitioner's hands. Clients may feel their bodies become more open, light, free or elongated. MFR may also generate a deepened sense of relaxation.

What should you expect during a session? When receiving a MFR treatment, you may be treated in areas that you may not think are related to your condition. The practitioner has a thorough understanding of the fascial system and will begin to release the fascia in areas of your body that have a strong pull or tension. This is a whole body approach to treatment.

The type of MFR technique chosen by the practitioner will depend on where in your body the practitioner finds the fascia restricted. Your feedback is important to your practitioner, and so is your comfort. You should feel open and comfortable to talk about your trouble areas. Also, you should verbalize any changes, or any pain you are experiencing. Ask if you have any questions. Some people may have an emotional response to MFR, perhaps feeling a joy that had been hidden or allowing deep sadness to surface. All of these are ordinary, healthy reactions from the body when profound, positive changes occur during the release of fascial restrictions.

Education

When experiencing MFR, do not let the gentleness deceive you. You may leave after the first treatment feeling like nothing happened. Within a day or two, you may begin to feel the effects of the treatment. MFR can be likened to pulling on a piece of taffy with only a small amount of sustained pressure. It may take awhile, but eventually, you'll see the results. As the practitioner holds each position, therapeutic effects will begin to take place in your body. It is important to drink a lot of water after your session and a day or so after treatment. This helps to rid your body of toxins and lactic acid that had been trapped in the muscles. Water will also help decrease any soreness that may occur after the treatment. Soreness, when present, occurs due to the release of tight fascia which grips the muscles, resulting in discomfort.

In general, acute cases can be resolved with a few treatments. The longer the problem has been present, the longer it usually takes to bring lasting results. Many chronic conditions that have developed over a period of years may require two treatments a week to obtain optimal results. Once the condition has improved, less frequent treatments can help to maintain progress. Many people have one treatment every few weeks and find this to be enough to keep them in good condition. Range of motion and stretching exercises will keep this regression between treatments minimal and enhance overall affects.

You can expect to pay between \$50 and \$70 per MFR session. However, sometimes these sessions are covered by insurance. To learn more about MFR or to find a practitioner in your area contact: John Barnes MFR Treatment Center at their website: www.myofascialrelease.com or at 1-800-MYOFASCIAL.

Books for Blind and Physically Handicapped Individuals

Issued January 2002

INTRODUCTION

A free national library program of braille and recorded materials for blind and physically handicapped persons is administered by the National Library Service for the Blind and Physically Handicapped (NLS), Library of Congress. Under a special provision of the U.S. copyright law and with the permission of authors and publishers of works not covered by the provision, NLS selects and produces full-length books and magazines in braille and recorded formats. Reading materials are distributed to a cooperating network of regional and subregional (local) libraries where they are circulated to eligible borrowers. Reading materials and playback machines are sent to borrowers and returned to libraries by postage-free mail. Braille books and magazines are also available on the Internet through Web-Braille. Established by an act of Congress in 1931 to serve blind adults, the program was expanded in 1952 to include children, in 1962 to provide music materials, and again in 1966 to include individuals with other physical impairments that prevent the reading of standard print.

FUNDING

The NLS program is funded annually by Congress. The fiscal year 2002 appropriation is \$49,788,000. Regional and subregional libraries receive funding from state, local, and

federal sources. Through an additional appropriation to the U.S. Postal Service, books and materials are mailed as "Free Matter for the Blind or Handicapped." The combined expenditure for the program is approximately \$166 million annually.

ELIGIBILITY

Any resident of the United States or American Citizen living abroad who is unable to read or use standard printed materials as a result of temporary or permanent visual or physical limitations may receive service. A survey sponsored by NLS found that two million persons with some type of visual impairment may be eligible and another million with physical conditions such as paralysis, missing arms or hands, lack of muscle coordination, or prolonged weakness could benefit from the use of reading materials in recorded form.

BOOK COLLECTION

Books are selected on the basis of their appeal to people with a wide range of interests. Bestsellers, biographies, fiction, and how-to books are in great demand. A limited number of titles are produced in Spanish. Registered borrowers learn of new books added to the collection through two bimonthly publications, *Braille Book Review* and *Talking Book Topics*. Through an international Union Catalog available on the Internet and on CD-ROM, every network library has access to the entire NLS book collection and to the resources of several cooperating agencies.

MAGAZINES

More than 70 magazines on audio cassette and in braille are offered through the program. Readers may request free subscriptions to U.S. News and World Report, National Geographic, Consumer Reports, Good Housekeeping, Sports Illustrated for Kids, and many other popular magazines. Current issues are mailed to readers at the same time the print issues appear or shortly thereafter. Magazines are selected for the program in response to demonstrated reader interest.

EQUIPMENT AND ACCESSORIES

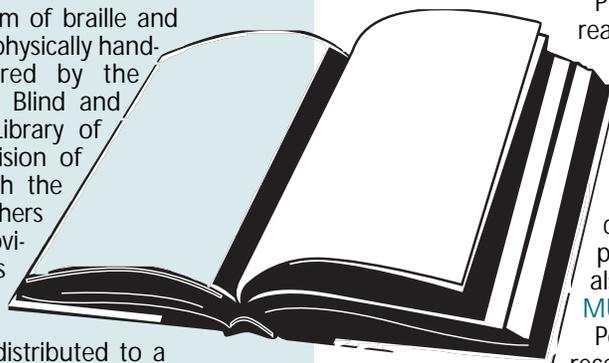
Playback equipment is loaned free to readers for as long as recorded materials provided by NLS and its cooperating libraries are being borrowed. Readers with very limited mobility may request a remote-control unit. Hearing-impaired readers may be eligible for an auxiliary amplifier for use with headphones. A cassette machine designed primarily for persons with limited manual dexterity is also available.

MUSIC SERVICES

Persons interested in music materials may receive them directly from the Music Section of NLS. The collection consists of scores in braille and large print; textbooks and books about music in braille and large print; music appreciation cassettes, including interviews and opera lectures; and self-instructional cassettes for voice, piano, organ, electronic keyboard, guitar, recorder, accordion, banjo, harmonica, and other instruments.

INFORMATION SERVICES

Questions on various aspects of blindness and physical disabilities may be sent to NLS or to any network library. This service is available without charge to individuals, organizations, and libraries. Publications of interest to people with disabilities and to service providers are free on request.



PSP and Good Oral Hygiene

It is more than just healthy teeth and gums

Persons diagnosed with PSP and their caregivers face increasing challenges as the disease progresses. The caregiver's tasks continue to increase and many times helping their care recipient to maintain good oral hygiene becomes a low priority. Yet, maintaining good oral hygiene will help prevent future problems with infection and pain. It will also promote the care recipient's integrity and comfort.

But, there is another important reason for the person with PSP to maintain good oral hygiene. As the disease progresses, swallowing problems develop because of throat muscle weakness and incoordination. Problems with swallowing thin liquids usually occurs before solid food. These weakened throat muscles have difficulty forming the watertight seal that separates the pathway to the stomach from the lungs. Food "going down the wrong pipe" is called aspiration. Frequent episodes of small amounts of liquid and food dripping into the lungs can cause pneumonia. Pneumonia is a serious infection or inflammation of the lungs. The air sacs in the lungs fill with pus and other liquid. Oxygen has difficulty entering the blood stream. The lack of oxygen causes body cells not to function properly. The infection can then spread throughout the body and can lead to death. "Aspiration pneumonia" is a bacterial infection and is the most common cause of death in PSP. Good oral hygiene is not going to prevent aspirating during eating and drinking, but good oral hygiene will minimize additional bacterial growth in the mouth which could be aspirated during coughing or choking spells. There are many difficulties in PSP that are out of our control – maintaining good oral hygiene is something we CAN take charge of.

DENTAL PLAGUE

Plaque is a dense mass of bacterial colonies that collects on teeth if they are not cleaned. Everyone has bacteria in their mouth. To prevent the formation of plaque, your teeth and gum area must be thoroughly cleaned every day because it



takes less than 24 hours for bacteria to colonize.

Plaque causes two problems. One is that bacteria produce enzymes and toxins that cause gingivitis, (an early infection of the gum tissue). If plaque remains on the teeth, it mineralizes into hard deposits called calculus (tartar). This bacteria can cause gingivitis - an early stage of gum disease. Gums become swollen and easily bleed. If left untreated, this can lead to a more serious gum disease called periodontitis - a condition where the membrane holding the tooth to the gum is broken down, bone loss occurs and this can lead to tooth loss.

The second problem is that bacteria/plaque produce acid by fermenting sugars from the food we eat forming an acid.

This acid can demineralize or destroy the enamel of the tooth leading to tooth decay.

TIPS

Take action steps early after diagnosis of PSP to avoid extensive dental procedures later when it will be much more difficult to tolerate.

- Make an appointment with your dentist as soon as possible after diagnosis. Make sure you have the list of all medical conditions and medications on hand.
- Take this opportunity to educate the dental staff about PSP.
- Although most dental insurances cover two cleanings a year, it would be a good investment to consider three/four cleanings a year.
- Ask your dentist about prescribing a fluoride dental paste that will meet your needs.
- Request a fluoride treatment.
- Ask your dentist to make sure partials or dentures are fitting correctly.
- Ask the dental staff if dental x-rays are up to date.
- Make sure the dental office is wheelchair accessible.

BRUSHING

- Make sure your care recipient's teeth are brushed at least twice a day with the last brushing being after meal/snack in the evening.
- Purchase an electric toothbrush. Some examples are the: Sonicare, Rotadent, Braun Oral B and Interplak. These electric toothbrushes usually cost between \$60-\$90.
- Battery operated rotary toothbrushes work well and cost around \$7. Example-Crest SpinBrush
- If you use as manual toothbrush, make sure the bristles are soft. Consider adapting the handle to meet your care recipient's needs such as punching the handle of a toothbrush into a hollow ball, build up the handle with aluminum foil or a bicycle handle.



- Make sure plaque and debris are removed from the teeth AND the gumline. First, aim the brush at a 45 degree angle to remove gumline plaque and go around the mouth. If you are using a manual toothbrush, brush using a circular motion.
- Brush the tongue-sweep the brush from the back of the tongue to the front.

Education

- After eating, rinse mouth with water and use a wet washcloth and sweep through the folds of the cheek to remove food that may be tucked away in these areas.
- Make sure your toothpaste is fluoridated. Over-the-counter fluoride rinses are also available.
- If teeth are sensitive, try using desensitizing toothpaste such as Sensodyne.
- If dentures are worn, remove dentures and use soft bristled toothbrush to scrub gums
- If a partial is worn, make sure it is taken out so all areas of the teeth and gum can be cleaned.

FLOSSING

It is difficult enough to floss one's own teeth. Flossing another's teeth is even more difficult and frustrating. So, experiment with some auxiliary flossing aids and "floss" once a day.

- A dental floss holder eliminates the need for placing fingers in mouth.

SPECIAL AIDS



Floss Mate - cleans area between teeth.



End Tuff - used to remove plaque along the gumline and between teeth



Interproximal Brush - cleans large areas between teeth select the proper size brush to fill the space

ANTI-PLAGUE MOUTHWASH

Rinse out with Listerine (Blue Mint) after brushing in the morning and after your evening brushing. If you use a generic brand, make sure that the ingredients are the same as Listerine because not all mouthwashes are antiseptic. Do not rinse with Listerine if you suffer from dry mouth.

DRY MOUTH

There are artificial saliva over-the-counter products that mimic natural saliva. Artificial saliva can help to relieve the soft tissues of the mouth as well as help with decay control. Example-Biotene products

WATER IRRIGATING DEVICES

Water irrigating devices use water under pressure to flush out debris and plaque between and around teeth. This is an excellent tool if your care recipient is able to use the device without aid. It is very difficult, though, for a caregiver to irrigate their care recipient's mouth. Example-WaterPik

DENTURE/PARTIAL CARE

Dentures and partials are very delicate and may break if dropped even a few inches. Always stand over a folded towel or a basin of water when handling dentures. Like natural teeth, dentures must be brushed daily to remove food deposits and plaque. Brushing dentures keeps one's mouth healthy and prevent permanent stains on dentures. It's recommended to use a brush designed for cleaning dentures. A toothbrush with soft bristles can also be used. Do not use hard-bristled brushes because they can damage dentures.

Some denture wearers use hand soap or mild dishwashing liquid, which are both acceptable for cleaning dentures. Do not use other powdered household cleansers, which may be too abrasive. And avoid using bleach because it can whiten the pink portion of the denture. When cleaning the denture or partial, the first step in cleaning dentures is to rinse away loose food particles thoroughly. Moisten the brush and apply denture cleanser. Brush every surface, scrubbing gently to avoid damage. Rinse the denture with water or Listerine after scrubbing. Do not allow the denture to dry out because it can lose its shape. Dentures should be taken out at night and placed in a denture cleanser soaking solution or in water.

TUBE FEEDING AND DENTAL CARE

Bacteria is still present in the mouth and these recommendations are for the tube-fed care recipient as well.

CONCLUSION

Yes, this seems like a lot of work, but it is very important for the overall "well being" of your care recipient.

Caregivers—all of these dental tips apply to you as well. Take time out to take care of your "well-being." YOU are important, too!

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



Support Groups As Of October 15, 2002

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

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

Caring for the Caregiver

Caregivers experience mixed emotions. Love for your family member and the satisfaction you derive from helping may coexist with feelings of resentment about the loss of your privacy and frustration at believing you have no control over what happens.



You may find it hard to accept the decline of the special person for whom you are giving care. Such feelings will depend in part on your prior relationship with your care receiver, the extent of your responsibilities as a helper, and daily activities in your life (professional, social, and leisure pursuits). Your conflicting emotions may cause guilt and stress.

To guard against becoming physically and emotionally drained, you must take care of yourself. You need to maintain your health and develop ways to cope with your situation.

CAREGIVER'S SELF-RATING SCALE

Below is a scale to evaluate your level of caregiving. It is an excellent effort to provide some guidelines for caregivers and to evaluate your level of care and value which you give your care receiver and yourself.

The scale is a 1-10 continuum which describes the various styles of caring. Circle the number or numbers which best describe your level of care.

1 2 3 4 5 6 7 8 9 10 Scale of Caregiving

1. Abandonment: to withdraw protection or support or to actively abuse your care receiver.
2. Neglect: to allow life-threatening situations to persist or to display consistent coldness or anger.
3. Detachment/Aloofness: to maintain an air of detachment or being aloof, perfunctory in your care, no genuine concern, only obligation. Concerned only with physical well-being of your care receiver.
4. General Support: given freely, with a guarded degree of warmth and respect, occasional feelings of manipulation. Concerned with both emotional and physical well being of care receiver.
5. Expressed empathy: the ability to feel what your care receiver feels. a quality relationship where feelings can be freely expressed and caringly received with nonjudgmental positive regard.
6. Sympathy: feeling sorry for care receiver, giving sympathy, focusing on the losses experienced by care receiver.
7. Occasional over-involvement: care characterized by periodic attempts to "do for" rather than "be with."
8. Consistent Over-involvement: care receiver regarded as object of series of tasks which must be performed.
9. Heroic Over-involvement: care characterized by sometimes frantic and desperate attempts to provide for every possible need your care receiver has; increased dependence, care receiver not allowed independence.
10. Fusion of personalities: between caregiver and care receiver. The caregiver's needs no longer have any value or meaning; the caregiver has abandoned him/herself to needs of the care receiver.

You can place yourself on the Scale of Caregiving to deter-

mine how you value your care receiver as compared to yourself. The low numbers give little or no value (honor) to the needs of your care receiver. The high numbers (8, 9,10) give little or no value to your own needs as an individual and as a caregiver. The numbers in the middle are where you find a balance between under care and over care. Neither of the two extremes is healthy; they represent positions where you are not helping your care receiver.

WHAT CAN I DO TO HELP MYSELF?

Acknowledge your feelings: Your feelings have a lot to do with the way you view and cope with caregiving. All feelings are legitimate, even those that may seem disturbing to you (including anger, frustration, and sadness). Recognizing and accepting your emotions are the first step toward resolving problems of guilt and stress. Learn to express your feelings to family members, friends, or professionals. Take the following caregiver Stress Test; determine how much stress you are under.

CAREGIVER'S STRESS TEST

The following test will help you become aware of your feelings, pressures and stress you currently feel.

Seldom Sometimes Often Usually True Always True

- ◆ I find I can't get enough rest.
- ◆ I don't have enough time for myself.
- ◆ I don't have time to be with other family members besides the person I care for.
- ◆ I feel guilty about my situation.
- ◆ I don't get out much anymore.
- ◆ I have conflict with the person I care for.
- ◆ I have conflicts with other family members.
- ◆ I cry everyday.
- ◆ I worry about having enough money to make ends meet.
- ◆ I don't feel I have enough knowledge or experience to give care as well as I'd like. My own health is not good.

If the response to one or more of these areas is "usually true" or "often true" it may be time to begin looking for help with caring for the care receiver and help in taking care of yourself.

SEEK INFORMATION

Check your public library for books, articles, brochures, videotapes, and films on caregiving. Some hospitals and Adult Education Centers offer courses on caregiving and additional information on resources that you can turn to for help. Help is available!

JOIN A CAREGIVER SUPPORT GROUP

In addition to offering useful information, such groups provide a unique forum for caregivers to come together and share their feelings in a supportive environment. Groups help caregivers feel less isolated and can create strong bonds of mutual help and friendship.

Participating in a support group can help manage stress, exchange experiences, and improve skills as a caregiver. Sharing coping strategies in a group setting lets you help others while helping yourself. It may also help you to realize that some problems have no solutions and that accepting the situation is reality.

SET REALISTIC GOALS

Caregiving is probably one of the many conflicting demands on your time. It is important to set realistic goals. Recognize what you can and cannot do, define your priorities, and act accordingly. Turn to other people for help - your family, friends, and neighbors. Prepare a list of tasks for anyone who may offer assistance. The list may include: running an errand for you, preparing a meal, taking your care receiver for a ride, taking your children after school one day.

Support

PRACTICE GOOD COMMUNICATION SKILLS

Do not expect that others will ask if you need help. It is up to you to do the asking.

COMMUNICATE WITH YOUR FAMILY & FRIENDS

Turning to family members or friends for emotional support and help can be a mixed blessing. Their visits may make you feel less alone and better able to deal with caregiving responsibilities. They can give you a break by spending time with your care receiver.

However, other relatives or friends can be critical of the way you provide care. They may feel the house is not kept clean enough; or they may not like the way your care receiver is dressed. Recognize that they are responding to what they see at that time and are lacking the benefit of experiencing the whole picture and any gradual changes in your care receiver's condition. Harsh criticism may be a response to their own guilt about not participating more in the care process.

Try to listen politely to what is being said (even though this might not be easy). However, if you and your care receiver feel comfortable with the way you are managing the situation, continue to do what meets your needs. Schedule a family meeting from time to time to help other family members understand the situation and to involve them in sharing the responsibilities for caregiving.

USE COMMUNITY RESOURCES

Investigate community resources that might be helpful. Consider using in-home services or adult day care. Employ a homemaker to cook and clean, or an aide to help your care receiver bathe, eat, dress, use the bathroom or get around the house.

USE RESPITE CARE SERVICES

When you need a break from providing care to your care receiver, look at respite care. For example, a companion can stay with your care receiver for a few hours at a time on a regular basis to give you time off. Or have your care receiver participate in an adult day care program where he or she can socialize with peers in a supervised setting; this gives your care receiver a necessary break from staying home all the time. Hospitals, nursing homes, and particularly residential care homes offer families the opportunity to place older relatives in their facilities for short stays. Your Area Agency on Aging can assist with arrangements.

MAINTAIN YOUR HEALTH

Your general well-being affects your outlook on life and your ability to cope. Taking care of yourself is important and involves:

- eating three balanced meals daily,
- exercising daily,
- enough sleep/rest,
- allowing yourself leisure time.

Food is fuel for your body. Skipping meals, eating poorly, or drinking lots of caffeine is not good for you. Learn to prepare and eat simple, nutritious, well-balanced meals. Avoid alcohol above 2-3 ounces daily.

Being physically active can provide you with an outlet that is relaxing and makes you feel good.

Stretching, walking, jogging, swimming, or bicycling are examples of invigorating exercises. Consult your doctor before starting an exercise routine. Your doctor can help design a program that fits your individual needs.

Leisure time allows you to feel better and more able to cope with your situation. Having time to yourself to read a book, visit a friend, or watch TV can also bring enjoyment and relaxation, and break the constant pattern and pressure of caregiving.

Sleep refreshes and enables you to function throughout the day. If your care receiver is restless at night and disturbs your sleep, consult your doctor and fellow caregivers on possible ways to handle the situation. You may need to have outside help in the evenings to allow you time to sleep.

If you are unable to sleep because of tension, practice relaxation exercises. Deep breathing or visualizing pleasant scenes can be helpful. Continued sleep disturbance may be a sign of major depression, which needs medical attention.

RELAXATION EXERCISE

Sit or lie down in a comfortable position. Close your eyes. Allow your mind to drift a few seconds, go with it wherever it goes. Wiggle your fingers and toes, then hands and feet, ankles and wrists. Loosen tight clothes, belts, ties. Sway your head from side to side, gently, gently. Now you have prepared yourself to relax physically and psychologically.

Now concentrate, still with your eyes closed, on some one pleasant thing you really want to think about; maybe it is a place you have visited in the past, or your dream place of your own imagination. It might be the seashore, or high on a hill, or in a field of grass and flowers. Become totally immersed in the place. Smell the smells you best remember. See the sights it offers. Hear the sounds. Feel it, whether it be water or sand or soil or snow. Fully realize this place or situation you are in: if it is on the sandy beach, sift your fingers through the warm sand and smell it, hold the sand to your cheek, smell the salt of the sea, search the skyline for gulls and terns and low clouds in the distance. Your body is totally weightless. You are totally in control of this scene. It is so relaxing and pleasant and beautiful, you are breathing slowly, peacefully. This is YOUR place and no one can take it from you.

After you have sufficiently experienced your peaceful imaging, whenever you have a chance, return to your special place, close your eyes again, tune in, relive those these special few moments in the world of your choosing where everything is perfect and everything is yours. This relaxation exercise can benefit you all day. Check your local library or book store for books, audio tapes, videotapes or films on relaxing and managing stress.

LAUGHTER IS THE BEST MEDICINE

This is an old expression popularized by Norman Cousins's book "Anatomy of an Illness" in which he describes his battle with cancer and how he "laughed" his way to recovery. His hypothesis and the subject of many studies suggests that there are positive effects to be gained from laughter as a great tension-releaser, pain reducer, breathing improver, and general elevator of moods. It sounds miraculous, is not proven, but studies continue. Groups such as the International Conference on Humor and many hospitals use "positive emotion rooms" and "humor carts." In short, humor therapy is valuable and it helps us through difficult or stressful times.



So for yourself and your care receiver:

- Try to see the humor in being a caregiver.
- Write on a card "Have you laughed with your care receiver today?" and place it in a conspicuous place in the bathroom or kitchen; read funny books or jokes, listen to funny tapes or watch humorous movies or videos that make you laugh.
- Share something humorous with your care receiver, a friend, or relative; attend social groups where there is a lot of camaraderie, joy and fun; be aware of how often you smile; it takes much less energy to smile than to frown.

If you find that you are feeling hopeless, and humor or laughter is not affording you the up-lift you want, contact a counselor. And remember, laughter is the best medicine. Try it, you'll like it!

AVOID DESTRUCTIVE BEHAVIOR

Sometimes people handle stressful situations in ways that are destructive. Instead of openly expressing feelings, they overeat, use alcohol, drugs, or cigarettes to mask their difficulties. Such escapes do not solve the problem and are harmful to health. If the strain results in neglecting or abusing the care receiver, it is a very serious problem. It is also against the law!

SEEK HELP

You do not have to go it alone. Turn to family members, friends, clergy members, professional counselors, or a caregiver support group for help and support.

BUILD YOUR SELF-ESTEEM

Continue to pursue activities and social contacts outside your home. Do what you enjoy. Go to a movie, play a musical instrument, or get together with friends for a card game. It may not be easy to schedule these activities, but the rewards for having balance in your life are great. Taking care of yourself benefits you and your care receiver. Meeting your own needs will satisfy you and give you additional strength and vigor to bring to your caregiving tasks.

You have rights, too. Below is a Caregiver's Bill of Rights. After you read them, post and keep them fresh in your mind.

CAREGIVER'S BILL OF RIGHTS

- ◆ Caregivers have the right to receive sufficient training in caregiving skills along with accurate understandable information about the condition and needs of the care recipient.
- ◆ Caregivers have the right to appreciation and emotional support for their decision to accept the challenge of providing care.
- ◆ Caregivers have the right to protect their assets and financial future without severing their relationship with the care receiver.
- ◆ Caregivers have the right to respite care during emergencies and in order to care for their own health, spirit, and relationships.
- ◆ Caregivers have the right to expect all family members, both men and women, to participate in the care for aging relatives.
- ◆ Caregivers have the right to provide care at home as long as physically, financially and emotionally feasible; however, when it is no longer feasible caregivers have the obligation to explore other alternatives, such as a residential care facility.
- ◆ Caregivers have the right to temporarily alter their premises as necessary to provide safe and livable housing for care receivers.
- ◆ Caregivers have the right to accessible and culturally appropriate services to aid in caring for aging care receivers.
- ◆ Caregivers have the right to expect professionals, within their area of specialization, to recognize the importance of palliative (ease without curing) care and to be knowledgeable about concerns and options related to older people and caregivers.
- ◆ Caregivers have the right to a sensitive, supportive response by employers in dealing with the unexpected or severe care needs.

Developed by the Caregiver Education and Support Services, Seniors Counseling and Training, Case Management Services of the San Diego County Mental Health Services, 1250 Moreno Blvd., San Diego, CA 92110.

Lessons on Coping

By Janet M. Edmunson,

Wife of Charles R. Edmunson who died at the age of 50 diagnosed with PSP but found on autopsy to be Cortical Basal Ganglionic Degeneration (CBGD).

Ten other people, suffering from various conditions such as chronic fatigue syndrome, severe headaches, and chronic pain, sat in metal fold-up chairs around a circle with Charles and me. Over the nine week program, Peg, the instructor, led us through a myriad of relaxation exercises and cognitive-behavioral techniques. We all hoped to learn how to cope with the debilitating symptoms, like sleepless nights and pain on movement—each one faced with their particular illness.

At the time, Charles was two years into his degenerative neurological disease with no clear diagnosis, but the options were progressive supranuclear palsy (PSP), multiple systems atrophy (MSA) and cortical basal ganglionic degeneration (CBGD). We were now attending the stress reduction program offered at a large hospital in Boston. Insurance paid for Charles to enroll. But I hit the jackpot when the director invited me to attend with Charles at no cost. It was obvious that I would need to assist him with projects during the class and help him take notes. But with the instructor's encouragement I, too, got to participate in the exercises.

"Breathe in deeply, now exhale slowly," Peg would say softly and deliberately during her instruction of the 15 minute relaxation techniques. But doing them at home, even with the cassette tapes seemed to be a chore.

One day, though, sitting on our love seat in the breakfast room after dinner, Charles asked me to do the relaxation tape with him. Taking slow breaths in and out, we practiced the technique we learned at the program. Unfortunately, though, we didn't continue with this exercise much after the class ended. But we did stick with the "mini" relaxation exercises that both of us found easier to fit into our busy days. When doing these, we simply count down from 10 to zero taking a deep breath in and out with each number.

During class each week we recorded whether Charles' symptoms, depression, loss of visual depth perception and fatigue, changed for the better or worse. Unfortunately, these didn't improve over the nine weeks. In fact, they continued to deteriorate with the progression of the disease. However, the



Charles Edmunson (center) with family and friends in Russia (wife Janet is 3rd from the left)

Support

class gave us tremendous insight into coping. Peg taught us that a crisis equals danger plus opportunity. In this course, she coached us to find the opportunity.

The techniques that seemed to help Charles and me the most taught us how to change negative thinking. At this point in the disease, the mounting losses Charles faced eroded his positive attitude. He kept feeling more and more like a handicapped person, which depressed him.



Charles Edmunson (L), mother-in-law Thelma (C) and wife Janet (R) at a 4th of July Celebration in Boston

Peg tried to help Charles figure out which thoughts were negative and irrational and then change his thinking about those. If the thoughts, though, were negative but also rational, such as, "This disease is getting worse," she encouraged us to accept this fact and then make meaning out of it. She asked

us to concentrate on pleasant thoughts and affirmations and believe that our lives have meaning and purpose.

To give insight on these irrational and negative thoughts, Peg conducted a powerful exercise using a log to record these thoughts. With my help, we filled out the form each week. "What stressful event did you experience today?" I'd ask. Charles responded one week with "I felt like I wasted my day." Other times he said, "I feel like I don't have influence at work," or "I felt handicapped today and got depressed," or "I'm not able to run without help anymore."

"What feelings did you have when facing that stressful event?" I asked next. "Depressed, frustrated, sense of loss, embarrassed, inadequate, disappointed," would typically be his response. "What thoughts were you having when you were experiencing those feelings?" the form prompted me to say. "I can't do things I use to do." "I can't even type anymore." "Even seeing keys on the phone is difficult." "I looked at my files and saw all the stuff I use to do and can't do them anymore." "I might as well give up." "I have to face the fact that I'm going to die soon." "I'm going to end up in a nursing home." "I will end up in a wheelchair."

Next, the hardest part of the exercise, we pointed out which of the thoughts were distortions to the truth and determined what would be a better, more positive, thought response. For instance, the thought "I can't do a lot these days" is a "should statement" which is like scolding yourself and it is also "perfectionism" which is not being happy unless you are perfect—both doomed to depress us. A more rational and affirming response to that thought might be "How can I find meaning in what I can still do?"

I used this exercise many times at home, especially on our morning jogs, when Charles would express a negative, destructive, thought. Most of the time, Charles seemed to appreciate this reminder. But changing to a more positive way of thinking continued to challenge him. This is so unlike the upbeat attitude he had prior to this incapacitating disease.

At our discharge session, Peg encouraged Charles to milk his illness for meaning and purpose, to explore being the object of his own mission statement (giving himself grace), and to increase his daily pleasures. And she was right on.

My Summer Trip

Jim Barrun
Pullman, WA

My wife, Mirriam, died at age 62 from PSP in December, 2001. During her illness I was fortunate enough to have found the PSP e-mail listserv sponsored by the Society in early 1998. It was an outstanding support group and without it I would have had a far more difficult time of dealing with PSP. Many of us on the listserv became very closely acquainted as we exchanged information on our experiences and learned a great deal from each other. Every day we had a place to vent our frustrations as well as lend a sympathetic ear to the same or other frustrations of our correspondents on the listserv. We also grieved together as a steady stream of people succumbed to the disease.

A few months after Mirriam died, I bought a small motor home and spent five months traveling to the east, northeast and in the Atlantic provinces of Canada from late April to the latter part of September. I resolved to visit some of my PSP friends during my travels and this is a brief report of what turned out to be a most rewarding trip. After informing people on the listserv of my plans, I received a number of invitations to stop for a visit. I was not able to meet everyone, but hope in the future to see more of my "extended family" on other travels.

I visited at length with six people who had lost a spouse or a parent to PSP, the daughter of one living person with PSP and three couples where one of the pair has PSP. Without exception, I was welcomed into ten homes with open arms and an eagerness to share experiences. They were delighted to see me and put a face to someone they had known only through e-mail contact. It may be true with other debilitating diseases as well, but the PSP experience does create a lasting bond among those of us who have traveled on that long journey. I cannot imagine ever meeting a PSP survivor or someone currently dealing with the disease who is not or will not be a close friend of mine. I hope I brought something positive to those meetings and the indications are that they were well received. I was able to give a little bit of advice here and there where I had some experience they had not yet had. In the case of the three couples, my previous contacts had been only with the caregiving spouse, but in each case the person with PSP was anxious to talk with me and greatly enjoyed the contact. In all three cases they had difficulty in speaking and without the "PSP speak" experience with Mirriam, I would not have been able to understand them much at all. In the event, we were able to communicate easily.

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



Support - Our PSP Stories

Please continue to share your "PSP Stories." Each journey will be unique—but each journey is filled with the love, strength, determination and courage of persons diagnosed with PSP and their families. You may email your story to The PSP Advocate Editor at NancyB501@cs.com or mail to Nancy Brittingham, 6 Bramston Drive, Hampton, VA 23666. Please include photographs if possible.

Miss Adele

This is the story of Adele Eslick. Miss Adele, as she is fondly referred to, will be ninety years old on December 19, 2002. Although she was never blessed with children of her own, she has nieces who have cared for her as if they were her "daughters" during the years of her illness. She has also been graced with many very loving and kind caregivers.

Fifteen years ago, she was diagnosed with leukemia. Then in 1990-1991, Adele started exhibiting balance problems, choking after eating and multiple coughing spells. It was at this time that she was diagnosed with progressive supranuclear palsy. The disease slowly advanced to the stage of 24-hour care by the end of 1999. Adele's devoted nieces and loving caregivers began their zealous assistance but allowed her to keep her dignity and continually encouraged her to do as much for herself as she felt capable. They have also worked diligently to keep her life as normal as possible. The caregivers have accomplished this in numerous ways such as providing help with her two dogs: Xena and Lady and taking Adele for scenic drives in her car. Her niece and one caregiver often have her accompany them when they are doing errands if she is feeling well enough. At other times, they provide her with opportunities to spend time outside to just sit and enjoy the birds and breathe in fresh air.

In January of 2000, the disease's progression necessitated that all of Adele's food be pureed and she also needed to be spoon-fed by her caregivers. With further advancement of the PSP, a peg feeding tube was placed in Adele in February 2001. Because of choking, she

was no longer able to take in nourishment by mouth. Her nutrition consisted of "2-cal" which is a high protein fiber formula, cranberry juice and orange juice administered through the peg tube. In addition all medications, vitamins and water were also provided through the peg tube. A detailed schedule of feedings and administration of medications is enclosed with this article. When a person can no longer take anything by mouth, other problems present themselves and it becomes necessary to supplement Mother Nature. In order to keep the mouth moist, such products as "Oral Balance" which can be found in most grocery stores should be used daily. The build-up of throat mucus can be treated with Robinal. Adele received 1/2 to 2 mgs. according to her needs. In addition, the mouth must be swabbed out many times during each twenty-four hour period. Enulose is dispensed daily to keep the bowels regular. If severe constipation does occur, another regimen is used consisting of stool softeners and magnesium citrate.

Since Adele's disease continued to progress, it was necessary for oxygen to be administered during the night, and any time there was a coughing spell during the day. Peg tube patients are still subject to severe coughing spells. The protocol used with Adele is as follows: first pull out 60 cc of fluid from the peg tube. If that does not relieve, then use the oxygen 15 minutes to 30 minutes. As a last resort, Phenagren with codeine syrup is used if success was not achieved with the other attempts.

In April of 2002, because of numerous kidney infections and the bladder's inability to empty, Adele had to have a Foley catheter. She was provided the medication Ditropan for bladder spasms two times a day. The addition of the catheter necessitated the visit of a home health nurse who changed the catheter on a monthly basis. A weekly visit by a private nurse to check her vital signs, peg tube, catheter, and review all the charting by the various caregivers was arranged.

Adele currently receives a massage from a therapist 3 times a week for one-hour visits. The objective is to keep her as limber and comfortable as possible. The therapist often uses

the Trager Approach. By definition this method is an innovative approach to movement education, created and developed over a period of 65 years by



Mary Ellen, Miss Adele and Barbara

Adele Eslick		Date:	Date:
Week of	Date:	Monday	Tuesday
.01 <td>Sunday <td></td> <td></td> </td>	Sunday <td></td> <td></td>		
Feeding - Two Cat			
Amount Given (ounces)			
Empty? Full?			
Time & Initial			
Residual?			
Quantity?			
Consistency?			
Time & Initial			
Coughing Spell?			
Any Mucus?			
Consistency? Color?			
Length of Time?			
Time & Initial			
O₂ Used?			
Why?			
How Long?			
Time & Initial			
Skin Tear?			
Where?			
Why?			
Time & Initial			
Bruise?			
Where?			
Why?			
Time & Initial			
Peg Tube/Site?			
Red or Clear?			
Loose?			
Leaking?			
Time & Initial			
Use "Speller to Communicate/Talk?			
Question Asked?			
Adele's Answer?			
Time & Initial			

Support - Our PSP Stories



Milton Trager, M.D., utilizing gentle non-intrusive natural movements. This is said to release deep-seated physical and mental patterns and facilitate deep relaxation, increased physical mobility, and mental clarity by giving a different feeling experience through the quality of touch and movement. Adele's caregivers also rub her legs during the day to keep them from getting stiff. As part of her care regimen, a physical therapist also works with her to keep the muscles in her legs strong enough to enable her to do some assisted walking.

Adele is an extraordinary lady with an extraordinary zest for life. At the time of this writing, she continues to make all financial and medical decisions and will continue to do this until such time that she can no longer make her wishes known. Then her designated durable power of attorney will take effect. She continues to have her manicurist and hairdresser visit her once a week in her home, so she continues to feel beautiful and perpetuates the normalcy of life. Samson Clinic in Santa Barbara, California and a local physician in Adele's hometown of Arroyo Grande, California, monitor her physical condition. Doctors have told Adele that she may be the longest living female survivor of PSP.

We are sorry to learn that on October 6, 2002 Adele Eslick passed away after declining from the debilitating progression of PSP.

GIVE A GIFT ONLINE

www.psp.org



Kisses for my Father

Susan Cavanaugh
Florida

It is amazing how much something as simple as giving your dad a peck on the cheek can change. I can remember as a little girl always giving my father a kiss goodnight before bed. No matter what was going on or even if he was already sleeping from a hard day at work. It always was a nice feeling to give him a kiss goodnight.

In late 1997, my father, Frank Paolantonio, was diagnosed with progressive supranuclear palsy after my mother found him on the ground by the family swimming pool. He suffered small strokes. Shortly thereafter, it seemed as if nothing about him was the same or right. He could no longer keep his balance and his movements were so strained. After several doctors and neurologists visits, he was diagnosed with PSP.

His digression was rapid and actually for that I am very thankful. Upon going from a walker to a wheelchair in a matter of months, his eyes were fixated and then he eventually lost his eyesight all together.

We were fortunate that he could remain home in my mother's care and also in the care of round the clock nurses including our local Hospice chapter which was a godsend. I was working full time and would go to his bedside straight from work and sometimes stay with him until the next morning and return to work in the same clothes on several occasions.

One very beneficial tool we invested in was a "lift" chair. This was a very comfortable looking recliner, which was the type of chair he was used to, but it also had a button we could push to stand him up vertically since he was unable to do so himself. This was very valuable to him and us.

My father became very ill with pneumonia in late December of 1998 and his illness continued downhill from there until January 17, 1999. On this day, I will always remember holding my fathers hand early that morning and giving him a kiss on the cheek. It was truly amazing how my father never complained about any pain or misfortune on his part. For someone so frail at that time, he was incredibly strong!



Marie and Frank Paolantonio

Guadeloupe Connection?

Dear Friends,

I am enclosing a contribution in loving memory of my mother, Ardis Holt, who on July 8, 2002 at age 79 ended her courageous 10-year battle with PSP. She was diagnosed with PSP approximately 6 years ago, but in hindsight, I think she began showing signs of the disease four years earlier. She had a car accident that fortunately resulted only in a broken ankle. She was not only embarrassed by the accident but puzzled as well. Mom was hit on the driver's side after carefully looking both ways before entering the intersection. It was only after reading in your wonderfully informative magazine, the *The PSP Advocate*, that automobile accidents involving PSP victims are common (due to vision impairment) that she began to feel less embarrassed and responsible for her mishap.



I am writing because I want to take this opportunity to extend my heartfelt thanks to all of you for the enormously valuable information that is provided to your readers in each issue. For the past 4-5 years, I have used *The PSP Advocate* to educate not only our family but some of mom's medical caregivers as well. I cannot imagine dealing with this insidious disease without the help and support the *The PSP Advocate* provides. **(Note from the Editor: Thank you - you have made my day!!)**

I found your research articles re: Guadeloupe natives and their high incidence of PSP with regards to their tropical fruits-personally interesting. My father, who predeceased my mom in 1990, was a pilot and he and my mother often flew into Belize, Guadeloupe and neighboring areas where she would have consumed their native fruits and vegetables. I also closely follow your research information re: the heredity factor since I have four adult children and two grandchildren.

My mother suffered through all the injustices of this horrific disease, slowly losing her independence and finally had to enter a nursing home last summer. During some of her most difficult and discouraging days, we discussed Dudley Moore (she, too, was an accomplished pianist) and our hope for more research and answers. Knowing that she was not the only one with PSP seemed to comfort her a little. When trying to explain Mother's disease, I found myself telling people "It's the same disease that Dudley Moore has."

I learned something of my mother's inner strength during her last week of life. She had not been able to move or to speak, but PSP had not clouded her mind or crushed her spirit. After struggling with this horrid disease without complaint or self-pity, she made a conscious decision to stop eating and drinking. I knew from previous discussions with her, as well as a living will, that she did not wish any life prolonging measures. Her caring and compassionate physician expected she would live another 2-4 weeks. Her family spent precious time with her and I had the opportunity to tell her, as I had many times in the past, how much I loved her and how brave she was. I also told her I supported whatever decision she made. She died peacefully just four days later.

I commend you all for your tireless work. I, along with others, pray that research will soon yield some answers for the sufferers of PSP and their loved ones. I will celebrate my mother's life and courage by sending a contribution to the Society for PSP on special holidays, since I can no longer celebrate with her.

Sincerely yours, Jane H. Hunt - Maine

My Mother-A Good Soul

Linda A. Rasmusen - daughter and privileged caregiver for Bobbie Rasmusen, Gary, IN

My mom was one of a kind. For starters, she was a Chicago Cubs Fan for over 60 years. That in itself should tell you something about her optimism and her spirit. She liked to be called "Bobbie". She never liked her name "Barbara." In fact, she would become angry if you called her by her full given name. Somehow mom reminded me of Lucy in the "I Love Lucy Show," always on the outlook to have a good time and some fun. She had a great laugh—one that came from deep inside.

Everyone liked her "no holds barred" honesty. She would tell you what she thought and people loved her for her directness. And it didn't matter who you were. She gave it to you straight. When she met John F. Kennedy in our hometown of Gary, IN early in his career, she frowned and looked disappointed at him when he mistakenly offered her his left hand to shake. He responded by giving her a brilliant smile while he switched hands. He then shook her hand firmly (using his right hand) and kidded her about the look on her face. You could always tell where you stood with my mother.



My mom grew up in the small town of Ironwood, MI. She met my father there after he graduated from college. He had accepted his first newspaper job in my mom's hometown where she worked as a telephone operator. After my dad returned from serving in the war, they settled in Gary where they raised my brother and me. Mom played golf and tennis, bowled, and even exercised regularly before exercise became the popular thing to do. She was never sick and always looked much younger than her stated years. I thought her to be a handsome looking woman.

The first thing we noticed that seemed amiss was mom began to complain of dizziness when she stood up. Since she had recently had cataract surgery, the family wasn't terribly alarmed. In fact, we attributed this symptom to the eye surgery. Also, my father had been recently diagnosed with prostate cancer and our focus was frankly on my father's health at that point in time.

We lost my dear dad in 1993 and the pace of my mother's illness seem to quicken. She started hanging onto furniture when she walked and she seemed unsteady on her feet. The dizziness persisted and in fact-worsened. We went from medical center to medical center in Chicago and a variety of diagnoses were offered. At one point, she was being treated for Parkinson's disease and was placed on the medication, Sinemet. However, my mom's falls became more frequent and more serious. One day I came home to find her lying in the driveway near her car. She had lost her balance on our slanted driveway and had fallen partway under the car. Another time, she had ventured out into the backyard, and had fallen in the snow. She lay on the ground for about 20 minutes. The wind chill was 30 degrees below zero that winter day.

We sold our family home because of the steep staircase to the second floor and moved mom into a one level home.

However, she seemed to be losing ground at an alarming pace. We sought assistance from home health agencies in order to keep her in her own home. This worked for a while. However, living alone soon became unsafe. Since she could no longer walk independently and was not able to manage alone (nor would she allow anyone to live with her), an assisted living arrangement seemed to be the answer. That is what we decided to do. She agreed to give it a try, thinking the arrangement would be temporary.

What struck anyone who visited with my mother the most was her uncomplaining and upbeat attitude. She was a favorite among the nursing staff. She liked to keep her hair neatly combed and styled. She still enjoyed wearing fashionable clothes as well as her "fun" jewelry. A daily spritz of perfume was a must as were her colorful earrings. She read two newspapers a day, participated in the home's various activities, watched every game her beloved Cubs played, and most of all, enjoyed going out to restaurants for meals. Since I lived in Chicago, I would visit mainly on weekends as I worked full-time. Every day that I was there with her, we went out to lunch or dinner. We hit every restaurant in the entire area. On occasion we would take in a movie, another one of her life long passions. She could tell you everything you ever wanted to know about any movie star you could mention to her.

Unfortunately, Mom's symptoms progressed. She began to cough when she ate and her speech became harder to understand. Her voice became softer and her handwriting changed. We eventually found our way to a movement disorder specialist at a major teaching hospital. There she was finally diagnosed with PSP. She eventually could no longer read her daily newspaper because of her lack of ability to move her eyes downwards. Her speech had become slurred and inaudible. She was getting almost impossible to understand. By now, she was incontinent and wheelchair bound. She had great difficulty eating her favorite foods. She was choking every time she ate. The expression on her face was no longer that of my mother's smiling face but rather the mask of the disease we had struggled so hard to identify. And worst of all, she continued to fall and fall hard, although she never broke a bone during the entire length of her illness. In that respect, we were fortunate.

My mom continued to attend Mass everyday in the nursing home's chapel, wearing, of course, her famous Cub's hat. She remained independent and fought the disease with everything she could. But it was not to be. She was eventually hospitalized with aspiration pneumonia and during her recovery, she suffered what appeared to be a massive stroke. We lost her several hours after that incident, my brother and I at her bedside. She died peacefully with her children holding her hand.

What I have learned from this experience is how a person can face total body failure and maintain a cheerful as well as optimistic attitude toward life. Mom continued to enjoy everyday pleasures such as a favorite meal, the unexpected visit of a dear friend or family member, or looking forward to an upcoming holiday. My mother was a pleasure to be with despite her deteriorating medical condition. She made the most out of her remaining time, demonstrating behavior so full of grace that I can only hope to one day come somewhere near achieving the same attitude in my lifetime.

When I am very quiet, I can still hear the sound of her laughter. My mother was a good soul and her spirit will always live in my heart. I miss her terribly and always will.

Tips for Increasing Calorie Intake

Maintaining weight is important for people diagnosed with PSP. Keeping weight up is easier if you include high-calorie foods as much as possible and maximize the calories you can make it easier to keep the weight up. Here are some high-calorie food suggestions.

- Ice cream—choose plain flavors, not one with "chunks" which could cause choking.
- Cream—plain, whipped, or sour cream—can be added as a supplement or topping.
- Refried beans—as a side dish or in a soft tortilla.
- Avocado—slices to dunk in salsa, or mashed as a side dish.
- Butter—can be melted and mixed with many foods such as mashed potatoes, vegetables, yams, or hot cereal.
- Creamed soups, chowders, or bisques—pureed in blender or food processor to get the best consistency.
- Mayonnaise—add it liberally to tuna, chicken or egg salad.
- Peanut butter, to avoid choking think smooth—NOT chunky.
- Cheese sauce for a topping for vegetables or potatoes.

Safety Tips for Preventing Falls in the Home

Falls can occur at any age, but the rates of injury resulting from falls are very high with persons diagnosed with PSP. This happens because of changes in vision, muscle and bone strength, and coordination that take place during the disease process. Falls and PSP go hand in hand and can cause serious harm. Here are some simple tips to try to minimize falls.

The following are guidelines you can use to make your home safer:

BATHROOM: Apply non-skid appliques on tub and shower floors. Install grab bars in tub and around toilet. Consider a shower chair. Always keep the bathroom well lighted. Avoid throw rugs or tack rugs down securely with double sided tape.

ALL AREAS: Make sure that stairways have sturdy handrails. Keep halls, stairways, and pathways well lighted and free of clutter. Keep walk areas clear. Apply slip strips on the edges of steps to reduce slick stair surfaces. Remove throw rugs if possible or tack down securely with double sided adhesive tape. Tape down carpet edges. Place electrical cords and telephone wires away from walking paths. Post emergency numbers at every telephone. Carry a portable phone.

KITCHEN: Keep commonly used items within easy reach. Avoid using wax or floor polish to reduce slick surfaces on floors.

BEDROOM: Keep a telephone and light within easy reach of the bed. Rise slowly from bed to sitting position. Dangle legs for a few minutes prior to standing and walking.

OUTDOOR HOME SAFETY MEASURES: Keep walk areas clear of rocks, clutter and tools. Keep well lighted at night. Keep walkways clear of snow and ice. Make sure walkways are level, free of cracks, loose gravel, holes, and constructed with slip resistant materials.

OTHER STEPS YOU CAN TAKE TO REDUCE YOUR RISK OF A FALL: Clean eye glasses often to improve visibility. Wear proper fitting, supportive shoes with low heels or rubber soles. Use walking aids when necessary.

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

Butterfly of Hope, Help Set Us Free, and Keep Us Free From PSP

The Society for PSP has embraced the monarch butterfly as its symbol of Hope because the monarch has survived a metamorphosis to emerge as a beautiful expression of life, freedom and joy. As donors, you are precious to us. Without your thoughtful and gracious gifts, we cannot survive. You are the wind beneath our wings. We recognize you, our donors, as precious "Monarchs of Hope."

To recognize donors beginning at the \$2500 level, the Society will present donors with an elegant crystal butterfly, a fine collectible object d'art in a delightful array of vibrant hues. Donors who make annual gifts may collect and display these fine mementos from the Society.

Giving Levels are as follows:

Amount	Level	Recognition
\$50,000	Diamond Monarch	An office in the Society's National Headquarters named in tribute to a loved one and a crystal PSP Butterfly of Hope
25,000	Platinum Monarch	A plaque in the Hall of Hope in the Society's office and a crystal butterfly
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1,000	Crystal Monarch	A crystal PSP Butterfly memento

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For those donors who designate planned gifts to the Society, we welcome them into the Monarch Circle. Donors will receive a certificate and an elegant PSP Butterfly of Hope.

All donors will be recognized in the *The PSP Advocate*, the Society's quarterly newsletter, all publications and annual reports. "Monarchs of Hope" will be invited to special events and will be recognized by the Society in programs and other publicity. Thank you for your thoughtful and generous gifts!

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Ray C. Simmons
Henry L. Dixon In Memory Of Gerald Dixon
Dr. & Mrs. J. W. Dixon In Memory Of Gerald Dixon
Larry Djerf In Memory Of Janice Waedekin
Jeffrey & Sharon Doliner In Memory Of
JoAnn Anderson
Calvin Donaghey Family In Memory Of
Frankie Crawford
Bruce, Mady, Liz & Dan Donoff In Memory Of
Anuita Blanc
Darlene Drewyour In Memory Of Fred Drewyour

John L. & Michelle Duffy, Jr. In Memory Of
Helen Mucci
Connie Dunckelmann In Memory Of
Wayne Emmett
Richard R. Duperey In Memory Of
Josephine Kelly
Maureen & Drew Durkin In Memory Of
Lawrence Costello
Eandi Family In Memory Of Wayne Emmett
Karen Eberspacher In Memory Of
Robert E. Webster, Jr.
Charles & Marie Ebert In Memory Of
Jane Robertson
Alan & Frances Eck In Memory Of
Theodore Hackett
Ecoban Finance Limited, LL In Memory Of
Christine de Got
Eva G. Elliott In Memory Of Nora Chavez
Emmanuel Lutheran Church In Memory Of
Ethel Knarr
Milton & Shirley Emmett Murray In Memory Of
Wayne Emmett
Employees of Sew Much Fun In Memory Of
Marvin Glazer
Exporters In Memory Of Christine de Got
Adam & Karen Falk In Memory Of Dorothy Barnett
Harry Farrell In Memory Of Joanne Grant
Warren Farrington, Jr. In Memory Of
Elizabeth Farrington
Fay Sales, Inc. In Memory Of
Walter F. Kleinpeter, Sr.
Heinz & Elizabeth Feil In Memory Of Virginia Swart
Harriet Feiner In Memory Of Sidney L. Feiner
Ronald & Sharon Felzke In Memory Of
Edward F. Felzke
Fidelity Bank of Florida In Memory Of Jack Garrison
Jane Fidler In Memory Of Paul Fidler
Richard B. Finger In Memory Of Frank Branisa
Ann Finkbeiner In Memory Of Dorothy Barnett
First Federal Credit Cont. In Memory Of
Helen Weinberg
Irene J. Fischer In Memory Of Ida Stelmach
Raymond & Ann Marie Fischer In Memory Of
Louis Milano
Robert & Marian Fish In Memory Of
Esther S. Cohen
Sharyn Fleming In Memory Of Ralph Fleming
Flight Safety International In Memory Of
Ann Griffith
Richard & Ann Flynn In Memory Of John C. Flynn
George & Laurie Fox In Memory Of
Sylvia Goldenbach
Jeffrey & Jean Fox In Memory Of Elbert Harris
Robert & Jan Fox In Memory Of
James Thomas Kennedy
Charles Frame In Memory Of Sandra Frame
Margaret Fratt In Memory Of Lillian M. Blandin
A. Joseph & Anna M. Froio In Memory Of
Mary Elizabeth Johnson
Sylvia Fung Chin In Memory Of Christine de Got
Angelina Gagliardi In Memory Of J. Leo O'Brien
Deborah F Gagnon In Memory Of John Gazda
James H. Gale In Memory Of Susan L. Clemedtson
Dorothy R. Gallison In Memory Of
Randoph R. Gallison
Joseph Gallo In Memory Of Janice Waedekin
Joseph & Anna-Maria Gammal In Memory Of
Mary Kail
Reuben & Sherry S. Gamoran In Memory Of
Covington Shackelford
John & Martha Garrison & Family In Memory Of
Jack Garrison
George W. Kennedy Construction Co., Inc.
In Memory Of Janice Waedekin

Georgia's Civil War Heritage In Memory Of
Iris Harmon Oehler
Andrew Gewirth In Memory Of Marcella Gewirth
Gila Ridge Pallet Co. In Memory Of Wesley Bassett
Diane J. Gilbert In Memory Of Joseph Latragna
Jeffrey & Julie Gilbert In Memory Of
Bernice Schmidt
Timothy B. Gilbert, MD In Memory Of Jean Gilbert
Margaret E. Gillenwater In Memory Of
William E. Gillenwater, Jr.
Glenbrook Middle School In Memory Of
James J. Murray
Daniel & Jane Goetz In Memory Of Betty Doud
Evelyn Goldfine In Memory Of Mary Beauregard
John Goodman In Memory Of Marjorie Goodman
James & Ann Gordon In Memory Of Lourdes Webb
Rhonda Grady In Memory Of Carol Rayworth
Siegbert & Madeline F. Greenbaum In Memory Of
Marion M. Epstein
Charlotte Greene In Memory Of Harris C. Greene
Mr. & Mrs. Todd Gregory In Memory Of Gayle Eads
Robert & Nancy Griner In Memory Of Sterling Price
Brad & Cecile Grunert In Memory Of Frederick Kroll
Hudson & Jean Gruwell In Memory Of
Mary Elizabeth Johnson
Edward & Dora Guay In Memory Of Wayne Emmett
Richard F. Guidelli In Memory Of Phillip Jackson
Craig & Patricia Haines In Memory Of
Nancy Richartz
Dolores Haines-McLaughlin In Memory Of
William E. Haines
Bill & Betty Hall In Memory Of Diane Keane
Randall & Lorraine Hall In Memory Of
Otis A. Wesche
James & Diane Hamburg In Memory Of
Lola Hamburg
Warren K. Hamburg In Memory Of Lola Hamburg
William Hansell In Memory Of Jon Whitney Aycock
William & Geraldine Harbour In Memory Of
J. Leo O'Brien
Evan & Delane Haren In Memory Of W. Tris Stevens
Joan Harkleroad In Memory Of Douglas Harkleroad
William & Anne Harmon In Memory Of
Iris Harmon Oehler
Robert D. Harrington In Memory Of
Eilene Harrington
Alan & Elizabeth Harris In Memory Of
Christine de Got
Inez Harris In Memory Of Thomas K. Harris
Donna M. Hart In Memory Of Martha J. Terry
Jill Hartmann In Memory Of Gladys Stephens
Eric & Felicia Hassett In Memory Of Wayne Emmett
Phillip & Sara Hawk In Memory Of Frank Branisa
John Hayes In Memory Of Geraldine Hayes
Patricia Haywood In Memory Of
Charles Thomas Haywood
Greg & Beth Hazlitt In Memory Of Allen Roder
Harry Heimburger In Memory Of
Walter F. Kleinpeter, Sr.
Chris & Sheila Heppel In Memory Of Merlin Rocker
Lawrence & Virginia Hicks In Memory Of
William F. Meinert
Michael & Patricia Hill In Memory Of
Deanna Scherrer
W.P.T. & Sally Hill In Memory Of Nancy Richartz
Patricia Hinckley In Memory Of Charles Hinckley
Robert G. Hitchcock In Memory Of Lillian Hitchcock
Joanne L. Hodgson In Memory Of
LaVerne E. Johnson
Dale & Barbara Hoff In Memory Of Elbert Harris
Stu & Sally Hoffer In Memory Of Nancy Richartz
Paul & Patricia Hoffman In Memory Of
Joan Anderson
Sara R. Hoffman In Memory Of Sara Pepper

Report Of Gifts

PATRONS \$100 AND OVER

continued

James & Diane Hamburg In Memory Of Lola Hamburg
Warren K. Hamburg In Memory Of Lola Hamburg
William Hansell In Memory Of Jon Whitney Aycock
William & Geraldine Harbour In Memory Of
J. Leo O'Brien
Evan & Delane Haren In Memory Of W. Tris Stevens
Joan Harkleroad In Memory Of Douglas Harkleroad
William & Anne Harmon In Memory Of
Iris Harmon Oehler
Robert D. Harrington In Memory Of
Eilene Harrington
Alan & Elizabeth Harris In Memory Of
Christine de Got
Inez Harris In Memory Of Thomas K. Harris
Donna M. Hart In Memory Of Martha J. Terry
Jill Hartmann In Memory Of Gladys Stephens
Eric & Felicia Hasset In Memory Of Wayne Emmett
Philip & Sara Hawk In Memory Of Frank Branisa
John Hayes In Memory Of Geraldine Hayes
Patricia Haywood In Memory Of
Charles Thomas Haywood
Greg & Beth Hazlitt In Memory Of Allen Roder
Harry Heimbürger In Memory Of
Walter F. Kleinpeter, Sr.
Chris & Sheila Heppe In Memory Of Merlin Rocker
Lawrence & Virginia Hicks In Memory Of
William F. Meinert
Michael & Patricia Hill In Memory Of Deanna Scherrer
W.P.T. & Sally Hill In Memory Of Nancy Richartz
Patricia Hinckley In Memory Of Charles Hinckley
Robert G. Hitchcock In Memory Of Lillian Hitchcock
Joanne L. Hodgson In Memory Of
LaVerne E. Johnson
Dale & Barbara Hoff In Memory Of Elbert Harris
Stu & Sally Hoffer In Memory Of Nancy Richartz
Paul & Patricia Hoffman In Memory Of
Joan Anderson
Sara R. Hoffman In Memory Of Sara Pepper
Richard Hohman & Elaine Hohman Chu
In Memory Of Robert E. Webster, Jr.
Hannelore Holland In Memory Of Bob Holland
Charlsie Holmes In Memory Of Henry D. Holmes, Jr.
Housholder, Artman & Associates, P.C.
In Memory Of Ina Clark
Carol Howard In Memory Of Larry Howard
Robert & Susan Huckman In Memory Of
Myron Steve Niehaus
Mark Huddell In Memory Of Bruce Sanderson, MD
Robertta Hunt In Memory Of Byron Hunt
Pamela & William Hussey In Memory Of
Sidney Miller
Pamela & William Hussey In Memory Of
Ruby P. LeBleu
Ingram Periodicals, Inc. In Memory Of
Janice Waedekin
Robert Insolia In Memory Of J. Leo O'Brien
Mark & Kathy Iocca, DDS In Memory Of
Marie Iocca
IPC Tapestries Two In Memory Of Bill Way, MD
Robert Jackman In Memory Of Eva Mae Jackman
Jackson Mountain Homes Staff In Memory Of
JoAnn Anderson
Christie Jahn In Memory Of Daniel Krueckeberg
Kennard & Mary B. Johnson In Memory Of
Hattie Bizzell

Dennis & Marcia Joines In Memory Of
Joseph Whiting
Robert Jones In Memory Of Elizabeth P. Jones
Gene & Holly Kaldunski In Memory Of
Wayne Emmett
Melvin & Lola Kamins In Memory Of
Audrey Jean Phelps
Rondee Kamins & Donald Buckley In Memory Of
Audrey Jean Phelps
Ed & Audrey Kancler In Memory Of Margaret Percy
Bill & G.M. Kaoudis In Memory Of Francis Rose
Eunice Karsakov In Memory Of Phillip Jackson
Nancy Quinn Keeler In Memory Of Christine de Got
Cecelia Keleher In Memory Of Christine de Got
James & Shirley Kelley In Memory Of
Ray C. Simmons
Patricia A. Kelly In Memory Of Josephine Kelly
James & Sandra Kendall In Memory Of
John G. Zimmerman
William & Madolyn Kerwin In Memory Of
Wayne Emmett
Richard Kissinger In Memory Of Johana A. Kissinger
Philip M. Klauber In Memory Of Detty June Klauber
Edna Kleinpeter In Memory Of
Walter F. Kleinpeter, Sr.
Kenneth & Lorraine Kliver In Memory Of
Robert VanWesten
Knickerbocker Apartments In Memory Of
Barbara W. Weiss
Knowledge Systems & Research, Inc. In Memory Of
Jane Robson
Mr. & Mrs. John J. Koback In Memory Of
Mary Elizabeth Johnson
Daniel & Ingrid Koch In Memory Of Hedvig Kloster
Carol A. Koehler In Memory Of John Casteen
Eleanor Kondziela In Memory Of William R. Todd
David & Stephanie Konsler In Memory Of
Covington Shackelford
Peter & Anna Koval In Memory Of Marie Kowalchuk
Tavia Kowalchuk & Richard Duro In Memory Of
Marie Kowalchuk
Jim Kozeny In Memory Of Patricia Kozeny
KPMG Consulting/Cablevision In Memory Of
Sidney Azralon
Rebecca J. Kranz In Memory Of Marie C. Sparks
Robert Kroll In Memory Of Eugene Kroll
Todd & Catherine Kromer In Memory Of
JoAnn Anderson
Toby Kruh In Memory Of Raye Heksel
Nicholas Kutka In Memory Of Frank Branisa
Jeff & Lori Lacker In Memory Of Delmar E. Knarr
Larry & Pat LaDassor In Memory Of Ethel Knarr
Steven Landsman In Memory Of Linda Holte
Mary Lane In Memory Of Harold E. Lane
Hazel Langhans In Memory Of Herman Langhans
Marilyn Largin In Memory Of Dorothy Holding
Lena M. Latragna In Memory Of Joseph Latragna
Augustine & Rose Lattanzio In Memory Of
Joseph Pacella
Austin & Jeanne Leake In Memory Of
Christine de Got
Leland & Joyce LeBlanc In Memory Of
Nancy Richartz
May & Vincent Leone In Memory Of
Nancy Richartz
John H. Levender, Sr. In Memory Of
Helen I. Levender

Harry & Carleen Lewis In Memory Of
Wayne Emmett
Helen Lewis In Memory Of Hughie Lewis
Richard Libretti In Memory Of Nancy Richartz
Alan & Deborah Lieberman In Memory Of
Ruth Stein
Daniel Lipman In Memory Of Aaron J. Rehr
Faith Little In Memory Of Helen Little
Faith Little In Memory Of Terry Lawson
Littleton Regional Hospital In Memory Of
James R. Snyder
John & Jessie Lodge In Memory Of Pearl Sherman
Theresa Lomasney In Memory Of Walter Lomasney
Gerald & Luceen Lopopolo In Memory Of
Frank Scelzi
Joan Louis In Memory Of Charles Richard Louis
Jimmy & Elsie Love In Memory Of John C. Flynn
John S. Lovell In Memory Of Allen Roder
Helen, Rodney & Cheryl Lovett In Memory Of
Clayton J. Reed
Roman Loyola In Memory Of Roman E. Loyola, Jr.
James Lundy In Memory Of June A. Lundy
Richard & Denise Lunoe In Memory Of
Catherine E. Souder
Delores Mahon In Memory Of Dorothy Holding
Don & Ruth Mainland In Memory Of
Henry B. Shovers
Gary & Diane Malinowski In Memory Of
Henry P. Malinowski
Miriam Malone In Memory Of Tom Connolly
Joseph N. Manfre In Memory Of Mary L. Manfre
Barbara Mann In Memory Of Donald Fosdick
Peter & Jana Mansoor In Memory Of
Audre H. McGranahan
David & Denise Marchand In Memory Of
John C. Flynn
Richard Marchlenski In Memory Of
Angela Marchlenski
Marlowe Family In Memory Of
Leonardo Chiricosta
Martine Avenue Productions, Inc. In Memory Of
Dudley Moore
Bertha Massey In Memory Of Jack Garrison
Peter Matthews In Memory Of Nancy Richartz
Russell & Dorothy May In Memory Of
John G. Zimmerman
Worthington Smith & Margaret Mayo-Smith
In Memory Of Christine de Got
MBI, Inc. In Memory Of Ann Cahn
Amy McAndrews In Memory Of Mary Beauregard
Rose McCarty In Memory Of Charles R. McCarty
Ruth M. McClughan In Memory Of James Thomson
Kathleen McCormack In Memory Of
Thomas J. McCormack
Constance McDade In Memory Of
James R. Snyder
Mary Ann McGrath In Memory Of John F. McGrath
Laura McGuire In Memory Of Josephine Kelly
Diana McKenna In Memory Of Wesley Bassett
Mclarand, Vasquez, Emsiek & Partners, Inc.
In Memory Of Celina Sally Lessner
Mr. & Mrs. John R. McSunas In Memory Of
Henry B. Shovers
Mr. & Mrs. John R. McSunas In Memory Of
Virginia Shovers
Medical College of Ohio In Memory Of
Donald Robinson

Report Of Gifts

PATRONS \$100 AND OVER

continued

Maude Meingast In Memory Of
William J. Meingast
Mr. & Mrs. William E. Meiser, Jr. In Memory Of
Cecil Meiser
Jonathan Mellin In Memory Of Mary Beauregard
Mary Anne Memminger In Memory Of
Shirley Snow
Mary Anne Memminger In Memory Of
Charles Memminger
Janet L. Mengle In Memory Of Donald C. Mengle
Mental Health Consultants In Memory Of
Elena Guastella
Frank & Carolyn Metcalf In Memory Of
Edwin Roscoe Chapman
Ms. Claudia Metz & Mrs. Tom Woodworth
In Memory Of Marion M. Epstein
Joyce Meyers In Memory Of C. Grafton Meyers
Melina & Larry Michaels In Memory Of
Joseph Michaels
Mary & William Michels In Memory Of
Mary Carleton Sinnott
Mickels & Williams Builders, Inc. In Memory Of
Christine de Got
Joseph F. Mifsud In Memory Of Frank Branisa
Jacqueline Milgrim In Memory Of Sidney Milgrim
John Paul Miller In Memory Of Marion M Epstein
Kay Miller In Memory Of David O. Miller
Bonnie Mitchell In Memory Of Theda Howell
Brian & Elizabeth Mockler In Memory Of
Nancy Richartz
James W. Moline In Memory Of June Kramer
Pauline Monty In Memory Of Patricia C. Smith
Polly J. Moore In Memory Of George B. Crowe. Sr.
Rick Moranis In Memory Of Phillip Jackson
Nancy B. Morgan In Memory Of Hattie Bizzell
Michael M. Morrow In Memory Of
Mary Beauregard
Mystic Dental Group In Memory Of Nancy Richartz
Lew Nadien In Memory Of Bonnie Nadien
Elizabeth Neiswender In Memory Of
Anne Constable
Marian B. Nelson In Memory Of Dorothy Barnett
David & Audrey Nester In Memory Of
Christine de Got
New York Life Insurance Company In Memory Of
Alexander M. Logan
Juanita Bing Newton In Memory Of Selma Koretz
Richard & Melissa Nicol In Memory Of
Vera M. Nicol
Henry Nields In Memory Of Olivia Nields
Nancy E. Nikiforow In Memory Of Mary Belle Fickel
Charles & Grace Nitzberg In Memory Of
Otis A. Wesche
Betty Nolen In Memory Of Floyd Nolen
Gerald & Suzanne Noonan In Memory Of
Christine de Got
North Side Homeowners Association, Inc.
In Memory Of Salvatore Rustico
Mr. & Mrs. Nicholas Ogan In Memory Of
Marvin Glazer
Philip D. Oiler In Memory Of Bonnie M. Oiler
Elizabeth Oldham In Memory Of Henriette Samson
Ellen Olean In Memory Of E. James Olean
Daniel Orlow In Memory Of Christine deGot
Carolyn Denton Palmer In Memory Of Philip Page
Betty Parham In Memory Of Herber L. Parham, Sr.
Paul & Susan Parhiala In Memory Of
Wayne Emmett
Parkway Dental Practice, PC In Memory Of
Stewart James Huston
Larry & Nancy Pascale In Memory Of
J. Leo O'Brien
David & Diane Patryn In Memory Of Shirley Patryn
Paul-Koehler Engineers, Inc. In Memory Of
Herb Philbrick
Elwin M. Peacock In Memory Of Frank Branisa
Pelican Mobile Home Park In Memory Of
Robert E. Webster, Jr.
Janice Penn In Memory Of John Slavik
Ann M. Peters In Memory Of Helen Moriarty
Marlys C Peters In Memory Of F. James Sauer
Mary M. Peterson In Memory Of
Margaret Pegge Maloney
James & Nancy Icet Pfeffer In Memory Of
Frank Branisa
Maryanne Philbrick In Memory Of Jenny Fannell
Lee & June Philpott In Memory Of Emilie Roloff
Pinkerton Government Services, Inc. In Memory Of
W. Tris Stevens
Lloyd Pique & Susan Silva In Memory Of
Wayne Emmett
Plan A, Inc. In Memory Of Philip Page
Brenda Planck In Memory Of Robert M. Houghton
Pointe Financial In Memory Of William Costello
Alex Pomnichowski In Memory Of
Jean Pomnichowski
Georgia Pontious-Butler In Memory Of
Stanley Pontious
PPG Industries, Inc. In Memory Of Bernice Schmidt
Clifford & Rebecca Preminger In Memory Of
Marvin Glazer
Frank & Jane Price In Memory Of Otis A. Wesche
Bert Quamme In Memory Of Phyllis Quamme
Betty Quick In Memory Of Frances Rosen
Earl & Joan Rader In Memory Of Otis A. Wesche
Michele L. Rainere In Memory Of Angelo Battista
Sari A. Rapkin In Memory Of Mary Beauregard
Bernard Rapoport In Memory Of Florence Rapoport
Cecily R. Raymond In Memory Of Robert Howe
Raytheon Global Health Resources In Memory Of
Frank Zybert
Sally & Lincoln Reed In Memory Of Dorothy Barnett
Isabella Reid In Memory Of Martha J. Terry
Philip & Jane Reidy In Memory Of Katharine Reidy
Joan Reifler In Memory Of Norman Reifler
Renewal By Anderson In Memory Of Rita Sommer
Richard Bowers & Company In Memory Of
John L. Garland
Dr. Frederick W. Richartz In Memory Of
Nancy Richartz
Emily Riley In Memory Of Lydia J. White
Jacqueline Riley In Memory Of William F Riley
John & Cletes Rines In Memory Of Francis Foss
James & Virginia Roberts In Memory Of
Jon Whitney Aycock
James & Ann Robins In Memory Of Nancy Richartz
Donald & Angenette Robinson In Memory Of
Nancy Richartz
Margaret Roder In Memory Of Jayne Hayter
Margaret Roder In Memory Of Allen Roder
Jan Como Rodriguez In Memory Of Ilio G. Como
Kristina K. Roggenkamp In Memory Of
Mary Belle Fickel
Nicholas & Peggy Rose In Memory Of
Marilyn Henery
Jacob I. Rosenbaum In Memory Of Marvin Glazer
Mildred R Rosin In Memory Of George Rantovich
Allan & Joanie Ross In Memory Of
Nicholas Channic, Jr.
Dorothy E. Roth In Memory Of Zeena Gensky
Ned D. Rubin In Memory Of Janice Waedekin
Kenneth C Ruhling In Memory Of
George S. Jankiewicz, Sr.
James & Martha Rumann In Memory Of
Patricia Benjamin
Andrew M. Rupp In Memory Of Esther N. Rupp
Grace A. Russell In Memory Of William F. Riley
Albert S. Ruxton In Memory Of Pauline Ireland
Arlene Ryder In Memory Of Eugene Kroll
Anna Saladino In Memory Of Nan Scelzi
William & Diane Salyer In Memory Of Marion Percy
Tom & Mary Sanderson In Memory Of
Bruce Sanderson, MD
Sheila Santry In Memory Of Anne Collins
Sue Savage In Memory Of Joyce Wolken-Cannon
Charles R. Schaller In Memory Of Jean S. Schaller
Fred B. Scheel In Memory Of Susan L. Clemedtsen
Jessica Schneider In Memory Of Philip Page
Paula Schnurr, Ph.D. In Memory Of J. Leo O'Brien
John Schoenecke In Memory Of
June Clarice Schoenecke
Victoria R. Schreck In Memory Of Albert Schreck
Stuart & Judith Schuck In Memory Of
Dorothy Barnett
Ms. Joan Schupp & Family In Memory Of
J. Leo O'Brien
John & Jane Seel In Memory Of Christine de Got
R.M. & Barbara Sewall In Memory Of
Otis A. Wesche
Shaklee Family In Memory Of Salvatore Rustico
Douglas & Nanci Sharon In Memory Of
Phillip Jackson
Catherine Sheehan In Memory Of Donald Boese
W.R. & Frances Shelnut, Jr. In Memory Of
Myron Steve Niehaus
Marvin & Jane Shaver In Memory Of
Vivian Davisson
Shiffer Family In Memory Of Jane Robertson
Jeff Shimizu In Memory Of Harry Cinquini
April D. Shinkle In Memory Of Hazel V. Shinkle
Dorothy Shrader In Memory Of William S. Fulcher
Siegel, Rutherford, Bradstock & Ridgway, Inc.
In Memory Of Aaron J. Rehr
Jennifer Sikes In Memory Of Dudley Moore
Gary Silicani In Memory Of Wesley Bassett
N. Susan Silvers In Memory Of Anuita Blanc
Ruth C. Simon In Memory Of John J. Simon
David & Sakinat E. Skinner In Memory Of
Abed Esman, Jr.
Nelson A. & Helen S. Sly In Memory Of
Myron Steve Niehaus
Akemi Smith In Memory Of Thomas Amory
Barbara P. Smith In Memory Of Madeline Pindar
Barbara P. Smith In Memory Of John Hohler
Berl A. Smith In Memory Of Berl S. Smith
Brenda & Karl Smith In Memory Of Jesse Smith
Frank G. Smith In Memory Of John L. Garland
Harold & Patricia Smith In Memory Of
Bernice Schmidt
Loda M. Smith In Memory Of William R. Smith
Rebecca Smith In Memory Of Mary Belle Fickel
Thomas & Ginny Smith In Memory Of
Jacquelin Hodowanic
Rita Snow, MD In Memory Of Shirley Snow
Sid & Sandy Socolar In Memory Of Anuita Blanc
Karsten & Sophie Soleng In Memory Of
Joan Anderson
Gerald Souder In Memory Of Catherine E. Souder
John Sparacio In Memory Of Nancy Richartz
Pearl Spielman In Memory Of Joan Anderson
Richard & Joyce Spindler In Memory Of
William De Ferrari
David & Nancy Springsteen In Memory Of
Christine de Got
St. Peters Lutheran Church In Memory Of
Ethel Knarr
Michael Stark In Memory Of Selma Koretz
Helen Staszak In Memory Of Francis Staszak
Joanie Waid Stephens, RN In Memory Of
Lois Jane Waid

Report Of Gifts

PATRONS \$100 AND OVER

continued

Goodwill & Valerie Stewart In Memory Of William Stearns
Lena Stockstill In Memory Of Prentiss G. Stockstill
Roger & Susan Stone In Memory Of Covington Shackelford
Lowell Stough In Memory Of Edith Stough
Jeffrey G. Stovall, MD & Adria P. Bernardi In Memory Of Covington Shackelford
Peter H. Strife, II In Memory Of Nancy Richartz
Ingrid M. Sullivan In Memory Of Russell Nelson
Mark & Rolande Sullivan In Memory Of Margaret E. Parker
SunTrust Bank In Memory Of John G Zimmerman
Survivair In Memory Of Lillian Hitchcock
Marja-Lou Swan In Memory Of Elbert Harris
Robert Swart, MD In Memory Of Virginia Swart
Mrs. Barbara Lee Tanner In Memory Of Tommy Tanner
Jo-Ann Tavarez In Memory Of Nan & Mim Scelzi
Dolores L. Taylor In Memory Of Harvey Taylor
Harriet Teboe In Memory Of Roland Guilkey
George & Geneva Telford In Memory Of Donald Roun
Abigail Terrones In Memory Of Alma Anita Judge
Graham J. Terry In Memory Of Martha J. Terry
Irma Tetzloff In Memory Of Alice Barkley
The Jean Pomnichowski Revocable Trust In Memory Of Jean Pomnichowski
The Lamm Family Foundation In Memory Of Shirley Lamm
The Playboy Foundation In Memory Of Janice Waedekin
The Springs Company In Memory Of Mary Taylor
Henry & Irene Thompson In Memory Of Malcolm Thompson
Jessie Thomson In Memory Of James Thomson
TM Power Ventures, LLC In Memory Of Bernice Schmidt
William & Brenda Toothman In Memory Of John L. Garland
Toovell Associates Inc. In Memory Of Salvatore Rustico
Margaret L. Travis In Memory Of Harry Cinquini
Gail Trenhaile In Memory Of Curtis Trenhaile
Mr. & Mrs. David E. Trevett In Memory Of Dorothy Barnett
Tru Cal Employees In Memory Of Janice Waedekin
Twin State Volkssport Association In Memory Of Robert E. Webster, Jr.
United Way of Bergen County In Memory Of Robert Bloom
Unity Health Services, LLC In Memory Of Rita Sommer
Trudy J. Valdez In Memory Of Walter Frederick
Rick & Renee Van Daal In Memory Of Donald Hoey
Wait Van Wagner In Memory Of Christine deGot
Mark & Allison Vandeven In Memory Of Angelo Battista
Mr. & Mrs. William C. Veatch In Memory Of William Keilbey
Ted Velikonja In Memory Of Allen Roder
Margaret W. Vezina In Memory Of Hilbert Beyer
Richard & Barbara Vinciguerra In Memory Of Gloria Mitchell
Richard & Denise Vinton In Memory Of Bernice Schmidt
Sandra L. Waedekin In Memory Of Janice Waedekin
Joan M. Waedekin-Crume In Memory Of Janice Waedekin
Shannon Wagner In Memory Of Bernice Schmidt
Michael & Carrye Walla In Memory Of Ray C. Simmons

Warner Publisher Services In Memory Of Janice Waedekin
Michael & Rosemary Waterman In Memory Of Robert Howe
Linda Webster In Memory Of Michael J. Rabalais
Linda Webster In Memory Of Robert E. Webster, Jr.
Paul A. Weier In Memory Of Jack Longar
Kevin & Elizabeth Weiss In Memory Of Anne Collins
Patrick & Susan Mauldin Welch In Memory Of David Lowder
Don & Doryce Hills-Wells In Memory Of Tom Neely
Ray & Janice Wermers In Memory Of Vivian Davisson
Westfall Dental Group, LLP In Memory Of Virginia Swart
David P. Whelan, Jr. In Memory Of Anne Collins
William Blunt White In Memory Of Nancy Richartz
Sharolyn Wilburn In Memory Of Marian Jenkins
Jeanne Williams In Memory Of Jim Williams
Robert Wilson In Memory Of Martha J. Terry
Carl & Lena Wolfe In Memory Of Jack Garrison
Carla S. Wolfe In Memory Of Jack Garrison
Margie R. Wood In Memory Of John H. Wood
Mr. & Mrs. Roy J. Yenoli In Memory Of Mary Elizabeth Johnson
William Yetter In Memory Of Jeanne B. Yetter
Michael & Erika Zulch In Memory Of Berta Danyluk

In Honor Of

GOLD PATRON - \$500 - \$999

Advantage One In Honor Of Fred Waddell
Ronald & Susan Benivegna In Honor Of Alberta Benivegna
Bronco Roofing & Construction In Honor Of Jim Gray
Donald L. Clement, Jr. In Honor Of Anna Tillie Clement
Dee C. Daniels In Honor Of Kathryn Daniels
Barbara Fedor In Honor Of Sandy Stern
William & Joyce Kravec In Honor Of Joyce Kravec
Pamela Schaff In Honor Of Jim Gray
Lloyd Silverman In Honor Of Majorie Silverman
Bill & Ursula Stephens In Honor Of Donald Lambrecht

SILVER PATRON - \$250 - \$499

Roger E. & Ruth E. Andree In Honor Of Ruth E. Andree
CWA-Local 7777 Officers & Members In Honor Of Donald Lambrecht
Jeff & Debbie Davey In Honor Of Diane Davey
Golden West Automotive In Honor Of Jim Gray
Lee, Lisa & Nadine Honigberg In Honor Of Saul & Sally Honigberg
Robert S. Karam In Honor Of Dale Ferris
Kathleen M. Keefe In Honor Of Jim Gray
Frank Knowlton, Jr. In Honor Of Lorna S. Trowbridge
Stephen S. & Frances A. Levitt In Honor Of Stephen S. Levitt
David & Martha Mangan In Honor Of William Mangan
John & Ann Mangan In Honor Of William Mangan
Margaret Mastrantonio In Honor Of Richard R. Beems
Daniel R. Miller In Honor Of Jim Gray
Richard & Ruth Northrop In Honor Of Ruth E. Northrop
Henry Torre In Honor Of Mary Torre
Michael Weber In Honor Of Ronald E. Weber
David & Rita Whitney In Honor Of Elizabeth Antipov

PATRONS - \$100 AND OVER

Leslie & Sheila Agasee In Honor Of Leslie Agasee
ALL WASHED UP In Honor Of Jim Gray

Deborah Altschuler In Honor Of Saul & Sally Honigberg
William & Joyce Amador In Honor Of Lillian Carter
Anonymous In Honor Of John McDaniel
John D. Armitage In Honor Of Gerrie Christian
Anne Barrington In Honor Of Donald Lambrecht
Corina C. Battista In Honor Of Angelo Battista
Ann Behnke In Honor Of Glenn Behnke
Charles Beltramello In Honor Of Lorraine Beltramello
Antonio Benivegna In Honor Of Alberta Benivegna
Shirlee Berger In Honor Of Wayne Berger
Leona Bielski In Honor Of T. Michael Bielski
Angelo & Elisa Biondi In Honor Of Alda Mocogni
Bartolomeo & Carolina Biondi In Honor Of Alda Mocogni
Margaret Bradford In Honor Of Mary Gentry Heun
Carolyn Brooks In Honor Of Alda Mocogni
George, Kathy, Justin & Lauren Broughman In Honor Of Joyce Deacon
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William H. & Carol L. Kersten In Honor Of Frank W. Moyer
Rosalyn Knapp In Honor Of Doris Hedrick
Stephen & Elsa Koallick In Honor Of Virginia Koallick
Elena Krawczyk In Honor Of Addison Jenrette
Carl J. & Sherri A. Kroonenberg In Honor Of Donald Lambrecht
Donald & Wallie Lambrecht In Honor Of Donald Lambrecht

Report Of Gifts

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Shirley E. Maurer In Honor Of Frank W. Moyer
W.J. McClendon In Honor Of Revia McClendon
Joanne Meinert In Honor Of William F. Meinert
George Merrick In Honor Of Jane Merrick
Ms. Claudia Metz & Mrs. Tom Woodworth In Honor Of Helen Weinberg
Christine K. Mitchell In Honor Of Frank W. Moyer
Robert & June Moyer In Honor Of Frank W. Moyer
John Pavis In Honor Of Fadetta Pavis
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Ole Sollie In Honor Of Dorothy Ann Kimball
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Richard B. Stevens In Honor Of Evelyn Stevens
Daniel J. Stewart In Honor Of Donald Lambrecht
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Phyllis Thompson In Honor Of Margie Wade
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PLEASE MAKE ALL CHECKS/GIFTS TO "THE SOCIETY FOR PSP."

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PSP Advocate, Third Quarter 2002

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