

Society for Progressive
Supranuclear Palsy

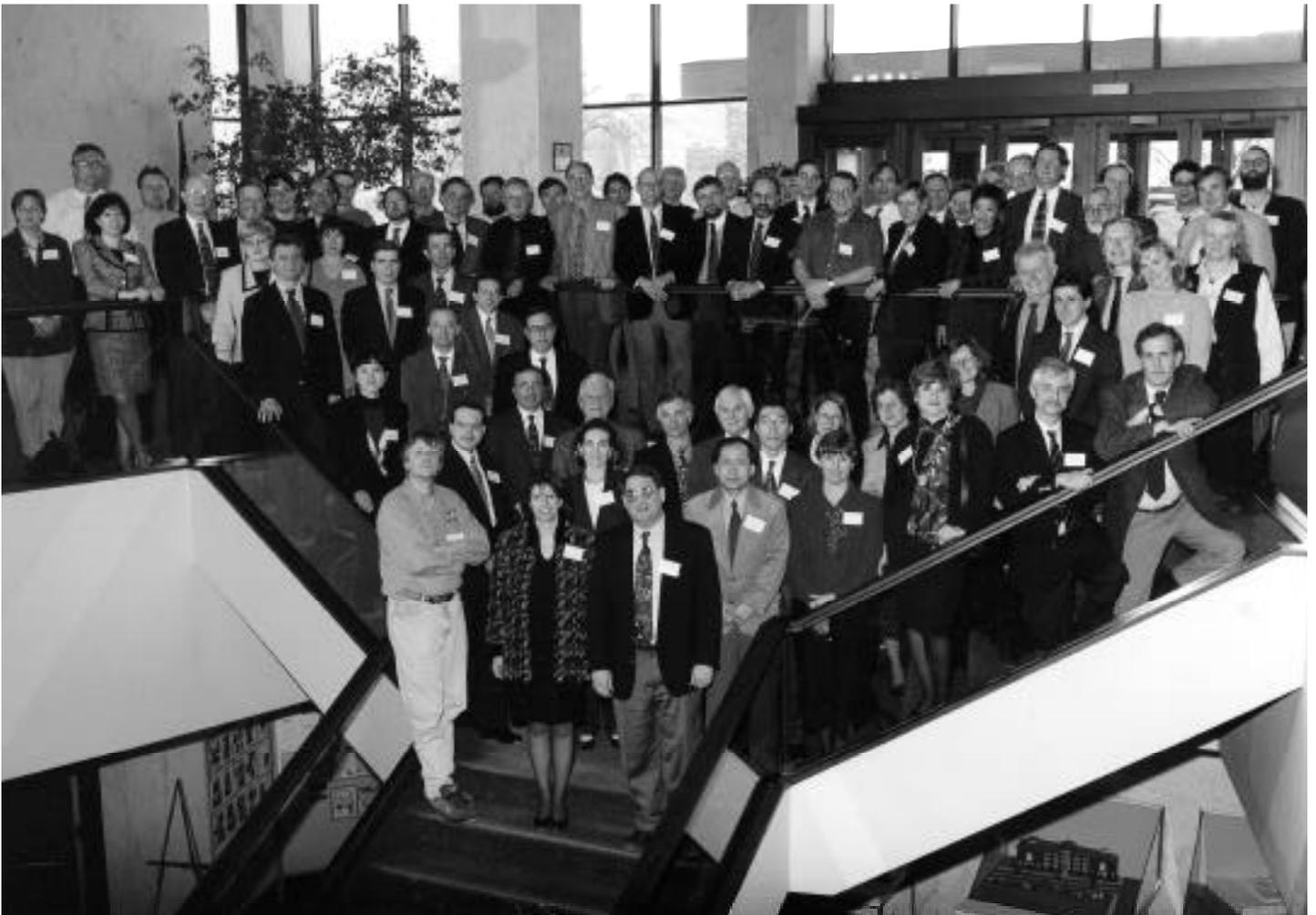


PSP Advocate

Official Newsletter of the Society for Progressive Supranuclear Palsy, Inc. (SPSP)

David and Reba Saks, Founders

First International Brainstorming Conference on Progressive Supranuclear Palsy



**Sponsored By the Society for PSP and
The National Institutes of Health
Bethesda, Maryland
March 18-19, 1999**

SOCIETY FOR PROGRESSIVE SUPRANUCLEAR PALSYP, INC. (SPSP)

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



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

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(In memory of Henry and Jane Ogiba)

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First International Brainstorming Conference on Progressive Supranuclear Palsy “Brainstorming Session Highlights”

Review by: Lawrence I. Golbe, M.D.
Chair, SPSP Medical Advisory Board
Professor of Neurology
Robert Wood Johnson Medical School
New Brunswick, New Jersey



Ellen Katz, SPSP Director, and Stephen Groft, M.D., NIH

The SPSP and the Rare Disorders Branch of the National Institutes of Health co-sponsored a research roundtable on March 18 and 19, 1999 in Bethesda, MD, at the NIH. It was organized by Irene Litvan, MD, of the NIH and a member of the SPSP Medical Advisory Board. The meeting, attended by 78 invited researchers, grew out of an initiative of the Medical Advisory Board to create interest in PSP among the world's best basic science researchers. The plan called for these laboratory researchers to interact with the neurologists who take care of the patients and who themselves do clinically-based research on the disease and could collaborate with the laboratory scientists in future projects.

There was little original data presented. The purpose of the meeting was to review what is already known and to plan strategies for the next steps. Therefore, the meeting began with a systematic presentation of the latest in each of these areas:

- Basic disease mechanisms (what's going wrong at the level of molecules and cells)
- The search for animal models (attempts to create "PSP" in animals in order to test new treatments or to understand how the brain reacts to the damage)
- The search for biologic markers (tests that can diagnose PSP accurately during life)
- Genetic studies (defects in DNA, possibly inherited, that can contribute to PSP)
- Basal ganglia circuits (what goes wrong with the brain's connections to cause the symptoms)
- Ocular motor studies (how studying the abnormal eye movements helps us understand the disease in general)
- Neurophysiology (tests of reflexes, brainwaves, etc., that can tell us what's going wrong in the brain)

- Cognitive studies (understanding how thinking and behavior are affected in PSP and what this means for understanding how the disease works)
- New therapeutic approaches (ideas for treating PSP)
- Neuroepidemiology (understanding how PSP occurs in populations and what factors affect one's chance of developing PSP)

Then, the participants formed 10 different special interest discussion groups, each in one of the above areas, to formulate a practical plan for taking PSP research to the next step in that area. The leader of each group then reported back to a final plenary session on the group's deliberations and all the participants could comment on each summation.

The issue that seemed to provoke the most interest was the question of a defect in the tau gene. Dr. Gerry Schellenberg of the University of Washington, a molecular geneticist, presented his data confirming the observation that people with PSP carry some sort of variation in the gene encoding tau, a protein important in maintaining the structure of brain cells. Tau accumulates in abnormal tangles in PSP. Dr. Dennis Dickson of the Mayo Clinic, Jacksonville, a neuropathologist, presented the corresponding microscopical and biochemical observations. The tau tangles in brain cells in PSP are composed nearly exclusively of "four-repeat" tau - that is, tau with four repetitions of a special section of the protein. That section binds to microtubules, an important "fiber" maintaining the

Continued Page 4



Brainstorming Session Highlights Continued from Page 3

brain cell structure. Healthy brains have tau in an equal mixture of three-repeat and four-repeat, but in PSP, it's nearly all four-repeat. Just how this causes the brain cells to die is unclear. Another disease in which tau accumulates in tangles, frontotemporal dementia, has more four-repeat than three-repeat tau. However, in Alzheimer's disease, the most common tau-tangle disease, the ratio is normal.

The question then becomes, "What causes the brain in PSP to fail to make three-repeat tau?" Part of the answer comes from the fact that the gene that encodes tau protein has 16 subsections, called exons, whose protein product are combined in various ways to produce various forms of tau. This is called "alternative splicing." To produce the four-repeat form of tau, exon 10 must be included from the alternative splicing plan. The questions then become, "What is causing exon 10 to always be included in PSP?" Is it a failure of the mechanism that sometimes excludes exon 10 from the alternative splicing in healthy individuals? Or is it a failure of the mechanisms that get the other exons involved?

Finding the answer will require laboriously working out the sequence of the genetic code of the tau gene in people with PSP. Dr. Schellenberg and others have done this for the exons of the tau gene - the parts of the gene that actually are translated into tau protein- and, disappointingly, found no defects. They announced this unpublished finding for the first time publicly at the meeting.

But a defect in alternative splicing would probably not arise not from a "misspelling" in an exon, as occurs in most genetic diseases, but from a more profound error in the instructions that regulate alternative splicing. These instructions are found in the areas between the exons called *introns*. The introns are much longer than the exons (hence more time-consuming for a researcher to sequence) and are mostly areas of genetic code that may have been used in our distant evolutionary ancestors but are inactive in humans. However, some parts of some introns function to regulate the production of protein by the neighboring exons. The introns next to exon 10 now fall under suspicion in PSP.

Molecular geneticists are now attempting to work out the genetic code sequence for all of the introns in tau in hopes of finding some variant that occurs in people with PSP and not in healthy people.

Continued Page 5



Breakout session



Panel Discussions with Irene Litvan, M.D.



Dr. John Steele recognizing Mr. Jay Troxel for his generous support of the Society



Nancy Brittingham, SPSP Editor, and Lynda Blute, "volunteer extraordinaire"



Irene Litvan, M.D. (Conference Chairperson) & Lawrence Golbe, M.D.

Brainstorming Session Highlights Continued from Page 4

If there is a genetic defect in tau causing PSP, it would be operating at "low penetrance," meaning that only a small proportion of people carrying the defect would develop the disease. Furthermore, the defect would probably be operating on a recessive basis, meaning that one would have to inherit a defective copy of the gene from each parent (neither of whom need have the disease during their lifetime) in order to even have the potential to develop the disease. Because of the rarity of PSP in family clusters, it seems likely that something else besides a genetic defect in tau is necessary to develop the disease. That something could be other genetic defects that are not necessarily inherited along with the tau defect, or it may be some sort of exposure to as-yet-unidentified chemicals.

The overall success of the Brainstorming Session was illustrated by the fact that soon thereafter, a record number of applications for research grants arrived in the SPSP office, submitted by session participants or their associates. By that measure alone, the Brainstorming Session succeeded in stimulating some of the world's best researchers' interest in finding the cause and cure for PSP.



Lawrence Golbe, M.D. recognizing Congressman Hal Rogers for promoting awareness in the field of Public Health and furthering research into PSP.

Change In Membership Dues

The revised SPSP bylaws state that there will no longer be membership dues. As a nonprofit health organization, SPSP is solely dependent upon the financial contributions of our friends and supporters to sustain our research, education, and outreach programs. Your contribution is tax deductible.

If you wish further information about the SPSP bylaws, please call the SPSP office at 1-800-457-4777

PLANNED GIVING

The Society for Progressive Supranuclear Palsy is establishing a Planned Giving Program. This new initiative is a program through which donors can make a contribution to the organization as a result of financial or estate planning. A planned gift maximizes advantages to the donor while providing funds to the organization. Planned giving differs from other types of fundraising. A planned gift is carefully thought out and arranged to fit the donor's financial and personal objectives.

Currently, SPSP is creating a volunteer Planned Giving Committee. The committee will develop policies and a plan, produce supporting materials and implement on-going strategies and activities throughout the country.

There is a role for volunteers in the Planned Giving Program. The planned giving committee will be made up of volunteers from within the community. They can include:

- Attorneys
- Trust Officers
- Certified Public Accountants
- Certified Financial Planners
- Certified life underwriters
- Real Estate Brokers
- Stock Brokers
- Major Donors
- Corporate Executives

Planned gifts have become a major source of income for many organizations. The Society for Progressive Supranuclear Palsy is ready to launch this new program. It will be an asset to the organization and an opportunity for donors to give thoughtful and generous gifts.

If you are willing to share your special talents and serve on the SPSP Planned Giving Committee, please contact Ellen Pam Katz, SPSP Director at 1 (800) 457-4777, (410) 486-3330, fax # (410) 486-4283, email address: SPSP@erols.com. We need your help!



PEDALING FOR PSP

Roger Rides Again!!

To celebrate the tenth anniversary of the Society for PSP, Roger Brisson will be facing another challenge in the spring of 2000! Roger is not ready to settle for his tremendous efforts in the "Climb for a Cause" event. Climbing Mt. Aconcaqua to establish the Margaret Parker Research Fund in honor of his aunt and raising over \$75,000 in contributions was quite an accomplishment. Now, Roger and his family are eager to raise even more funds to support the ever growing number of PSP grant research proposals. So..... Roger is planning his next challenge! He will be PEDALING FOR PSP across the United States. Watch for the upcoming details and learn how YOU can become an important part of this extraordinary event!!!!

Toronto What A City!



Nancy and Ellen in Toronto

Its gleaming skyscrapers, its pristine lake and inlets, its sophisticated elegance reflected in the theaters, restaurants and sports arenas. People are polite, the pace is moderate and the atmosphere is welcoming.

I attended the Annual Meeting of the American Academy of Neurology. However, I had the opportunity to network with many nonprofit “advocates” like myself and most importantly—to meet persons whose fate has been forever changed by PSP. After a whirlwind week of activities, I am awaiting my flight back to Baltimore. I am filled with yet unsorted impressions of the many activities that I was involved with.

I was blessed to have Nancy Brittingham as my partner on this trip. For more than two years, we have come to be ebullient work partners as well as considerate traveling companions. Our week began with the “first” Canadian Symposium organized by Janice Stober, Kim Anderson and Sandy Jones of the Parkinsons Foundation of Canada. Over 100 persons attended from throughout Canada, Michigan, Upstate New York, and even Texas. Like the U.S., the needs of PSP families are critical. The comradery and feeling of goodwill was infectious. Many great things will come from this new link to our Canadian neighbors. Many thanks to Dr. Mark Guttman, Angela Gei, Kathleen Holmes, Lynn Wymgaarden, Ruth Story and other volunteers for their assistance throughout the week. Many thanks to Dr. Dennis Dickson, Dr. Mark Guttman, Dr. John Growdon, Dr. David Zee and Rebecca Gruber (Physical Therapist) for speaking at the Symposium.

At the AAN exhibit, Nancy and I with our special volunteers distributed updated information and new brochures about the Society. A physician’s PSP diagnostic scale developed by Dr. Golbe was also distributed to the medical profession.

Nancy and I spent considerable time networking with other members of the nonprofit advocacy community. We questioned our counterparts on issues of board structure, patient services, support services, and managing a nonprofit organization on a national and local level. Each organization

has its unique style and the Society will look at other successful models as well as problem areas and try to address these issues in our strategic plan. There are many precedents already established and the Society will not have to create new things—only better develop what will work for us.

Society business was our first priority! But, we did have a few moments to “run” through the fabulous Eaton Shopping Centre and visit the top of the CN Tower. What a sight!

Other Society highlights included a most interesting lecture on the history of neurology in Toronto and how PSP was described at the Toronto University Hospital by Dr. John Steele along with his colleagues, Dr. J. C. Richardson, and Dr. J. Olszewski. We spent an evening with John’s sister, Barbara, who lives in Canada and also met with Canadian volunteers who wish to expand the Society’s programs and services within Canada.

Well, flight AC1434 has just been called and I must run! Farewell, Canada, but I shall never forget those grand first words of your anthem, “Oh, Canada.” Oh, what a trip!

Best regards,
Ellen Katz
Director

SPSP’S STRATEGIC PLAN

SPSP’s Board of Directors is currently developing a strategic plan that will take the organization into the 21st century. The need for strategic planning is critical. Current and prospective volunteers and donors want to be provided information about how the organization is managed, how its programs are serving its constituents and how their investment in the organization is being used. Through the planning process, organizations assess where they are, where they want to go, and how and when they will get there. Planning is not an easy task, but it is necessary and can pay great dividends to the organization.

At its last meeting, The SPSP Board of Directors undertook the responsibility to begin this process. The goals were to:

- Focus attention to specific issues
- Set objectives that promote the organization’s growth and development

Specific areas were addressed and committees were created to discuss these topics in more detail. The critical issues included research, board development, education and community outreach. Each committee was asked to create a structure or framework that will serve as a guide, set priorities, develop strategies and determine financial and human resources to implement the activities.

At the next Board of Directors meeting, each committee will present its report. Board members will discuss each report and determine its strengths, omissions, and suggestions for improvement. Ways to implement the plan will be the next step.

**1999 BALTIMORE PSP SYMPOSIUM
SATURDAY, NOVEMBER 13, 1999
BWI AIRPORT MARRIOTT**

Plan to attend this informative conference for persons with PSP and carepartners.

Early registration and a welcome reception will be held on Friday, Nov. 12 at 5:30 pm. A get acquainted dinner will follow with seating determined by hometown states! Saturday morning registration and continental breakfast begins at 7:30 am and the programs scheduled from 8:30 am to 4:30 pm. The BWI Marriott has a special block of rooms available at \$89 per double. Lunch will also be provided.

Nationally and internationally recognized clinicians and scientists will present informative programs including topics such as: frailty and preventative physical therapy, recent advances in PSP treatment, summary of the SPSP/NIH Brainstorming Conference, eye problems, swallowing problems, stress management, and doctor/carepartner's panel.

Watch for more details and registration in the next ADVOCATE. Learn more about PSP and share your experiences with other PSP families.

ANNUAL GIVING

Many thanks to the donors of our Annual Giving Campaign. There were 826 gifts to the campaign totaling \$81,711 or an average gift of \$99.00. Seventy percent of the funds given represent renewal donors while 13% represent donations from the Board of Directors (\$10,500). New donors acquired, totaled 17% of the total funds. On behalf of the Board of Directors, we thank 612 donors for renewing their commitment to the Society and 214 donors who made their first donation. **Your generosity is deeply appreciated.**

We wish to thank Mr. Jay Troxel for his continuous expressions of support for the Society. Mr. Troxel has recently given an additional \$30,000 to the Society for the purchase of additional computers, software, hardware and furniture needed to ensure the Society's ability to expand its services. Mr. Troxel, you are our guardian angel!



Contribution Cards Available
"Make your gift by phone or fax"

The Society can send a beautiful acknowledgment card to someone special for any any occasion and we will personalize your message.

Cards are printed on blue linen stock. Very classy. Just call our office at 1-800-457-4777. Visa, MasterCard, and American Express accepted.

Videotape: Society for PSP/NIH Brainstorming Conference

I wish to order the March 18-19, 1999 videotape "Highlights of the SPSP/NIH Brainstorming Conference" featuring Irene Litvan, M.D. and John Steele, M.D. The tape contains a layman's review by Dr. Litvan of the research topics discussed at the Conference. Patient/family issues are presented by Dr. Steele during his visit to Baltimore on March 20, 1999.

COST: \$25 + \$3 postage US and \$5 outside US. AVAILABLE July, 1999

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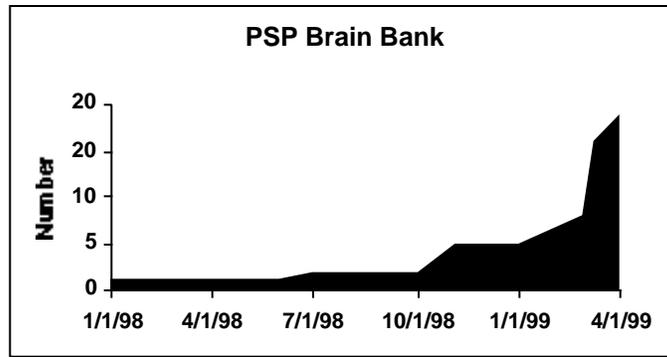
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CUMULATIVE INDEX OF BRAINS RECEIVED BY THE PSP BRAIN BANK



With only a year of operation, the SPSP Brain Bank has collected nearly 20 brains.

Progress Report

Prepared by Dennis W. Dickson, M.D.

March 22, 1999

Progress has been made in the organization of the Society for PSP Brain Bank at Mayo Clinic Jacksonville. During the initial period, we developed a brochure about the brain bank. The SPSP duplicated this printed material and distributed it to interested persons. We also participated in the recent California PSP Symposia and provided additional information about PSP research and the brain bank.

To date, we have received 17 brains (9 men and 8 women with an average age of 74.1 +/-6.7 years) from ten states. The diagnosis of PSP was confirmed in 70% (7/10) of cases. Misdiagnoses were due to multiple system atrophy, pallidonigral degeneration and basal ganglia infarcts. Seven cases are pending evaluation. A neuropathology report is issued and sent to the referring pathologist an average of 26 calendar days after receiving the specimen.

Most cases had both fixed and frozen tissue. The fixed tissue has been dissected and processed for diagnostic studies, which includes routine application of fluorescent microscopy and immunocytochemistry. Semiquantitative assessments of lesion density and distribution are tabulated for each case.

While it is unrealistic to expect that there would have been much research accomplished with this small sample collection, some of the tissue was distributed to several laboratories for biochemical (Shu-Hui Yen, Mayo Clinic Jacksonville), genetic (Michael Hutton, Mayo Clinic Jacksonville) or immunocytochemical (Peter Davies, Albert Einstein College of Medicine, New York-results presented at the PSP Brainstorming Conference in Bethesda, March 17-19).

At some point in the near future, it will be important for the Society to make it known to the scientific community that this resource of brain tissue is available and a mechanism will need to be developed for distribution of tissue.

It is clear that the amount of material being submitted and processed shows a steady growth with nearly as many cases processed in the first three months of 1999 as all of 1998.

Society for Progressive Supranuclear Palsy Brain Donation Program

For Diagnosis and Research on PSP

Society for PSP Brain Bank

Supported by the

Eloise H. Troxel Memorial Fund

Mayo Clinic Jacksonville • Jacksonville, FL 32224

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

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

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

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

DR. JOHN STEELE'S VISIT TO BALTIMORE HIGHLIGHTS BRAIN AWARENESS WEEK

After the NIH Brainstorming Conference, Dr. John Steele, the Society's Honorary Chairman, visited Baltimore. He was booked up for five days with Board of Directors and committee meetings, touring the beautiful SPSP office and getting acquainted with the dedicated SPSP staff. Dr. Steele's most important function was to present an overview of the NIH/SPSP Brainstorming Conference to Society friends. Eighty persons from MD, VA, DC, PA and NJ attended Dr. Steele's presentation addressing highlights of the recent landmark research conference at NIH. Dr. Steele greeted friends, people with PSP, and caregivers in an informal setting and answered audience questions. This meeting was videotaped and a copy can be ordered by calling the SPSP office.

In honor of Brain Awareness Week, John Steele was interviewed on MIX 106.5 radio by Tamara Nelson, whose father has PSP. Dr. Steele presented a fascinating lecture on "The Mysteries of Neurological Disease a World Away" at the Sinai Wellbridge Fitness Club. He spoke to a full house of persons fascinated by his life and experiences on Guam as well as his knowledge of Parkinson's disease, ALS, and current trends in treatment and research. The Society is deeply appreciative of Dr. Steele's time, caring and sharing. We are blessed to have him as a goodwill ambassador for the Society. Well done, Dr. Steele!! Please come again, soon!



Radio station interview with Tamara Nelson-MIX 106.5 Radio.



Dan Lake, Board of Directors, meets with the Baitas family.



Dr. John Steele meeting with Addie Hoepfner.



SPSP Office Staff and Dr. John Steele.



Virginia Gratz, person with PSP, and loving son, Phillip.

Helpful Hints

Dear Nancy,

I made this railing for my mother, Veone, who has PSP. I made it out of PVC pipe, elbows, tees, etc., and a sheet of half inch plywood. The materials altogether cost about \$95. After seeing the



cost of factory railings, I decided to make my own. I thought if you could put this in the ADVOCATE, others could get a good idea of how to make their own railing.

I made this railing out of one and a quarter inch PVC pipe, elbows, tees and adapters that screw into one and a quarter inch galvanized flanges that screw on to a half inch 4 ft. by 8 ft. sheet of plywood. The tall open part of the railing is about 2 inches higher than my mother with a railing going across the bed and attached to a board that is attached to the wall (which is the only place that is actually attached to any walls or floor) and from that there is a trapeze type of bar to pull oneself up. The bed is covering the rest of the plywood which helps hold it firmly in place. It does not look as nice as a factory railing but it does a wonderful job and is a lot cheaper.

Thank you,

Tom M. caregiver to mother Veone

Dear Nancy,

I spoke to you back in January and sent some information for the newsletter to you. Since, then, I discovered a place to get prescriptions very reasonable for people that do not have insurance. It is COSTCO WAREHOUSE CLUB and they are located in most states.

For example, Zantac at a regular pharmacy cost \$29.95 for 30 tabs at 150 mg. It cost \$12.79 at Costco's. My mom's Xanax at the pharmacy was \$18.49 at the pharmacy and \$8.69 at Costco-the same amount and strength!

My husband, Del, has to use THICK IT 2. I was paying anywhere from \$8.99 to \$14.99 for an eight ounce can. I talked to Costco's Pharmacy and they ordered me a thirty ounce can for \$18.99 Also, I have to use vinyl exam gloves and they cost about \$20. At Costco's, they were under \$8.00 for a box of 100. Another nice thing about Costco is when they order your supplies, they have them the next day. Club membership is \$40.00 but well worth it.

I hope this may be of some use for someone.

Sincerely,
Janet M.

Dear Nancy,

Getting my mother out of the car has been becoming more and more difficult. I recently purchased a Swivel Cushion. The portable cushion allows 360 degree movement in any direction from any seated position. It is great for in and out of the auto. The cover is removable and washable and it costs about \$30.00.

I had also looked into buying an "electric lift chair" but could not afford it. Someone told me about the portable seat lift. The hydraulic action of the portable seat lift raises or lowers a person to and from most chairs. It lifts 75 to 80 % of a person's weight accommodating 70-240 lbs. For more information call the company at 1-800-235-7054.

I want you to know that I read every word of the PSP ADVOCATE! I have learned that my family is not alone suffering through this disease. We are all here to help each other. I learn so much and share it with all our health care contacts as well as family and friends. Keep up the good work! God bless you and the Society for PSP.

Sincerely,

Catherine B.

(Thank you for the kind words!)

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

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

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A GOOD DEATH

By: Alice Kitchen, LCSW, MPA

Director of Social Work and Community Services
The Children's Mercy Hospital
Kansas City, MO 64108-9898

A good death is a strange concept, one not thought about often by those unfamiliar and uncomfortable with life's most predictable culmination. But once one is caught up in the dying process of a loved one, the notion becomes significant, and one becomes acutely aware of the opposite possibility that often exists in health care: dying alone and forgotten in a sterile hospital room, without comfort—a kind of dying that robs the individual and family of the meaning of the life that preceded it.

Almost six years ago, my husband was diagnosed with progressive supranuclear palsy (PSP), a neurologic disease that has no known cause or cure. This disease was horrible for Ron to endure and dreadful to watch. This disease forced us both to consider dying, its meaning, and in doing so we experienced what, to us, was a good death.

What made Ron's final days a "good dying" and a good death, if there is such an experience? Ron's last two days were humane and lacked the tragedy often associated with death. There were several reasons for this. It was clear from the research on his disease that there was no known cure or treatment. This knowledge led to early acceptance and a series of activities that allowed us to focus on Ron's life—on his living—and not get caught making difficult decisions with little time to consider them carefully. Early in Ron's illness we completed our advance directives, do-not-resuscitate declarations, we made burial plans and did our financial planning. With these things completed, we were free to focus on Ron's life while he was alive.

What was "good" about how Ron died? His death was natural; he had little pain, medical intervention, and discomfort. Ron died in our home, surrounded by family and friends, by familiar sounds and smells, by the comfort of pets.

Although Ron had lost his ability to talk, he was fully conscious and communicated through writing and visual cues. One of the most difficult junctures in his illness occurred when Ron began to lose weight because he could no longer chew, swallow, and digest food. His doctor suggested the feeding tube. "It is only humane," he told us. I talked to a nutritionist experienced in ethics and also read about the pros and cons of feeding tubes. Staff from the home health agency gave Ron information on feeding tubes.

Finally, through written notes, he let us know that he did not want the feeding tube. This decision, I believe, resulted in a less painful death. He had no infection or pain sometimes associated with feeding tubes. Ron did not aspirate or contract pneumonia, two common causes of death for persons with PSP. Instead, his body shut down naturally.

Two days before Ron died, our home health aid caring for him called me at work to tell me that he was not doing well and wanted me to come home. On that day, Ron stopped eating and drinking. We called in our hospice nurse who ordered oxygen for comfort and helped our family and friends understand what was happening and what we could expect during the next hours. Ron's breathing was loud, laborious, and echoed through the house. Each breath sounded as if it would be his last.

My sister, Julie, kept vigil with me through the first night. Ron's heavy, loud breathing, she said, reminded her of the breathing process she experienced giving birth to each of her five children—the labor, the agony, the relief when it was over. Throughout the night the sound of Ron's breathing was with us, filling the house.

We played soft, reflective music that seemed in sync with Ron's breathing. The music soothed us all—Ron and those who loved him. When our priest came to give Ron the Sacrament of the Sick, we lit a candle, held hands, and prayed together.

Don and Bill, two of Ron's close friends, came to be with him during that time. Unafraid to see him in total helplessness, they squarely faced their own mortality whenever they looked at Ron. I sense they are stronger for their friendship and for being with Ron in his dying. One beautiful moment came when one of them stood to go, then bent over, kissing Ron's forehead. "You have been a good buddy," he said softly.

I was with Ron the whole time and that was important to me. We revisited old times, told stories, watched home movies. We all said our goodbyes to Ron in our own way; we let him know how much he was loved and that it was all right to let go.

Ron's dying was accompanied by people and sounds and smells that soothed him and not interrupted with intrusive, heavy-duty medical tasks. As he breathed his last breath, he exuded a beautiful smile. In his dying and in the light of that smile, our healing began.

Ron's "good death" meant we were there with him in a very natural way, attending to his final journey.

Ron died January 9, 1997 at 7:30 p.m.

Alice Kitchen: spouse of twenty one years, friend and caregiver—social work administrator, activist in health care insurance reform and issues of the uninsured.

THANKS TO ALL OF YOU! SPSP/NIH Brainstorming Conference

The Society wishes to thank the following persons for their assistance with the planning, coordinating and implementation of the landmark SPSP/NIH Brainstorming Conference.

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A WONDERFUL GIFT!

Dear Society for PSP,

Please accept this contribution of \$250 in honor of my father, Alfred Berger, who is afflicted with PSP. My eleven year old son, Josh, decided that he wanted to help fund a cure for PSP. He asked his friends to make a donation to SPSP instead of bringing him a birthday present for his recent birthday. We are very proud of his love and concern for his Grandpa and others with PSP.

Sincerely,
 Jan Meisel

Party!!!!!!!!!!!!

Josh's 11th Birthday

For: Josh Meisel

Date: March 6th

Time: 11:30-2:30 (lunch will be served)

Place: Brunswick Valley Bowl

My grandpa has an illness called Progressive Supranuclear Palsy. The cause and the cure are unknown, so I would like to help the researchers find a cure. I would like to ask you not to buy me a present, but instead, please bring a donation to the Society for Progressive Supranuclear Palsy (SPSP).





Support Group News

The Society would like to thank the following Support Group leaders who take their time and show their concern by sponsoring support groups, phoning and visiting PSP families. Please reach them at:

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SUPPORT GROUP NEWS

Baltimore Support Group Our Biggest Crowd Ever



At our February meeting, the SPSP conference room was filled to capacity-people attending to hear the presentation of Albert Katz, Doctor of Pharmacy. Dr. Katz focused on the role of the pharmacist in treating PSP and discussed side effects and drug interactions of Parkinson's medications as well as other meds. used to manage PSP. He gave practical tips on accessing drug information, vitamin therapy, eye problems, issues affecting the digestive system, and hints on finding durable medical equipment. The importance of seeking both a pharmacist and pharmacy that offer service and open lines of communication was stressed. Thank you for the important information, Dr. Katz.

NORTHERN VIRGINIA'S SUPPORT GROUP

BY: Audrey Scruggs

Northern Virginia's Support Group held their meeting on March 30. Ten people attended the meeting-three are new members. We missed Bev Clark-she recently moved to New Jersey.

Susan Baggette (author of "Jonathan and Papa"-a book about the adventures of a grandson with a grandfather that now has PSP) shared information that she learned while volunteering at the recent SPSP/NIH Conference. Julian Ewell, whose wife died from PSP, gave some realistic aspects about what to expect when one is dealing with PSP. The Society for PSP supplied printed information about PSP.

It was a difficult-yet wonderful-evening. All of us shared our concerns, helpful hints, and offered our support to one another. Kathy Sands, Wanna Hinchoe, Bob & Kate Baker and Audrey Scruggs provided refreshments. We plan to meet again in May. If interested in joining our support group, please call Audrey at 703-780-2641.



CAREGIVER'S TOOL BAG

By: Bernice Bowers

I have a big ol' satchel
Lying limp beside my bed
And I likewise depleted
Lay down my weary head.

In the morning as I stretch and yawn
I kick it with my feet
I'm reminded that it's empty
And in need of full replete.

I bend down on my knees
To move it from my way
And while I'm there in kneeling form
I then begin to pray.

God, thank you for protecting us
Throughout the long, cold night
And thank you for the day forthcoming
Bathed in golden light.

Along with all the blessings
The days demands are many
But when it comes to coping tools
I really have not any.

I open up my tool bag
And ask you to supply
The love and patience that I'll need
Before the day goes by.

When my supply of strength is thin
Please loan me some of yours
And put a scoop of laughter
To sprinkle on my chores

I'll need some with about me
In case something goes awry
But, if I do run low on that
Please make sure you are nearby.

A bridle for my tongue
That sometimes lopes ahead of sense
A bundle of forgiveness
And kind words for recompense.

I ask you for direction now
Before I stub my toe
On self-will, which you know Lord
Is often my main foe.

And now as Sol climbs higher
And skies are glowing light
I see my bag has overflowed
My heart is feeling light.

I thank you for the many gifts
I'll use throughout the day
To carry out your work and mine
And yes, to even play.

When night shades start to lower
And the days demands do wane
I'll return my empty duffel
To your feet-my rest to claim.

WHAT LESSONS CAN WE LEARN FROM THE ISLAND OF GUAM ABOUT PROGRESSIVE SUPRANUCLEAR PALSY?

Katrina Gwinn-Hardy, M.D.
Mayo Clinic
Jacksonville, Florida

As I recently planned to travel to Guam, I was filled with excitement and interest, but, a fair amount of doubt. I was excited as a young neurologist to have the opportunity to see for myself the disease called "lytico-bodig" by the indigenous people and known as "parkinsonism-dementia complex of Guam" by American researchers. I was anxious to meet Dr. John Steele, known as one of the three individuals that first identified Steele-Richardson-Olszewski Syndrome or Progressive Supranuclear Palsy. Rumor had it that he had moved to Guam to study lytico-bodig in part because of its striking clinical similarities to PSP. However, I was not sure what I would accomplish on the island and hoped that it would be something worthwhile.

After I arrived on the island, I went on to meet over forty people with lytico-bodig and I was struck by several things. Individuals exhibited signs and symptoms of Parkinson's disease, PSP, or amyotrophic lateral sclerosis (ALS). Some had findings of dementia, reminiscent of Alzheimer's disease. All of these diseases can be termed "neurodegenerative diseases" because in all of them parts of the nervous system degenerate or die. My husband, Dr. John Hardy, who also studies neurodegenerative diseases including PSP. "It is clear to me that what is going on is right under our eyes, but we cannot see it," I said to him. I continued saying that lytico-bodig looks like every neurodegenerative disease but is not quite like any one of them exactly. My husband quickly stated, "You are exactly right and that is what everyone else says that experiences this."

In examining these individuals, some of them were indistinguishable from the PSP patients I have seen in my own practice. Yet, most people with PSP have never been to Guam. If the disease is infectious, they could not have caught it from a Guamanian source. Likewise, if this is environmental, how could people on the mainland have been exposed to the same things? If genetic, (which we are currently studying in our lab since most people with lytico-bodig are related to each other) why in the US and Europe do most people with PSP have no affected relatives?

I realized that if lytico-bodig is occurring in other places than Guam, it might be missed. "An isolated case of PSP (or another disease)," might be the conclusion of the physician and that would be correct. On Guam, it is called lytico-bodig because it is occurring on that island. But, it is clear that there is something the two groups could teach us about each other.

I realized that in Guam, in individuals affected with the disease, the nervous system was responding to an insult in all the ways that it could. In the anterior horn cells of the spinal

cord, the nerve cells are dying causing the symptoms of ALS. In the outer layer of the brain (the cortex), the insult leads to dementia and when it occurs in the midbrain it is very much like PSP or PD. I realized that while we have not learned the cause of parkinsonism-dementia-ALS syndrome of Guam (lytico-bodig), we have discovered from these patients that neurodegenerative disease can have a very broad clinical spectrum with marked overlaps between syndromes within a given patient or group of patients where the cause is the same.

We must keep an open mind about diagnosis and their relationships to each other. If there is a family in which both PSP and Parkinson's disease occurs in quite a few numbers and some others have dementia or ALS, this family might also give us clues as to a genetic risk factor for neurodegenerative disease with broad reaching significance. These clues might then help us to learn more about lytico-bodig, which in turn, would teach us once again about the other disease it resembles.

I decided that in my work, in which I seek to uncover hereditary factors leading to parkinsonism, I need to maintain a high level of suspicion for the importance of any neurodegenerative disease in every family-no matter what the diagnosis is of any one person in that family. If I find a family with three or more people with a neurodegenerative disease, I need to try to find out if there are other people in that family with a neurodegenerative disease. I will collect the larger families, in which there are more than three living people with a neurodegenerative disease, especially if more than two generations are living and three generations are known to be affected. In this way, I will try to isolate any genetic factors leading to neurodegenerative disease. In some families, people may have PSP and their immediate family members have PD and extended family members have what is called dementia. I want to be sure to include these families as well as the ones we are already studying with "typical" Parkinson's disease. When the genetic factors leading to neurodegenerative disease are isolated, we can look for similar causes in other people who do not have a family history. When those factors are discovered, we can develop strategies to prevent or fight the disease process.

Lytico-bodig on Guam is like a lens," I told my husband."There is neurodegenerative disease all over the world in individuals with PSP, Parkinson's disease, and dementia. But, on Guam, it is focused in one place. We can use this lens to focus our knowledge and that will allow us to go and tackle the more diffuse occurrence-the more isolated cases."

"Now that," he said, "is a good idea."

1999 RESEARCH GRANT RECIPIENTS The Troxel's Gift to the Society at Work Again!

The SPSP's Eloise H. Troxel Memorial Grant and Fellowship program, made possible by a generous donation from Mrs. Troxel's family, attracted some excellent applications for the December 1, 1998 deadline. The program offers to fund one grant and one fellowship, each a maximum of \$50,000 for one year. However, the Medical Advisory Board asked the SPSP's Board of Directors to find some way to fund what it considered three very deserving applications for the Troxel Grant and one for the Troxel Fellowship. Thanks to a donation from the CAP Foundation, this is possible. The SPSP is pleased that the four funded applications come from four different countries,-the U.S., Canada, Great Britain and Australia. The Society has long welcomed grant applications from researchers anywhere in the world who would make headway against PSP.

IS BRAIN OXIDATIVE STRESS AND DAMAGE A CHARACTERISTIC OF PSP?

By: Stephen J. Kish, Ph.D.

Center for Addiction and Mental Health - Toronto, Ontario

Preliminary data suggest that the brain neuronal death in PSP might be related in part to excessive oxidative stress and damage. The specific aim of our study is to establish whether such oxidative disturbances are present in PSP. This will be achieved through measurement of key indices of oxidative stress and damage in autopsied brain of 17 patients with PSP as compared with brain tissue from a control group carefully matched with expect to age, sex, postmortem time, and agonal status. Our working hypothesis is that brain oxidative changes will be observed in PSP in the direction of oxidative stress and damage. Should we be successful, this postmortem brain data will provide the basis for a major grant application for funding of a clinical trial in PSP of an antioxidant compound (e.g. Centaur CPI- 1189).

IDENTIFICATION OF THE PSP GENE

By: Parvoneh Navas, Ph.D.

Division of Gerontology and Geriatrics
University of Washington, Seattle

Autopsy study of PSP shows neurofibrillary tangles (NFT's) in the degenerating brain cells. The main component of NFT's is tau, a protein associated with the skeleton and internal transport system of the brain cells. Six forms of tau are made in the human brain by assembling various tau sub-components in different patterns. In PSP, the tau filaments in NFT'S are comprised of only the two larger form of tau. We and others studying frontotemporal dementia (FTD) in the gene for tau have shown its cause to be in the gene for tau's genetic code (an "exon"), rather in a part of the tau gene that regulates how the various protein components are assembled- (an "intron"). We ask whether a similar defect in tau DNA could be a contributing cause for PSP.

The goal of this proposal is to identify the role played by the tau gene in initiating and/or modifying PSP. We have worked out the genetic code of the tau gene's exons in 80 PSP subjects and have only detected a single mutation in one subject. We therefore want to check the introns and other regulatory components in and close to the tau gene. To do this, we will compare the human and mouse tau genes. The portions that are held in common between the two species will then be sequenced in 80 people with PSP and 96 people without PSP to determine if any sequence variants (mutations) are associated with PSP.

SYNAPTIC PROTEIN AND PSP

By: Elizabeth B. Mukaetove-Ladinska, M.D.

Roger J. Keynes, MRCP

University of Cambridge, Cambridge, UK

PSP is a progressive degenerative disorder affecting elderly individuals. It is characterized by a variety of clinical symptoms among which the most frequently reported are the motor disturbances (especially rigidity), eye movement problems along with behavioral problems including personality changes, impaired comprehension and forgetfulness. Dementia develops in many PSP sufferers and its frequency and clinical characteristics are not well defined.

The brain tissue of PSP individuals show certain changes to the cells in the deep brain structures. Some of these changes lead to cell lose and it is thought that the process leading to cell dying is responsible for the clinical symptoms of the disease. While this may account substantially for the movement disturbances, the biological substrates of behavioral changes and memory loss are most likely to be associated with more discrete alterations in other brain regions that appear to be unaffected by visible changes to neuronal structures.

To define the causes of memory decline and behavioral problems in elderly PSP cases and to identify chemical changes in the initial stages of the disease, it is important to base the research on well documented clinical information and human brain samples. We propose to test the hypothesis that psychiatric symptoms in PSP are associated with molecular changes to the cells in the brain tissue that appear normal on histology. In particular, we will analyze the changes at synaptic levels in these areas and address if these synaptic changes associated with disordered growth of nerves in the PSP brain and correlate them with the extent of dementia and disturbed behavior.

THE ROLE OF THE THALAMUS IN PSP AND PARKINSON'S DISEASE

By: Jasmine Henderson, Ph.D.; Glenda Halliday, Ph.D.

Prince of Wales Medical Research Institute
Sydney, Australia

People affected by PSP have symptoms such as abnormal vertical eye movements and falls early in the disease which are quite distinct from Parkinson's disease. Furthermore, people with PSP exhibit more neck than limb rigidity and do not have tremor at rest unlike PD. The thalamus is a brain structure essential for normal activation of specialized areas of the cerebral cortex which enable normal movements, emotional and higher intellectual functions. Increasingly, some of the symptoms observed after damage to the thalamus are reminiscent of symptoms observed in PSP such as problems with speech, abnormal eye movements and emotional changes. Very little

Continued Page 18

research has been directed towards studying the involvement of the thalamus in PSP and compare the results to PD in order to investigate a potential contribution of degeneration of the thalamus to some of the distinct symptoms experienced by people with PSP.

MECHANISMS OF NEUROFIBRILLARY TANGLE FORMATION IN PROGRESSIVE SUPRANUCLEAR PALSY

By: Nancy A. Muma, Ph.D.

Loyola University Medical Center, Maywood, IL

Progressive supranuclear palsy is a progressive disease in which neurons in select brain regions accumulate abnormal structures and die. The abnormal structures in the neurons are called neurofibrillary tangles and are composed of tau protein. Normally, tau protein binds with other proteins to help form a skeleton in neurons. The skeleton called a cytoskeleton is involved in many important functions in cells such as maintaining their normal shape. In progressive supranuclear palsy, tau binds to itself to form neurofibrillary tangles instead of binding to other protein to form the cytoskeleton. The mechanism responsible for the self binding of tau into neurofibrillary tangles in PSP is not known. We have data that suggest that the over production of one form of tau and an increase in a bond which crosslinks tau protein may underlie the formation of neurofibrillary tangles in progressive supranuclear palsy. The crosslink is produced by an enzyme named transglutaminase. We will measure the activity of the enzyme and the crosslinking of tau protein by the enzyme in autopsy brain samples from individuals who have died from progressive supranuclear palsy and neurologically normal individuals. These comparisons will allow us to determine if this type of crosslink could lead to the formation of neurofibrillary tangles. The results from this study would form the foundation for testing inhibitors of the transglutaminase enzyme which could prevent neurofibrillary tangle formation, neuron cell death and ultimately be beneficial in the treatment of progressive supranuclear palsy.

INTUIT has done it again!!

We wish to thank the Intuit Corporation for their generous donation of the upgrade to QuickBooks 6. This innovative software enables us to merge accounting information into a wordprocessing (WORD) and spreadsheet (EXCEL) layout. This is the second time that Intuit has contributed software to the Society and we are deeply appreciative of their thoughtfulness and generosity.

CLEVELAND CLINIC DIAGNOSTIC STUDY PEOPLE WITH PSP AND FAMILIES NEEDED

The Movement Disorders Program at the Cleveland Clinic Foundation has developed a battery of tests for the early diagnosis of Parkinson's disease. Close relatives of Parkinson's disease patients often have abnormal results on the test battery. The test may also be helpful in identifying people with PSP and in determining whether that disease also runs in families. The simple test battery evaluates movement, mood and sense of smell. The researchers are interested in testing people with PSP and their healthy sons, daughters, brothers and sisters. Those who wish to participate would have to travel to the Cleveland Clinic in Cleveland, Ohio. The researchers can test family members even if the affected relative cannot travel. In such cases, they would confirm the diagnosis of PSP by talking with the affected family member or his or her physician by phone. For further information, call Dr. Ken Baker at (216) 445-1109 or 1-800-223-2273 ext 51109.

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OUR PSP STORY

This is the story of our mother, a healthy, happy and active person before PSP. She had three children, seven grandchildren, and eleven great-grandchildren. We wanted to send you the story of her illness. Our father devoted his life to take care of her. He strived to make her life as normal as possible. During mother's illness, we met many kind and compassionate people. We pray for a cure for PSP. Enclosed is a donation in the memory of Mary Ann Wilson generously contributed by her neighbors.

Sincerely,

Judy Roberts, Louise Cargo, John D. Wilson, and John L. Wilson (husband)

Our mother's journey with PSP began in the summer of 1993. The family all met together for an outing at an amusement park in Ohio. Everyone was enjoying the day until Mom started to complain about a pain in her foot and that she did not feel well. This was unusual for her to complain. Starting that day, the life of our mother and family would never be the same.

Our mother then began to fall. She began to withdraw, quit driving the car, stopped doing her crossword puzzles and crewel work as well as other activities. Our long succession of doctor's visits began. Unfortunately, all attempts to diagnose were unsuccessful including surgeries, medications, and physical therapy. One physician recommended that we meet with a neurosurgeon. His diagnosis was Parkinson's disease. Now, we all felt somewhat relieved. We knew what we were dealing with and could begin to help Mom cope.

After six months of treatment for Parkinson's disease, our mother's eyes did not move normally. An appointment was made in Pittsburg at the Falk Clinic and it was at this time that the diagnosis of PSP was made.

For the next few years, our father cared for our mother. Dad took care of all her needs while always praying for a miracle. He tried to help mom live everyday to the fullest. Their life was centered around church rarely missing a daily Mass. Dad would take her on shopping trips, to favorite restaurants, read to her and pick up the books on tape that she so enjoyed. The Council on Aging provided an aide to bathe our mother.

Mother's decline gradually continued. She developed lung problems and great difficulties eating and speaking. A feeding tube was eventually inserted. Our father had to make the difficult decision of admitting his wife to a nursing home. Dad now visited the nursing home twice a day and would take her for walks in the wheelchair. He continued to read to her and they attended Mass together at the nursing home. The setting had changed but the love and devotion remained steadfast.

On November 28, 1998, our mother passed away at 8:30 am. Her life had come to an end in the way that she had lived-peacefully.

Our mother will always be honored and cherished by us for the love she showered upon her family, She fought a courageous struggle that she endured without complaint showing tremendous inner strength. Our family will never forget the example of sacrifice and dedication that our father unselfishly displayed as he lovingly took care of our mother. We miss our mother but rest in the knowledge that she is now at peace.

THE STORIES OF PEOPLE WITH PSP

Dear Friends,

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

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

Praying for a cure,

Nancy Brittingham, Editor, The Society for PSP



SPSP/NIH Conference

Micheal Koe (Director of PSP Europe), Dr. John Steele, Ellen Katz, George Jankiwicz (Chairman, SPSP), Dr. Irene Litven, Dr. Lawrence Golbe, Congressman Harold Rogers, Kentucky.

Coming East?? Please Plan A Visit to the SPSP Office.

The SPSP Board and staff will roll out the red carpet for Society friends who have the opportunity to include the SPSP office on their visiting itineraries. The Society office is located only 15 minutes from Johns Hopkins School of Medicine and is only 45 minutes from the NIH. If you are on vacation-please let us know. We will give you a special tour of the office and update you on the Society's activities. We will even feed you!!!

A special thanks to Debby Rodriguez and her family for spending two days with us. It was wonderful spending time together and we appreciate your great efforts in traveling from California to Baltimore- just to visit us and share in the activities of the Society for PSP. Looking forward to our next visit together! God bless all of you.



Debby Rodriguez with her family and Lynda Blute (SPSP Volunteer), Adrienne Bantum (SPSP Bookkeeper), and Marcia Tepper (Administrative Assistant)

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.



Yes! I wish to be included on the Society for PSP's mailing list.

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Thank you for your TAX-DEDUCTIBLE contribution!

A copy of the Society's financial statement is available upon request.

The APDA Challenge

“Long Term Care Insurance”

Those individuals and families who face the challenge of living with Parkinson's disease are always concerned about the problem of making suitable arrangements for adequate and affordable long term care, both in the home environment and in an institution. That is why APDA has followed with great interest developments in the field of Long Term Care Insurance. For the benefit of our members, APDA presents here an impartial overview on the availability, effectiveness and problems of Long Term Care insurance products that are available in the marketplace today. This presentation is based upon three sources: a discussion held in April of this year between APDA leaders and executives of the New York Long-Term Care Brokers, Ltd.; a White Paper by the Long Term Care Campaign, a Washington, DC - based organization; and a news release by Ailsup, Inc., a company that specializes in qualifying individuals for Social Security disability benefits.

THE NEED:

It is estimated that 40% of all people who reach the age of 65 will need to spend some time in a nursing home. Furthermore, there are five times as many people receiving some type of regular care at home than there are residents in nursing homes. Finally, there are a growing number of individuals who are now in “assisted living facilities,” an intermediate solution that is essentially a private residence environment with the built-in availability of certain special care and health-related services and facilities. Each of these three types of care is expensive. One year care in an American nursing home may cost anywhere from \$40,000 to \$80,000. The cost of an assisted living facility, depending on the level of assistance provided, may cost up to \$50,000 a year. The average cost of in-home care is \$20,000 a year.

Paying for such care arrangements for an extended period of time, and often for the rest of a person's life, is one of the major challenges that confronts any family that must deal with a progressive condition such as Parkinson's disease.

THE OPTIONS:

A. GOVERNMENT ASSISTANCE

There are three government-funded programs that can provide significant funds for individuals facing major long-term care costs:

MEDICARE:

Medicare is not currently designed to cover the costs of most long-term care situations. The only type of long-term care that it will pay for is what is known as “skilled” care, that is the more intensive and specialized care usually provided in a hospital-type environment by licensed nurses and other trained health care professionals. However, 95% of all those in long term care environments are receiving what is classified as “custodial” care, which is not covered by Medicare. Unfortunately, most Health Maintenance Organizations (HMO), indemnity insurance plans and “Medicare Supplement” policies similarly refuse to cover “custodial” care.

MEDICAID:

Medicaid is a program that is jointly funded by the Federal government and state governments. The types of coverage offered by Medicaid will vary significantly by state, but many will pay for various forms of custodial care. However, all states require that Medicaid recipients first pass a means test, meaning that they must have exhausted most of their personal funds and resources, effectively impoverishing themselves, before qualifying for Medicaid assistance.

SOCIAL SECURITY DISABILITY:

The Social Security system will provide disability benefits to all individuals in the system who can prove that they have been disabled. The Social Security Administration follows a five-step process to decide whether or not applicants for these benefits are qualified. They must prove that:

1. They are not currently working full time
2. Their ability to work has been significantly impaired for an extended period
3. Their impairment meets certain medical definitions
4. Their impairment prevents them from continuing in their previous job
5. Their impairment or age prevents them from performing any other similar type of job

According to Ailsup, those individuals with Parkinson's disease who suffer significantly from rigidity, slowed movements and/or tremor meet the medical definitions for disability, particularly if they disrupt a person's ability to use their hands and arms for delicate manipulations, or if they impede their ability to walk or stand.

B. LONG TERM CARE INSURANCE

Long term care insurance is specifically designed to help people to pay for the costs of living in a nursing home, assisted living environments and in-home care. However, it is not sold to individuals who are currently suffering from Parkinson's disease. Such insurance may be available to other family members, in which case the following considerations should be weighed:

1. ELIGIBILITY - Most long term care insurance policies are not sold to those individuals who are judged to be most likely to need it. That includes those who are currently disabled in one form or another, those who are diagnosed with a chronic disease, or those whose health histories indicate that they are more likely to need long term care, such as those who have suffered a heart attack, asthma, alcoholism, epilepsy, etc. Furthermore, many insurance companies will refuse to sell long term care insurance to anyone over the age of 80, at any price.

2. AFFORDABILITY - Long term care insurance is so expensive that only an estimated 10-20% of the elderly can afford to buy it. Furthermore, the cost of the insurance rises rapidly with advancing age. According to insurance industry statistics, the cost of a typical policy was: \$1252 per year at age 50; \$2525 per year at age 65; and \$7,675 per year at age 79. (Note again that once you reach the age of 80, most companies will refuse to sell you the coverage.) For that price, in 1991, those who passed the insurance company's medical standards could buy a policy which would pay \$80 a day for nursing home care and \$40 a visit for home care for up to 4 years, including inflation protection. Furthermore, the income of the elderly typically declines with the passage of time, at the same time that their premiums for long term insurance are climbing quickly. This leads to the problem of:

3. LAPSED COVERAGE - According to the US government's General Accounting Office, at least 60% of those who purchase long term care insurance allow their coverage to lapse within 10 years, leaving them totally unprotected against long term care costs. That is the highest lapse rate for any type of insurance sold. Thus, even though about 2.4 million long term care insurance policies have been sold, most are no longer in force, and their purchasers are now left unprotected.

4. INADEQUACY OF COVERAGE - According to the Long Term Care Campaign, most policies now on the market do not include inflation protection, meaning that as health care costs rise, the financial protection value of these policies decreases. This can be particularly troubling in the many cases when there is a lapse of 10 or 20 years between the time when the policies are first purchased and the time when they begin to pay out benefits. According to a recent study conducted by the Alzheimer's Association of 11 leading policies now on the market, someone faced with the need for long term care for much as \$4000 per year. Also, because long term care insurance is a relatively new product, it is still not known for certain whether the premiums being charged are adequate to meet the claims that will eventually be made against these policies. In other words, when the time comes, it is possible that some of the smaller insurance companies selling these policies now may not have the money to pay the claims.

CONCLUSION

There is currently no way that Parkinson's disease sufferers can protect themselves against the costs of long term care. They may be able to qualify for Social Security Disability benefits if they can meet the other stringent qualifications, but private insurance is simply not available to them and Medicare will only pay for "skilled" care. Medicaid will not cover the cost of their custodial care unless they can prove that they are impoverished. For those under age 80 who are not yet diagnosed with Parkinson's disease, and who are in relatively good health, long term care insurance may be available, but only at an extremely high price. Furthermore, it, too, will often fail to provide the necessary financial protection. A recent study found that 38% of married people aged 65-79 are willing to spend as much as 25% of their discretionary income for long term care coverage. But many of these people will not be able to find a policy that they can buy or afford to pay for, and even if they do find one, it may not be adequate to their eventual needs.

RECOMMENDATIONS

The challenge of providing long term care affects a large and growing percentage of the American public, and is apparently beyond the ability of the private insurance industry and current government programs to solve. APDA believes that private insurance policies for long term care now on the market are not adequate to meet the needs of America's elderly. Many people, including Parkinson's disease sufferers who need this coverage the most, cannot buy it at any price. For most of the rest, it is unaffordable, or rapidly will become so. APDA encourages the insurance companies to try to improve their offerings in this field, by making them more affordable and more widely available, and we will continue to report to our members on any progress in this direction. APDA also encourages the efforts of those who are urging the United States government to address this problem in the larger context of the revisions in the Social Security, Medicare and Medicaid systems now being considered. In cooperation with these efforts, we ask all APDA members to raise the issue with their elected representatives. If all of us can work together: individuals, the private sector and the government, APDA hopes that a broader and more effective solution will eventually be found to the national challenge of long term care.

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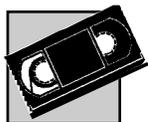
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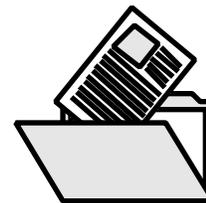
“The Diagnosis of PSP” (#2)

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Pamphlets



“PSP: Some Answers” (#1)

This is a highly regarded, widely circulated discussion of PSP by Dr. Lawrence I. Golbe that is easy to read, and easy to understand. Recently revised, updated, and printed in booklet form. Specify English or Spanish.

“The PSP Advocate” (Newsletter) (#4)

PSP Advocate, the popular quarterly published by SPSP to chronicle its activities, keep you up-to-date on PSP research, provide a support forum, inform readers on participation in research studies, and tell you about self-help mutual help opportunities through advocacy.

“PSP: Swallowing Problems” (#6)

This pamphlet deals with one of PSP's most critical problems. It offers recommendations for managing the symptoms and suggestions for avoiding its dangers. Written by Laura Purcell Verdun, M.A., CCC (Research Speech Pathologist).

“Personality Changes in PSP” (#7)

Some PSP patients undergo changes in personality and behavior that bewilder family members and caregivers. This pamphlet discusses the problem and offers suggestions.

“Helping The Helpers Who Care For People With PSP” (#8)

Dr. Stephen Reich discusses the vital role of the caregiver in PSP. He offers important advice for self care in the interests of the patient.

Eye Movement Problems in PSP (#9)

Dr. David Solomon explains how PSP affects the eye motor system and suggests some treatments.

PSP Fact Sheet (#11)

8 1/2 x 11 easy guide to PSP can be copied and distributed.

“Baltimore Sun” Article (#12)

Reprints of feature PSP article in Baltimore Sun written by Diana Sugg.

Brain Bank Information (#14)

Packet of information about the PSP Brain Bank. Details how to make preparations to make brain donations and help in the search for the cure for PSP.

Physician Referral Cards (#15)

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Questions: Parkinson's Web <http://pdweb.mgh.harvard.edu>

e-mail: SPSP@erols.com

Please e-mail the addresses of any sites relating to PSP or other neurological disorders, caregiving issues, etc. to SPSP@erols.com and we will list them in the next *ADVOCATE*.

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 Outbuildings, The Old Rectory

Wappenham, Nr Towcester, Northamptonshire

NN12 8SQ

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