



PSP Advocate

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

David and Reba Saks, Founders

STATE OF THE SOCIETY



George Jankiewicz, Jr. (SPSP Board Chairman), Joanne Armstrong (SPSP Vice Chairman) thank PSP Volunteer, Sal Biederman.

The Society for PSP has made remarkable gains in all areas of service to PSP families and health professionals. It has touched people throughout the United States, Canada, Europe and Asia via many types of written and electronic communications, but most importantly— person to person and face to face. The Society's informational packets, its 1-800 information and referral services, website, support groups, and presentations at major medical conventions, and symposiums have brought lonely and isolated sufferers together. Its research initiatives offer hope. We have made a difference and will continue, with your generous support, to conquer the challenges of this insidious disease.

The move to larger offices in May, 1998, has been our biggest accomplishment. Now the staff, people affected by PSP, and technology can merge in a superb, high-tech environment that enables us to effectively serve people. We thank Mr. Jay Troxel and Mr. and Mrs. William Budge for their gifts that enabled us to move into our new offices.

Thanks to the generous gifts of 4,800 donors, the Society's income swelled from 1997's \$500,000 to \$700,000 in 1998. This increase does not include the major research gift

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CALIFORNIA PSP SEMINARS

The Society's goal of educating and supporting those who suffer from PSP made huge strides in November when two separate programs were held in California. Held on November 6 in Sunnyvale (northern California) and on November 7 in Anaheim (southern California), the symposia attracted a total of 150 participants—consisting of people with PSP, their care partners and family members, as well as health care professionals. Although both programs treated the same topics—ranging from scientific studies to clinical care to suggestions for dealing with the frustrations of chronic, progressive illness—each location took advantage of the expertise of local professionals to enhance the value of the information received and provide local resources as well.

Co-sponsored by the Society for Progressive Supranuclear Palsy and the Parkinson's Institute, the seminars featured the following speakers:

- "Medical Care for People with PSP"—James W. Tetrad M.D., The Parkinson's Institute, Sunnyvale / Bruce Miller M.D., University of California, San Francisco
- "Current Research in PSP"—Dennis Dickson, M.D., Mayo Clinic, Jacksonville, Florida
- "Living with PSP—Suggestions for Making Life Easier"—Janet Bialson, O.T.R., El Camino Hospital Mountain View / Melinda Guttry P.T., Anaheim Medical Center
- "Speech and Swallowing Problems in PSP"—Laura Purcell Verdun, M.A.-CCC., Research Speech Pathologist-NIH / Crista Byrum, M.A.-CCC, Speech Pathologist, Anaheim Medical Center
- "Help and Hope: Practical Suggestions for Living Well with PSP" facilitated by:
 - Pearl Ann Tabor, R.N., The Parkinson's Institute; Lila Kirkpatrick, Care Partner; Pat Rivera, Family Consultant, Family Caregiver Alliance (Sunnyvale)
 - Don Roberts, person with PSP; his care partner Penny; Carolyn Cheek, care partner; Pat Krueger, care partner; Ed Garza, Family Consultant, Orange Caregiver Resource Center (Anaheim)

Continued Page 4

SOCIETY FOR PROGRESSIVE SUPRANUCLEAR PALSY, 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 PSI, 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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WELCOME NEW SPSP BOARD MEMBERS



Cordelia W Slaughter

Cordelia has been married for 22 years and has one daughter. She has lived in Baltimore, MD for 23 years and has worked in medical publishing 18 of those years. She has been a member of the following professional associations: Baltimore Publisher's Association (BPA), Baltimore Marketing Association (BMA), and the American Medical Publisher's Association (AMPA).

She is active in her church having taught Sunday school for six years and was one of the youth leaders for the United Methodist Youth Group. Cordelia has also been involved in various community activities with most of this time committed to the Baltimore Public Schools of which her daughter attended.



Dale Ferris

Being an Air Force daughter, Dale was fortunate to travel many places before her parents moved back to their hometown of Somerset, MA. She now lives in Fall River, MA with her husband, Ronald and children Marissa and Michael. She is currently Executive Manager of Ferris Realty. She is a member of the Board of Directors of the Bristol Community College Foundation, Board of Trustees for the Home for the

Aged People, Fall River, MA and a member of the Friends of St. Anne's Hospital. Dale helped to organize and promote the Margaret Parker Research Fund for PSP. Her mother, Margaret Parker, was diagnosed with PSP about eight years ago and passed away last August.



Kelley Harrison, Ph.D.

Dr. Kelley Harrison is a licensed clinical psychologist and assistant director of the Child and Family Therapy clinic in the outpatient Department of Behavioral Psychology of the Kennedy Krieger Institute. She holds a faculty appointment as assistant professor at the Johns Hopkins University School of Medicine, Department of Psychiatry and Behavioral Sciences. Dr.

Harrison specializes in the assessment and treatment of childhood behavior problems and functions as a clinician, staff and intern supervisor, administrator and researcher. Born and raised in Brevard County, Florida, she graduated summa cum laude from the Florida State University with a bachelor's degree in psychology. She completed her doctoral training at the State University of New York at Binghamton and her predoctoral internship at the Kennedy Krieger Institute and Johns Hopkins School of Medicine. Dr. Harrison became an active volunteer with SPSP after her father, Joseph Harrison, was diagnosed with PSP in March of 1997. She is the facilitator of the Baltimore support group and became a board member in September, 1998.

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.



Daniel K. Lake

Dan, a professional civil engineer and land surveyor, sold the family business in 1997 and currently works part time as consultant for the firm Lake, Roeder, Hillard, and Beers of Willow Street Lancaster, PA. Born in Dover, N.J., he graduated with a BSCE from Penn State University and has lived his married life of 40 years with Shirle in Lancaster County, PA. Dan is past state president of the PA Society of Land

Surveyors, past chapter president of the PA Society of Professional Engineers, and currently editor of their newsletter, past president of the Willow Street Lions Club, past president of the BSA and past senior warden and vestryman of St. James Episcopal Church, Lancaster. Shirle passed away in April 1998 after being diagnosed with PSP in 1993.



Howard I. Hurtig, M.D.

Dr. Howard I Hurtig is known for his work in the field of Parkinson's disease and movement disorders. He founded the Parkinson's Disease and Movement Disorders Center of the University of Pennsylvania Health System in 1982 at Graduate Hospital in Philadelphia. The Center relocated to Pennsylvania Hospital in July 1997. He received his medical degree from Tulane University and

completed an internship and a year of residency in Medicine at New York Hospital-Cornell Medical Center. After a residency in Neurology at the Hospital of the University of Pennsylvania, he joined the Penn Faculty in 1973. In 1981, he became the Chair of Neurology at Graduate Hospital where he worked until July 1997, when he moved to Pennsylvania Hospital. He was appointed Chair of Neurology at Pennsylvania Hospital in May and Interim Chair of neurology for the University of Pennsylvania Health System in December 1998.

Dr. Hurtig is Professor of Neurology at the University of Pennsylvania School of Medicine. He is a member of the American Academy of Neurology, the American Neurologic Association and the Movement Disorders Society. Dr. Hurtig has authored or coauthored 100 original papers, abstracts, reviews and book chapter. He has co-edited three books: *Cerebral Vascular Disease* (with Martin Reivich), *The Comprehensive Management of Parkinson's Disease* (with Matthew Stern and *Medical Clinics of North America Parkinson's Disease and Parkinsonian Syndromes* (with Matthew Stern).



Jennifer Shattuck

Jennifer Shattuck became interested in becoming involved with the Society for PSP when her father was diagnosed with the disease. With her family living away in California and Jenny in Maryland, she was determined to find a way to help long distance and is now serving as a member of the SPSP Board. Jenny is the Executive Director of Ladew Topiary Gardens, an historic house and gardens operated as a

non-profit organization in Monkton, Maryland. She has served on several other non-profit boards including environmental organizations and independent schools in both California and Maryland. Jenny is a certified public accountant (gone astray in the gardening world!) holding an MBA from New York University and graduated from Williams College in Massachusetts.

CALIFORNIA PSP SEMINARS

(Continued from page 1)

The panel presentations were particularly well received in both locations, primarily because of the honest and practical points made by participants. One of the highlights was a touching testimonial made by Don Roberts, who suffers from PSP, regarding his wife Penny and her years of loving care for him. Both locations featured representatives from a state-wide network of agencies devoted to helping and supporting caregivers of those with neurological illness or brain impairments. Pat Rivera, representing Family Caregiver Alliance of San Francisco, and Ed Garza from Orange Caregiver Resource Center provided resources available for those who care for someone with PSP.

The positive evaluations which the seminars received pointed to the importance of offering both scientific information and practical help. The Society hopes to plan further seminars in other parts of the country in future months; thus, the experience gained from these two "pilot" programs will be invaluable.



Laura Purcell Verdun (SPSP Board Member) Pearl Ann Tabor (The Parkinson's Institute) and Carol Marchi (SPSP Board Member)



Guests at the Symposium



Dr. Dennis Dickson, (M.D., Mayo Clinic, Jacksonville, FL) and Dr. James Tetrund (M.D., The Parkinson's Institute, Sunnyvale, CA)



Carol Marchi and Rosemary Taylor (PSP Support Group Initiator and Communicator)



Carol Marchi, Ellen Katz (SPSP Director), Dr. Dennis Dickson, Dr. J. William Langston (The Parkinson's Institute) and Carole Cassidy (Development Director)

EMOTIONAL INCONTINENCE IN PSP

Emotional incontinence is the inability to inhibit emotional expression. Some patients with PSP abruptly cry or less commonly, laugh out of context. This may happen spontaneously or be triggered by a minimal stimulus, often one that is neither sad nor happy. Emotional incontinence results from dysfunction of the frontal lobes of the brain in PSP which serve to keep certain inappropriate behaviors under wraps. If spontaneous crying or laughter is infrequent, short-lived, and not bothersome, no treatment other than reassurance that this is part of the disease and not necessarily a sign of sadness or happiness, is necessary. Yet when sudden displays of emotion occur frequently and are bothersome, medication is available to help. The most commonly used medications are tricyclic antidepressants such as amitriptyline (Elavil), or nortriptyline (Pamelor).

The Director's Doings . . .



Ellen Pam Katz
Director, SPSP Inc.

I wish I had five pairs of hands and five mouths all emanating from one body. I might look bizarre but then I could efficiently accomplish my always-expanding job (and not raise the personnel budget!). However, reality is what it is--- we currently require more board and volunteer participation along with more professional staff.

We are fortunate to have 15 board members with access to financial and organizational resources. More importantly, they are charged with developing the strategic plan that will focus the Society's efforts for the next 3-5 years.

Our staff is growing with the addition of Marcia Tepper as Administrative Assistant. Marcia assumes the position of office manager as well as handling many of my administrative duties. For the past three years, Marcia was the administrative assistant for the administrator of the Wilmer Eye Institute at Johns Hopkins University. Prior to that, she was the office manager for Gynecologic Specialties, also at JHU. Her

organizational, interpersonal and computer skills are impressive. We also welcome Bonnie Barker as Administrative Secretary. She was with JHU's Department of Epidemiology for the past nine years doing database management and research. Congratulations to Adrienne Bantum, the Society's bookkeeper who since October, 1997 has fulfilled her duties as an independent contractor. Thanks to her ability to be flexible, handle her job from home and via modem, the bookkeeping has been impeccable. Adrienne now joins us as a full-time employee.

As we grow the Society, we grow as a family-expanding our contacts and our network of supporters. We are a large and loving family who care about each other and persons with PSP their families and caregivers.

Watch for the strategic plan as it will be an opportunity for the Society family to keep branching out to find a cause, cure and treatment for PSP as well as provide critical informational and outreach services. It's on the way!

Sincerely,
Ellen Pam Katz
Director



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

Name _____

Address _____

City _____ State _____ Zip _____ Country _____

Phone _____

Fax _____

E-mail _____

Person with PSP _____ Family _____ Physician _____ Other _____

Name of Family member with PSP _____

Enclosed, please find my contribution to help support the mission of the Society.

\$25 Supporter _____ \$50 Sponsor _____ \$100 Patron _____ \$250 Silver Patron _____

\$500 Gold Patron _____ \$500-\$1000 Gold Benefactor _____

Charge to VISA _____ Mastercard _____ American Express _____

Account No. _____ Expiration Date _____

Signature _____

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

Thank you for your TAX-DEDUCTIBLE contribution!

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

What About Treatment With Medication?

Lawrence I. Golbe, M.D.

Professor of Neurology

University of Medicine and Dentistry of New Jersey

Robert Wood Johnson Medical School

Chairman-SPSP Medical Advisory Board

Several medications, all available only by prescription, can help PSP in some cases.

Sinemet. This is the brand name for a combination of levodopa and carbidopa. Levodopa is the component that helps the disease symptoms. Carbidopa simply helps prevent the nausea that levodopa alone can cause. When levodopa came along in the late 1960's, it was a revolutionary advance for Parkinson's but, unfortunately, it is of only modest benefit in PSP. It can help the slowness, stiffness and balance problems of PSP to a degree, but usually not the mental, speech, visual or swallowing difficulties. It usually loses its benefit after two or three years, but a few patients with PSP never fully lose their responsiveness to Sinemet.

Some patients with PSP require large dosages, up to 1,500 mg. of levodopa as Sinemet per day, to see an improvement, so the dosage should be pushed to at least that level; under the close supervision of a physician, unless a benefit or intolerable side effects occur sooner. The most common side effects of Sinemet in patients with PSP are confusion, hallucinations and dizziness. These generally disappear after the drug is stopped. The most common side effect in patients with Parkinson's disease, involuntary writhing movements ("chorea" or "dyskinesias") occur very rarely in PSP, even at high Sinemet dosages.

Patients with PSP should generally receive the standard Sinemet (levodopa/carbidopa) preparation rather than the controlled-release ("Sinemet CR") form. The CR form is absorbed from the intestine into the blood slowly and can be useful for people with Parkinson's disease who respond well to Sinemet but need to prolong the number of hours of benefit from each dose. In PSP, however, such response fluctuations almost never occur. Because CR is sometimes absorbed very little or erratically, a poor Sinemet CR response in a patient with PSP might be incorrectly blamed on the fact that the disease is usually unresponsive to the drug. Such a patient might actually respond to the standard form, which reaches the brain in a more predictable pattern.

Dopamine receptor agonists. There are four such drugs on the market - Parlodel (generic name, bromocriptine), Permax (pergolide), Mirapex (pramipexole) and Requip (ropinirole). These are helpful in most people with Parkinson's disease, but in PSP, they rarely give any benefit beyond that provided by Sinemet. However, a large trial of Mirapex is under way at a number of North American medical centers to better assess that drug's benefit against PSP. There is also a possibility that Mirapex (and possibly the other drugs in this group) may help slow the long-term progression of PSP. The current trial will also assess this exciting possibility.

The main possible side effects of these drugs are hallucinations and confusion, which can be more troublesome

for PSP than for Parkinson's, excessive involuntary movements, dizziness and nausea.

Antidepressants. Another group of drugs that has been of some modest success in PSP are the antidepressant drugs. The anti-PSP benefit of these drugs is not related to their ability to relieve depression. The best antidepressant drug for the movement problems of PSP is probably Elavil (generic name, amitriptyline). It has been used against depression since the early 1960's. The dosage should start at 10 or 25 mg. or less once daily, preferably at bedtime. It can be increased slowly to at least 100 mg. per day (taken divided into at least two doses) for an adequate trial in PSP. Elavil is also a good sleep medication for elderly people and may provide this benefit in PSP if taken at bedtime. One important side effect in some people is constipation. Others are dry mouth, confusion and difficulty urinating (in men).

Symmetrel. This drug (generic name, amantadine) has been used for Parkinson's since the 1960s. Because it affects more than just the dopamine system, it can be effective in PSP even if Sinemet is not. It seems to help the gait disorder more than anything else. Its benefit generally lasts only a few months, however. Its principal potential side effects are dry mouth, constipation, confusion, and swelling of the ankles.

Experimental drugs. In the past ten years, research trials have been completed with the drugs physostigmine, idazoxan and methysergide. While each showed initial promise and prompted an optimistic article or two in a prestigious neurological journal, none has proven effective enough to justify use in patients. The most recent trial was of efaroxan, a drug similar to idazoxan, but it, too, proved ineffective. Aricept, which is modestly useful against the dementia of Alzheimer's disease, is being tested for the mental difficulties of PSP.

Botox. A different sort of drug that can be useful for people whose PSP is complicated by blepharospasm is Botox (botulinum toxin). This substance is produced by certain bacteria that can contaminate food. Its poisonous action occurs because it weakens muscles. A very dilute solution of the toxin can be carefully injected by a neurologist into the eyelid muscles as a temporary remedy for abnormal involuntary eyelid closure.

Botox can also be used for involuntary turning or bending of the head that occurs in PSP, but injection of Botox into the neck muscles can sometimes cause slight weakness of the swallowing muscles, which are nearby. In PSP, where swallowing is already impaired in many patients, caution should be used when considering use of Botox in neck muscles.

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

SPSP RETREAT

In an effort to address its goals and objectives for the 90's while planning new strategies to meet the challenges of the 21st century, the Society for Progressive Supranuclear Palsy held a one day Board Retreat in conjunction with its January Board of Directors meeting. Suzanne Dagar, CFRE, Consultant, Services for Non-Profit Organizations and development consultant for the Society, facilitated the retreat. Generally, a board retreat focuses on one or two main goals and a few objectives for achieving these goals. Organizational Development was determined to be the first priority for the Society. The Board wanted to identify issues and needs of the organization and plan strategies for SPSP's growth and development.

The retreat began with a review of the mission and a brief history of the why, how, when and who created the organization. This overview highlighted the commitment of the volunteers and the progress and success of the Society for Progressive Supranuclear Palsy since its inception nine years ago. Guest speaker, Harvey W. Cohen, National Director of Development for the Foundation Fighting Blindness, gave insight to the challenges and opportunities for expanding programs and fundraising efforts across the country. As a national organization, providing support to people with PSP and their families worldwide is a critical issue for SPSP.

The members of the board divided into small groups to discuss the organization, its activities and current needs for the future. At the conclusion of the retreat, the participants determined four essential issues to address in a strategic plan: National Presence, Board Development, Research, and Education.

Small member task groups made up of members of the Board are currently working on these issues. The objective is to have a strategic plan ready for action within the next six months. This plan will convey the vision, mission and program goals

that inspire people to support SPSP in its mission to: provide information, education, support and advocacy to persons with PSP and their caregivers, and to educate physicians and allied health professionals about PSP and how to improve patient care.

The PSP ADVOCATE will keep you informed and up to date with the progress of the strategic plan. If you have any suggestions or comments, please contact Ellen Katz, Director, at the Society for Progressive Supranuclear Palsy.



Harvey W. Cohen, National Director for the Foundation Fighting Blindness, addresses the SPSP Board of Directors



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

The Society Thanks “Retiring” Board Members

The Society for PSP would like to thank our “retiring” board members. Each has generously shared their time, talents, and treasures in our mission to promote and fund research in to finding the cause and cure for PSP, provide information, education, support, and advocacy to persons with PSP, their families and caregivers and to educate physicians and allied health professionals on PSP and how to improve patient care. Thank you for your hard work and dedication!

Laura Purcell Verdun

Laura Purcell Verdun joined the SPSP Board in 1995. She has been a speech language pathologist in the Johns Hopkins University Department of Otolaryngology-Head and Neck Surgery since 1991. Additionally, she conducts research in the Voice and Speech Section of the National Institutes of Health. Laura has written our informational pamphlet: “Swallowing Problems in PSP.” She graciously volunteered as the Board Secretary. Her skills were appreciated in planning patient symposiums, and serving as a resource person or speaker. She served on both the Executive and Nominating Committees. She is maintaining her involvement with the Society through participation in local support groups and planning the 1999 PSP Fall Symposium.

Claude Vannoy

Claude Vannoy joined the SPSP Board in 1995 when his beloved wife Margaret was battling PSP. During this time, the organization was at a crucial juncture in its development. Claude and Margaret’s generous gift of \$50,000 enabled the Society to fund more research grants in larger amounts. The Bylaws Committee and the Development Committee benefitted from Claude’s knowledge, experience, and wisdom. Since Claude has maintained an interest in the financial structure and soundness of the Society, he plans to continue to serve on the Budget Committee.

Richard Janney

While Richard Janney has served on the Board since 1993, he has really been part of the “kitchen table” beginning of the SPSP; his office copier duplicated many early newsletters and fact sheets. Whenever there was a need for Board members to travel from Baltimore to Washington, DC to meet with Directors at NIH, to network with other organizations involved in Brain Awareness Week, to lobby on Capitol Hill for increased NIH funding, to push forward legislation for movement disorders centers or the Udall Bill, Richard was there and brought others. Richard served on the Fundraising and the “Climb for a Cause” Committees.

Helpful Hints

Dear Nancy,

My husband, Del, was diagnosed with PSP two years ago this past November. In January of 1998, his speech became more impaired and his balance problems worsened. Swallowing difficulties continue to increase. When Del was losing his balance, I had a gait belt which really was of little help. I then found a physical therapy belt in a North Coast Medical Catalog. This has been my life line in helping my husband. This belt has been tested to 1,000 pounds. The para-medics that have been called during our emergencies have been very impressed with it and use it to transfer to the gurney. Within this catalog, I also found a Deluxe Shampoo Basin that is very comfortable for him during his bed bath.

In the Sears Home Health Care Catalog, I found the Seat Scale to be very handy as well as the toilet seat riser; as it is the only one I could find that would still allow the lid to go down. I also have my 89½ year old mother suffering with Alzheimer’s disease living with us. The riser is very secure and does not move.

With Del’s swallowing problems, I have found that THICK IT II is better as it is concentrated and goes twice as far as some of the other thickeners.

The **North Coast Medical Catalog** can be ordered at 1-800-821-9319. There is same day shipping if ordered by 4pm. The **Sears Home Health Care Catalog** can be ordered at 1-800-326-1750.

I hope these hints will be of help to others.

Sincerely,
Janet M.

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:

Nancy Brittingham, Editor
PSP Advocate

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Suite 515
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Baltimore, MD 21208

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Living with the Enemy

by
Susan K. Baggette



I am writing this in my home office, surrounded by reminders of what I cherish most. Photographs of my family. Copies of my favorite children's books. There's also a little container of dirt. I scooped it up a few years ago from the banks of the Delaware River at the place where General George Washington crossed that fateful Christmas night in 1776 to get his rag-tag army to Trenton and defeat the Hessians. That night a terrible storm raged. Ice and wind cut through the men's threadbare clothing. Some were barefoot, their footprints leaving thin ribbons of blood on the snow. Finally reaching the New Jersey shore, they still had a nine-mile march. All but three of those 2,000 men made it to Trenton where, as Washington had suspected, they completely surprised the Hessians and won the battle without losing a man. It was a victory, and now I'm praying for one.

My husband, Hal, was diagnosed in November 1997 with PSP. Before then, there were signs that something serious was wrong. He complained of double and blurred vision. Always very precise, he became intermittently confused about numbers, time and directions. During his career as an officer in the Air Force he frequently served as flight navigator. Now he couldn't remember how to get to our local Walmart. He had always worked tirelessly in the garden, remodeled our house and worked on complex projects on his computer. Now he was always tired and complained that his neck, arms and legs ached. He said every step he took felt like he was walking through molasses. He felt dizzy, often losing his balance and banging into walls. Then there was the day he tripped down the stairs, grabbing for the banister which he ripped right off the wall. He landed at the bottom of the steps still clenching the banister, as if he was about to pole vault.

We were scared. Our family physician sent us to a neurologist who sent Hal for blood tests, MRIs, CAT scans, EEGs, and finally a PET scan. I still have the notes I took in the neurologist's office. When he suggested PSP that chilly November day, we said "P-S-What?" I carefully wrote down: progressive supranuclear palsy. Those three words have gradually taken command of our lives, and now we are living with the enemy.

When Hal and I retired in 1996, we enthusiastically started a children's book publishing company we called The Brookfield Reader. We began a toddler board book series about our grandson, Jonathan, who was with us two days a week while his Mommy worked. The Jonathan Adventures were a perfect blend of our activities together as a family, exploring local places like the fire station library and airport. PSP was certainly not one of the "places" we intended to explore.

I think our reaction to Hal's diagnosis was pretty typical. We gathered information from the internet and library. We began traveling to Baltimore to see Dr. Hyder Jinnah in the Neurology Department at Johns Hopkins. We thought with proper diet, medication, exercise and support we could conquer PSP, after all, Hal was strong. He was determined. We were in denial. As the weeks turned into months Hal was no longer able to work in the garden, spend hours at his computer or swim at the local pool. We became frustrated and angry.

Now every day is a challenge. Often it's a struggle. We recently took a week-end trip to Philadelphia to the American Library Association's mid-winter exhibit with our business partner and Hal's nurse. The logistics of traveling with a wheelchair, getting on and off a shuttle bus, and maneuvering through crowds was exhausting. But it was exhilarating, too. That weekend, we beat the enemy and had fun doing it.

Hal and I visited the Society for PSP's headquarters in Baltimore for the first time last December and met with Ellen Katz and her staff. My past professional association working for not-for-profit organizations was instantly aroused. Efficiency, prompt response to members' inquiries and compassion abound within those 1,000 square feet of new office spaces. Now when we feel especially down-in-the-dumps, we know where to go to replenish our spirits. The Society has been an oasis in our storm. Someone is always there to listen, offer hope and help us network with physicians, therapists, other people with PSP and caregivers. We've also learned so much from articles in the PSP Advocate.

After our December visit, Hal wondered how we could help the Society raise money that is so necessary to find a cure for this insidious disease. We established a fund in his honor and solicited contributions through our Christmas letter to 200 friends, family members and business associates. At this writing, Hal's fund has received more than \$1,200 in contributions.

Then we had another idea: publish Jonathan and Papa as part of our toddler board book series. It was an arduous task, taking several photo shoots, using ten rolls of film and practicing lots of patience. A sticker on the cover of each book states that wherever "Jonathan and Papa" is sold a contribution will be made to the Society for PSP in Hal's honor. The inside back cover gives readers information about PSP and how the public can contribute to finding a cure. Best of all, every page is filled with wonderful activities that Jonathan and Hal still share together, from racing to the playground in their respective vehicles to drawing together at the kitchen table. There is no weeping in this book just Jonathan's joy of sharing his day with Papa and a poignant vision of Papa being well enough to stand up and march in a dreamland parade "just like me."

We have decided to expand our offer to solicit contributions. A contribution to the Society for PSP will be made from the purchase of any "Jonathan" title in our series as a direct result from the flyer inserted in the PSP Advocate. We are convinced that these funds can further research to help overcome the disastrous effects of this disease. This is our mission.

Like Washington's monumental effort before the Battle of Trenton, we intend to cross perilous waters, march on the other side and live with this enemy. Our fight, by no means, is over.

Meet the Boss

Lynda Blute's golf skills are impressive. She boasts a 17 handicap and shoots in the 80's. She hones her skills at least four times a week as weather permits with her husband Bill at a golf course near her Annapolis home. She has only considered part-time work so that she can play golf full time, but why won't she golf on Thursdays?



Each Thursday since May of 1997, Lynda assumes the role of "Boss", as the SPSP staff fondly call her at the SPSP office.

As volunteer extraordinaire, Lynda assembles and mails the informational packets, special requests for brochures, doctor's packets and videos to persons with PSP, caregivers, families and health professionals. In two years, she has mailed over 5,000 packets and 2,000 informational requests. She is always there for the Society, rarely missing "coming to work."

Her commitment is exemplary considering that she drives two hours daily and covers 80 miles from her Annapolis home to the new SPSP office. (60 miles to the JHU office). Since May, 1997 she's contributed 400 volunteer hours, driven 200 hours while commuting over 7,000 miles. Now, that's a volunteer!!

What is Lynda's motivation? Lynda explains, "I do this

to honor my friend, Jo Webber, a victim of PSP. When I married Bill and moved from England to California, I was introduced to Jim and Jo Webber. They became my family and never allowed me to be lonely. Our friendship has endured for 20 years even after we moved to Annapolis."

Lynda continues, "On occasion, I would call John Ricker, a PSP caregiver who has maintained records by communicating with many other PSP families. He recommended I make contact with the SPSP office in Baltimore. In April of 1997, I came to the Johns Hopkins Outpatient cafeteria to meet Ellen Katz for lunch. She recruited me to volunteer while I was enjoying the most delicious bowl of carrot soup and I was hooked!"

Lynda recommends everyone to volunteer because of "its intrinsic value". I feel like I am doing something for Jo. SPSP Director Ellen Katz feels that Lynda's dedication has contributed to the Society's success. "We depend on her service as well as her jokes and wit that keeps us all laughing on Thursdays.

The Society will honor Lynda by designating May 1 as "Lynda Blute Appreciation Day." To acknowledge Lynda's contributions, won't you send your written expressions of thanks to the SPSP office? We will put them in a special SPSP mail sack and present them to her on May 1. Although your greetings can't compare in numbers to what she has mailed out, she will appreciate your letters. Please e-mail them to spsp@erols.com, or fax to 410-486-4283, or mail to Lynda Blute at the SPSP office. Address your mail to "LYNDA BLUTE, Society for PSP, 1838 Greene Tree Rd. Baltimore, Md 21208. Let's fill those sacks for the lady who has made a real difference-- thank you Lynda!!

CANADA PSP SYMPOSIUM

PROGRESSIVE SUPRANUCLEAR PALSY RESEARCH AND PATIENT CARE

A Seminar for Persons with PSP, Care Partners, and Health Care Professionals

Sponsored by the Society for PSP and The Parkinson's Foundation of Canada

Sunday, April 18, 1999 • 10 A.M.-3 P.M.

Location: Inn on the Park, 100 Eglinton Ave., E., Toronto, Ontario, Canada M3C 1R8

PROGRAM:

- Dennis Dickson, M.D., Mayo Clinic, Jacksonville, Florida, Director, SPSP Brain Bank supported by the Eloise H. Troxel Memorial Fund "*Advances in PSP Research*"
- David Zee, M.D., Professor, Neurology, Ophthalmology & Otolaryngology, Johns Hopkins University School of Medicine "*Eye Movement Problems with PSP*"
- John Growdon, M.D., Professor, Neurology, Harvard Medical School "*PSP-Behavioral Changes*"
- Mark Guttman, M.D., FRCPC, Assistant Professor of Medicine and Psychiatry, University of Toronto, Center for Movement Disorders "*PSP - A Medical Perspective on Diagnosis and Treatment*"

Accommodations: Inn on the Park (416)444-2561 (Ask about special rates)

For More Information: Contact Kim Anderson, Office Manager, The Parkinson's Foundation of Canada 1-416-9320315

Fee: \$25 per person. Scholarships available (lunch included):

PAYMENT BY CHECK:

1. If you reside in Canada-make check payable to: "The Parkinson's Foundation of Canada"
2. If you reside in the United States-make check payable to: "The Society for PSP"

Mail registration form and check to: The Parkinson's Foundation of Canada, 55 Eglinton Ave., E., Suite 400, Toronto, Ontario, Canada, M4P, 1G8 (Please copy registration form for each person attending.)

CANADA PSP SYMPOSIUM REGISTRATION

Name _____

Tel.# _____ Street Address _____

City, State, Zip, Country _____

of People _____ Total Amount of Check _____ I Request a Scholarship _____

**The Society for PSP
Recognizes and Thanks
SPSP Chairman of the Board,
Stephen G Reich, M.D.
1991-1998**



Stephen G. Reich, M.D., Associate Professor Neurology, Johns Hopkins University School of Medicine, served as SPSP's first Chairman of the Board. Dr. Reich has nurtured the organization and watched it grow from a mailing list of 60 to one of 9,000, a Board of Directors from 5 to 15, and an annual budget from a few hundred dollars to \$700,000. He has written the informational pamphlet

"Helping the Helpers Who Care For People With PSP" and has been a featured speaker at each of the biennial symposia since the first one in 1991.

Although he is stepping down as Chairman of the Board, Dr. Reich will still be involved with the organization as a member of the the Education Committee and Nominating Committee.

In recognition of his valued leadership, the Board has given him the title of Chairman Emeritus.

**Neurology Branch National Institutes of
Neurological Disorders & Stroke
National Institutes of Health
Seeks People with a Diagnosis of
Progressive Supranuclear Palsy for a
Clinical Drug Trial**

- We are looking for patients between the ages of 40 and 80 who are diagnosed with PSP but physically healthy to participate in upcoming clinical trials.
- Referred patients will receive thorough neurological evaluations, as well as laboratory tests at no cost.
- If patients are suitable candidates for the Therapeutic study, they will be offered participation. Travel and hotel expenses for the therapeutic part of the study will be covered. The therapeutic study is an outpatient study requiring 4 visits of 2 to 3 days to the National Institutes of Health over the course of 4 months
- Referring physicians will be appraised of the results of our evaluations and clinical trials. The National Institutes of Health team has expertise in the evaluation and management of patients with PSP.

If you are interested in being considered for the therapeutic study, please have your physician mail or FAX a referral letter, including copies of pertinent medical records, to the Principal Investigator.

Irene Litvan, M.D.
NIH/NINDS/MND

Federal Bldg., Room 714 • 7550 Wisconsin Ave.
Bethesda, MD 20892-9130
Fax: 301-496-2358

NEW MEDICAL EQUIPMENT EXCHANGE PROGRAM

The National Organization for Rare Disorders, Inc. (NORD) announces the new *Medical Equipment Exchange*. The program's purpose is to provide people who have inadequate health insurance with a means to purchase needed medical equipment. This includes, but is not limited to, items such as telecommunication equipment for individuals who are hearing or speech/language impaired, hospital beds, wheelchairs, toiletting equipment, and even canes and crutches.

While many people have used medical equipment that is no longer needed by their family, the problem has been linking potential buyers and sellers. WORD, via the Internet, will forge this link through the *NORD Medical Equipment Exchange*. Eligibility is not limited to only those who are diagnosed with disorders but is available to anyone with a medical need. Information about this program can now be found on the Internet by accessing NORD's home page at <http://www.NORD-RDB.com~orphan>

Exchange information may also be obtained by writing to NORD, P.O. Box 8923, New Fairfield, CT 06812. NORD acts as the program's facilitator and assumes no responsibility for the quality, performance, or medical results of the equipment. All sales are the individual responsibilities of

buyer and seller.

NORD was established 15 years ago out of sheer necessity to help those with rare or "orphan" diseases. An orphan disease is one that affects a small number of people - fewer than 200,000 Americans. However, when multiplied by the more than 5,000 different orphan diseases, 20 million people in the U.S., or one in 12, are affected by these illnesses.

NORD is a federation of more than 140 nonprofit health organizations dedicated to serving people with rare disorders. These illnesses unheralded by telethons and famous spokespersons, nonetheless are very real to millions of Americans. Users of NORD's services are those diagnosed with rare disorders, their families, medical professionals, and the general public, to name just a few.

NORD is about people. It's for people and supported by people. NORD is a private charity relying solely on individual donations. The *NORD Medical Equipment Exchange* is a unique new program aimed at helping people with disabilities to find the help they need. People with used medical equipment that is no longer needed are urged to send their ads to NORD via the Internet, e-mail, or regular mail.

HOW YOUR PSP RESEARCH DOLLARS ARE SPENT

How does the Society find and choose research projects to support?

How do researchers communicate their findings to other researchers?

Lawrence I. Golbe, MD, Chairman of the Society's Medical Advisory Board responds:

SPSP GRANT PROGRAMS

In 1998, the SPSP awarded \$209,000 in grants. It has two grant programs. The "regular" grants are awarded twice a year, with application deadlines on April 1 and October 1. The maximum award for these is \$20,000 for one year's work. The number of grants awarded is determined by the number of deserving applications and the money the Society has available at the time. The other grant program, with deadline December 1, is named after Eloise H. Troxel, whose husband endowed the program in her memory. Only one Troxel Memorial Grant is awarded each year, with a maximum of \$50,000 for a year's work. The Society also awards an annual Troxel Memorial Fellowship. That sum of \$50,000 is to be used for the salary and benefits of a young researcher newly finishing training. The application is made by a "mentor," an established, senior researcher who generates the scientific idea and who would supervise the awardee.

The availability of PSP grants is announced in neurological journals, in the SPSP's website, at its booth at professional meetings, and in publicly available databases of sources of medical research funding. At least as effective is word-of-mouth among researchers. Whenever I give a lecture or presentation to other researchers, I mention the grants program and my e-mail address. I also make personal contact with productive researchers in the areas related to PSP, encouraging them to put together a PSP project and apply for a grant.

GRANT APPLICATION PROCESS

Nearly all of the applicants are faculty members at medical schools. About a third of the grants funded by the Society to date have been outside the U.S. The completed application itself comprises a three-page description of the proposed work, including a brief summary of previous relevant work, an explanation as to why the new project is needed and a research plan. The latter includes the source of patients, schedules of treatments, laboratory techniques and statistical tests. The applicant must also include a detailed budget, a lay-language summary of the proposal for possible publication in the Advocate, and a two-page curriculum vitae listing previous publications in the similar areas or that used similar techniques.

GRANT EVALUATION PROCESS

The applicant sends me 12 copies of the completed application packet. I forward a copy to each of the 10 other members of the Medical Advisory Board and one to the SPSP office. I enclose a rating form that requests a score from 1 (worst) to 5 (best) on each of the following five points: scientific interest, originality, appropriateness of the proposed methods, ability of the applicant to perform the work, and appropriateness

of the budgetary request. The form includes a space for freeform comments.

The MAB members fax their completed ratings to me within 6 weeks. I average the scores for each grant, omitting the budget score from the calculation. Applications with an average score of at approximately 3.75 or higher are considered of sufficient merit as to be "fundable." I pare down the budgets as necessary, using the MAB's budget scores as a guide. I then discuss with the Board of Directors how much money the SPSP is able to make available for research at that time. We then fund as many of the fundable projects as we have money for, starting with the highest-scoring. In our letter to any deserving but unfunded applicants, we explain that the application was of sufficient merit but that our finances did not permit its funding at that time and that a re-application is welcome. The whole process takes 3 months, a very short turnaround time, made possible by the small size of our organization, which has not developed a cumbersome bureaucracy. The NIH, by contrast, requires at least 9 months to evaluate and fund a grant.

FINANCIAL NUTS AND BOLTS

Half of the monetary award is sent at the start of the grant period. After I receive a satisfactory six-month progress report, another 25% of the award is sent. After I receive a satisfactory final report, the last 25% is sent. The checks are sent not to the researchers themselves, but to financial officers of their institutions, who makes the money available to the researcher through the institution's usual purchasing mechanism.

Like most small, charitable organizations, the SPSP does not pay "indirect costs." This is a bonus amounting to anywhere from 20% to 75% of the actual cost of the research that is paid to the researcher's institution for administrative costs. The SPSP's funds are used mostly for technicians' salaries, expendable laboratory supplies and small durable equipment items. We do not allow our grant money to be used for salary for the principal researcher or for large items of durable equipment.

PROTECTING VS. PUBLICIZING

While we encourage the funded researchers to reveal their findings in these progress reports, we do not require them to do so. We require only that they state the specific tasks carried out. This policy avoids inadvertent publicizing of findings before the researcher has the chance to send a formal paper to a journal. Many of the most prestigious journals refuse to publish information that is already widely known. Without publications in top-rank journals, researchers find career advancement and future grant funding difficult. Furthermore, researchers often prefer to keep their hard-won findings private long enough to set up the next, sometimes conclusive, experiment rather than allowing this to be done by a competing researcher who did not perform the difficult preliminary work. On the other hand, a researcher with a hot new finding will want to write up a paper and have it published as soon as possible, before he is "scooped" by another researcher. This would, again, reduce the chances of his paper being accepted by a first-rate journal and deprive him of the claim to priority.

Continued Page 13

A report from Guam about research studies supported by a grant to SPSP through the Jerome and Dorothy Blonder Research Fund

For more than a century, Chamorros living on the Mariana Islands in the western Pacific Ocean have suffered extremely high rates of *bodig*, a unique form of Parkinsonism which scientists term the Parkinsonism-dementia complex of Guam (PDC). In 1982 when John Steele came to this island, he began to study PDC and he was the first to identify close similarities between it and progressive supranuclear palsy (PSP) which he had described with Drs. Richardson and Olszewski in 1964. For 16 years, Steele has worked to understand the disease of the Chamorros on Guam, and expects that understanding of it will give knowledge about PSP. (John C. Steele. "An interview." PSP Advocate Fourth Quarterly, 1996, Vol.6, No.4)

In 1997, Steele and his colleagues received \$10,000 from the Dorothy and Jerome Blonder Research Fund to permit their research about the genetic and environmental causes of *bodig*. They are now pleased to provide this progress report for readers of the ADVOCATE.

Their research has focused on the small southern village of Umatac where the disease is most common. During 1997-98, Ms Asherdee Duenas (a University student from Umatac) and Al Williams (a geneologist at the University of Guam) worked with Steele to develop an extensive pedigree for all the families of Umatac. Their work was also assisted by Dr. Huw Morris, a PSP research fellow from the Institute of Neurology who traveled to Guam to work with them in 1997 and again in 1998. (Dr. Huw Morris. "More research on Guam", PSP Advocate First Quarterly, 1998, Vol.9, No 1)

During November 1998, Professor Hardy and his wife, Katrina Gwinn-Hardy, neurologist and movement disorder specialist at Mayo Clinic, came to Guam and collected blood samples from many patients which Steele and his staff identify with *bodig*. During the next year, the DNA content of these samples will be analyzed by Jordi Perez-Tur, a Mayo Clinic research scientist and Huw Morris in Jacksonville and London. Professor Hardy is optimistic that these studies will give greater understanding of *bodig* and related neurodegenerative diseases, including PSP. He intends sharing the samples with others and he promises to keep the Guam Lytico-Bodig Association and the Society for PSP updated on his results.

During 1999, Steele and his staff will continue their genetic and environmental studies in Umatac and begin new projects on Guam He and his colleagues appreciate the Society for PSP's interest in the success of their studies. They particularly thank Mr. Blonder and his family for their generous support of this work.

Professor John Hardy and Dr. Katrina Gwinn-Hardy visit Guam in November 1998.

Front row, left to right: Professor Hardy, Madeleine Z. Bordallo (Lieutenant-Governor of Guam and President of the Guam Lytico-Bodig Association), Dr. Gwinn-Hardy
Rear row; Dr. Steele, Dan Koon (CEO, FHP and Pacificare Asia Pacific), Dan Featherman (Vice President, Pacificare Asia Pacific)

How Your PSP Research Dollars Are Spent
Continued from page 12

ANNOUNCING RESULTS TO OTHER RESEARCHERS AND THE PUBLIC

Aside from publication of papers in scientific journals, an important route for researchers to inform their colleagues of their results is to present them at scientific conferences. An annual meeting such that of the American Academy of Neurology has about 1,200 original presentations in less than a week and the Society for Neuroscience has about 10 times that many. Most are in the form of "posters," printed material posted on a 4x6 ft. board for a few hours, during which time the researcher must spend some time standing by to answer questions. Some presentations are in the form of 10-minute slide shows that typically allow another 5 minutes for questions from the audience. The presentations at the more important meeting are of findings not previously published. A volume of 300-500 word summaries of the presentations is mailed to the attendees and to medical libraries a month or so before the meeting. Therefore, this volume is eagerly awaited by researchers, who want the latest on developments in their field months before the full articles appear in journals.

When researchers feel their work is particularly important, they will ask their institution to issue a press release. Often, it is the researcher's department chairman or dean who initiates the publicity. News organizations typically respect requests to "embargo" the results until the day of their publication in a technical journal. To publicize it earlier violates a rule shared by many of the prestigious journals and would jeopardize that researcher's chances of future publication there. An exception is when a medical or science reporter peruses the volume of summaries of presentations at an upcoming meeting and contacts the authors of an interesting presentation. Sometimes the publisher of the journal, particularly if that publisher is a medical organization such as the American Medical Association, will draw the attention of reporters to an article in one of their journals that they consider worthy of the public's attention.

The SPSP and most other granting organizations insist that any publication or public presentation of work that they have supported include mention of the funding source. This helps publicize the SPSP and its grants program to researchers and gives credit where credit is due - to you, the donors to the SPSP's efforts to find new treatment or prevention for PSP.



Social Security Disability. What You Should Know.

Barbara B. Comerford, Esq.

The Social Security Administration administers two disability based programs for individuals who suffer from a medically documented illness which prevents him/her from working for a period of at least twelve months.

The Social Security Disability program (SSDI) is funded by FICA taxes through the Social Security Trust Fund. Adults over 31 years old generally must have earned 20 out of 40 credits to qualify; younger individuals less, regardless of present income/assets. Check whether you have enough credits by calling the SSA 800 number 1-800-772-1213 and request a PEBES (Personal Earnings Benefit Estimate Statement). Errors in earnings can be challenged, usually with income tax returns, W-2's or other income data. Disabled workers, some disabled widows, and certain disabled adults with childhood disabilities can apply.

The Supplemental Security Income (SSI) program is a welfare entitlement funded by the General Treasury and, unlike SSDI, income and assets are considered to determine non medical eligibility. Call the 800 number to arrange a phone interview to ascertain your eligibility for benefits. To file, go in person to the local Social Security District Office or apply by phone by arranging an appointment with the 800 operator (see number above). After the application is received, SSA will submit the case to the State office of Disability Determinations (DDS) to review the medical evidence and arrange for a doctor called a consultative examiner hired by the state to examine you. Recent proposals by SSA to give the opinion of the consultative examiner almost as much weight as your treating physician have come under heavy attack by disability organizations and fortunately may not become law.

If the application is denied at the first step, you will be notified by SSA in writing. You have 60 days to appeal the denial and "request reconsideration" Send your request in writing and if possible, by certified mail. Once again DDS reviews and develops the medical evidence.

If reconsideration is denied, you will be notified in writing by SSA and again you have 60 days to request a hearing before a U.S. Administrative Law Judge (ALJ). The ALJ reviews the case and you and your representative have the right to examine and copy the Judge's exhibit file. A hearing is generally conducted before the Judge during which time you and other witnesses can testify and you can submit updated medical reports.

If the ALJ decides against you, you have 60 days to appeal the case to the Appeals Council which is the last administrative level in SSA. If the Appeals Council denies the case, you have 60 days to appeal to the Federal District Court which begins the federal court appeals process, your last avenue of appeal, which could ultimately end at the U.S. Supreme Court.

SSA determines whether you satisfy the disability requirements by examining your case through a five step process known as Sequential Evaluation. Rather than explain each step, I will describe what SSA is looking for. Any and all

work efforts (intended for pay or profit) that you have engaged in since your disability began will be analyzed to see if it constitutes "substantial gainful activity". Generally if you earn more than \$500 a month you will run into problems, while less than \$300 a month, is acceptable. The time and effort you put into that work is what interests SSA. The more time and effort you dedicate the more problems you may encounter. There are exceptions which is why you should consult with a competent Social Security lawyer.

The following are crucial in building a strong case: Document your condition with objective test results; (eg. bloodwork, MRI, x-rays, etc.) be treated by a specialist: visit the specialist as much as he/she requires, follow prescribed treatment: keep a diary of ALL your limitations with particular emphasis on: sitting, standing, pushing, pulling, reaching, bending, lifting, climbing stairs, manipulating objects, seeing, hearing, speaking, kneeling, walking, concentrating and remembering things; give your doctor and your lawyer a copy.

You should also notify SSA of ALL your medical complaints. Commonly overlooked complaints are: headaches, dizziness, nausea, tremors, insomnia, forgetfulness, depression, anxiety, mood swings, irritability gastrointestinal problems, and secondary illnesses as well as side effects of medications. SSA wants to know about ALL illnesses that impact on your ability to do work related activities, not just the primary disease process.

My rule of thumb is to include as much information about your illness and how it adversely affects your everyday life as possible. Look back on the jobs you've had for the last fifteen years and the duties required of you. Your present medical conditions must preclude you from doing these jobs and any other job in the national economy.

You can contact the author of the article at 24 Godwin Ave., Midland Park, NJ 07432, Telephone (201) 444-4493.

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COMMUNICATOR'S LIST

The Society is updating its communicator's list. Communicators are persons who phone, write, or make friendly visits to persons and their families in their area or state. If you wish to be added or deleted from the list, please contact our office. If you would like a listing of the Communicators in your state, please call or write:

SPSP, Inc.
Woodholme Medical Building, Suite 515
1838 Greene Tree Road, Baltimore, MD 21208
1-800-457-4777

STATE OF THE SOCIETY

Continued from Page 1

from Jay Troxel in memory of his wife Eloise. This increase was the result of Roger Brisson's awesome mountain adventure, "Climb for a Cause", in January, 1998 which yielded \$72,000 for research, the Annual Campaign which to date has raised \$75,000, the major gifts of the CAP Foundation (\$50,000) and the gift from the estate of Frank Weymouth (\$90,000). There were increases in giving from other major donors as well as in memorial and donations restricted to research. Development efforts will continue to expand under the guidance of Sue Dagurt, CFRE, SPSP's development consultant.

In the area of research, the Society pledged \$208,000 to fund 9 grants in 1998-1999. We have established the Eloise H. Troxel Memorial Brain Bank at the Mayo Clinic in Jacksonville, FL where Dr. Dennis Dickson is actively engaged in genetic, biochemical and immunological research. Guided by the expertise of Dr. Lawrence I. Golbe and the collaboration of the Medical Advisory Board, we have attracted major investigators to our research program. As a result of the SPSP/NIH Brainstorming Conference, the focus of research will increase while funding larger grants will become a priority. In 1999, The Society is currently considering requests for \$195,000 in research grants.

The increasing requests for information have been carefully documented by the SPSP office. In 1998, people requested 2,900 new information packets and 1,000 additional brochures and videos. We answered 5,700 incoming calls on the 1-800. The database grew to 9,000 up from 6,000 in Dec. 1997. About 42% of the database are donors. We had 120,000 hits on the website and subscribed 200 persons to the daily list serve/mail program. In 1998, volunteers formed eleven new support groups. Foreign mail has increased to 500, representing Canada, Europe and Asia.

Educational efforts have been bolstered by the exceptional skills of Nancy Brittingham, former board member and who assumed the position of editor of the Advocate as well as other PSP communications. The newsletter has magnificently developed in size as well as its presentation of vital information and resources. With the help of Dr. Golbe and Laura Purcell-Verdun we have revised "PSP Some Answers" and "Swallowing Problems in PSP". A new brochure on "Eye Problems in PSP", is in production.

The Society has been in the forefront of medical education by its presence at major medical meetings including the American Academy of Neurology, the American Psychiatric Association, the American Ophthalmological Association and the Movement Disorders Society. We mail quantities of PSP materials to large clinics and have instituted a "Medical Edition" of the Advocate.

Under the guidance of a committed Board of Directors, a skillful and caring staff supported by volunteers and PSP families who nurture this significant organization, the Society for Progressive Supranuclear Palsy is thriving.

We thank you for your trust in our ability to fulfill the mission of the Society. And we thank you for your generous gifts which has enabled all of this to happen.

George Jankiewicz, Jr.
SPSP Chairman of the Board

PSP AND ME

*I'm Russell King and I'd like you to know
How I am feeling and why it is so.*

I have this disorder called PSP

That's why it's so hard for me to see.

My Eyes won't move 'cause the muscles freeze

And my balance is bad, takes me to my knees.

I cannot talk (and a talker I was)

Muscles again are the prevalent cause.

Thoughts swirl through my head all day long

With no way to express them, not even is song.

My memory, though slow, is really O.K.

You'd be surprised if my thoughts I'd convey.

My lack of response would seem to imply

I don't understand, but alas, it's a lie.

Emotional incontinence is part of my bag

Of tricks PSP plays as muscles flag.

If I'm unable to laugh, cry or grin

It's cause my emotions can't even begin.

They're all there though the same as before.

Don't let this poker face fool you any more.

My hand mouth coordination is practically nil

I can't feed myself, I hope someone will.

Sometimes when I eat my "swallower is broke"

To get it to work is really no joke.

I throw back my head where it demands to go

PSP muscles again are running the show.

My feet that once carried me at my command

Now turn in and trip me, please understand.

My hands once used as the tools of my trade

Keep ever so busy, my frustrations allayed.

I need understanding and patience too

When I have an accident I'm unhappy and blue.

My friends are now scarce, can't accept how I am

Just don't understand "I Yam Who I Yam"

I need stimulation and often feel gloom

I love to be taken out of my room

to enjoy all events and sometimes a show,

But especially the music I now enjoy so

I hope you now grasp the way that I feel

As PSP my body does steal.

- By Dawn King

The Study of the Tau Gene and PSP

William G. Johnson, M.D.

UMDNJ - Robert Wood Johnson Medical School

Research studies directed toward prevention and cure of PSP require extra thought because PSP is different in significant ways from other diseases in its group. The group of degenerative diseases with onset late in life has been found in recent years to be genetic in or mostly genetic in origin and mostly autosomal dominant in inheritance. This has been helpful for research because the genetic tools for research are very powerful. If a clearly dominant pedigree is found for a disorder, then the causative gene can be located and cloned, its function can be determined, and therapeutic approaches can be designed. However, with PSP, the pedigrees available are few and small. One has to face the fact that PSP is not a genetic disorder, at least not one fitting the usual model.

However, these few small pedigrees for PSP do suggest that there may be a genetic component to the disorder, perhaps with a large environmental influence. If this is the case, then perhaps genetic technology can be used to identify the genetic component. The large environmental component, then, becomes an optimistic feature, because environmental factors are much easier to influence than genetic ones. Perhaps the genetic part of PSP can be used to identify the way the disease originates and progresses and the environmental factors can be manipulated to prevent or cure the disease.

Postmortem examination of brains from PSP patients have implicated the brain protein called "tau." This has come about because far-seeing PSP patients and families have made sure that their brains were donated after their death to research institutions. This tau protein is associated with microtubules and can perhaps influence the structure of the nerve cell or transport of materials from the nerve cell body through the long process called an "axon" that acts as an electrical conduit connecting one nerve cell with another or even many others. These electrical conduits are extremely long. A human nerve cell has a cell body too small to see with the naked eye, but its axon may be even thinner than the nerve cell itself and may be several feet long! In whales, such an axon may be more than 50 feet long, but still too thin to see with the naked eye.

Recently, Dr. Joseph Higgin's research group conducted groundbreaking studies on the gene for the tau protein in PSP patients. He studied a portion of the tau gene that is highly variable. That is, the two copies of the tau gene that every person has will often be different in this region. He found that PSP patients were more likely than healthy individuals to have a particular form of tau as one of their two, and many people with PSP had two copies. Our laboratory confirmed these findings. There are now two pieces of evidence tying the tau protein to PSP: the autopsy evidence and this new genetic evidence.

What does this evidence mean? It is not clear that this variant form of the tau gene is itself abnormal. Many people have this variant, even two copies of it, and don't get PSP. Yet, this variant form of the tau gene has been linked to PSP. How can this be? One possibility is that this variant form causes PSP only in the presence of another, yet unknown abnormal gene. Another is that this variant form is not itself abnormal, but is a marker, or genetic fellow-traveler, for another variant either within the tau gene or close to it that is the real cause of PSP. Of course, it is possible that both explanations are true: that the variant associated with tau is a marker for the real, as yet unknown tau variant that causes PSP, and also that the participation of other genes is necessary to produce PSP.

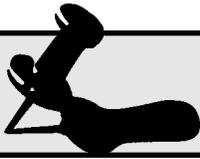
We would prefer to study the entire tau gene DNA sequence to see if we can find such a mutation. However, tau is a very large gene. Sequencing the whole gene would be a huge task. Also, some DNA variation always occurs from person to person and it would be difficult to tell if such a DNA sequence change in PSP were the causative mutation or just a normal variant.

Instead, with the help of a grant from the Society for PSP, we will examine the messenger RNA (mRNA) for tau. This study is much less time-consuming than sequencing the whole gene. mRNA is an intermediate between a gene (a string of DNA bases) and the resulting protein (a string of amino acids). A functional abnormality of the tau gene of whatever sort is likely to produce a change in the tau mRNA. The quantity or size of the tau mRNA might be increased or decreased.

An abnormal tau mRNA size would suggest that the tau protein abnormality could be due to alternative splicing of the message. Alternative splicing is a normally occurring property of many proteins wherein under certain conditions, or in certain places in the body, the same protein may have entire sections omitted. The tau gene is known to have extensive alternative splicing and the single tau gene normally produces at least six alternatively spliced forms of the tau protein.

If the tau mRNA has a normal size but is increased or decreased in quantity, then a point mutation is implicated in the part of the message that codes for amino acids in the tau protein. Of course, these are guidelines not absolutes, but this approach can often save a lot of time and resources in locating a mutation.

Any of these findings would point toward abnormal function of the tau gene in PSP. This would have the advantage of giving further weight to tau as a causative factor in PSP and also giving an idea of what kind of tau abnormality we are looking for. This approach is a first step toward determining the abnormal function of tau in PSP. We are hopeful that this work will bring us closer to better diagnosis for PSP and ways to prevent and treat this disabling disease.



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:

Carolyn Cheek
23009 Nadine Circle - Unit A
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Janice Clements
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(802) 893-1263

Janice Stober
NPF Center for Excellence
c/o Dr. Mark Guttman
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Markham, Ontario,
CANADA L6B1A1
(905) 472-7082

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Framingham, MA 01701
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Allen Rohfling
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Virginia Beach, VA 23456
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Karen Kennemer
2235 Cedar Falls Drive
Kingwood, TX 77339
(281) 358-2282

Debbie Mills
Tri-State Parkinson's Association
Cincinnati, Ohio
(513) 558-7312

Attention: Please notify the SPSP if you are in a PSP support group not listed above. Anyone interested in starting or joining a support groups, please call the society office at 1-800-457-4777.

*Florida Support
Groups now forming.
The Society is forming
support groups
throughout Florida.
Call the office for
more details*

SUPPORT GROUP NEWS

South Carolina Support Group:

South Carolina's PSP Support Group sponsored by Doris and Harry McCray continues to grow. January marked the first birthday of this special group of people. Neurologist Dr. Mario Bangco continues to offer his support and expertise at these meetings. Most recently, a dietician from a community hospital spoke at a meeting offering information and answering questions. The next meeting will be on March 20. Please call Doris for details at (803) 445-7480.



Dr. Mario Bangco providing information at SC Support group meeting



SC's group continues to grow.



SPSP Director, Ellen Katz, greets guests at the Baltimore PSP Support Group December Christmas party.

The Society for PSP Dedicates The First Brainstorming Conference on Progressive Supranuclear Palsy March 18-19, 1999 To the Memory of Eloise C. Troxel



Mr. Jay Troxel has gifted the Society with a generous contribution to be used for research given in memory of his beloved wife, Eloise. This gift continues to be a driving force in stimulating research in finding the cause, cure, and treatment of PSP.

Thank you Mr. Troxel

“Kaleidoscope”

Mary Marino

I was born in New York City on September 7, 1940. I lived a fast life. Time was my most precious commodity. At age 21, I entered religious life. I was a Catholic sister for twenty-seven years. Then my mother, my very best friend and confident, was taken ill suddenly. She had to have her leg amputated, after which she had a stroke. I was stationed in California as director of a retreat center. I flew to New York and opted to bring my mom out here so that I could care for her. I took a leave of absence from my community during which time I was diagnosed as having progressive supranuclear palsy (PSP). It was an “older person’s disease” I was told. “Go home and lead a normal life,” another neurologist said. “There’s nothing anyone can do about it.” I saw eight doctors regarding my condition, and had extensive tests done. One doctor suggested that I don’t read about it because usually the worst case scenarios were presented. I felt numb. My blood seemed to have turned to water. I felt weak all over and very much in the dark. I walked in fear of ignorance, not knowing what to expect.

The first symptom I experienced was visual. I began to find it increasingly more difficult to move my eyes up and down. This, I later was told, was due to a diminishment of my vertical saccades which controls up and down movement and whose center is located in the mid-brain. Thus the term “supranuclear,” which alludes to its position in the brainstem. The palsy occurs in eye movement.

I was employed as coordinator of social services at a long term care, sub-acute rehab facility. Approximately 75% of my job involved writing: taking notes, writing chart assessments, and doing written reports. I used to be fast and neat. Now I was embarrassed to sit near anyone whenever I had to take notes. My handwriting became illegible and microscopic (micrographia). I bought myself a typewriter and taught myself how to type.

Things that I had taken for granted were slowly becoming increasingly more difficult going up and down steps, looking up and down, writing, making eye contact with others conversing. There were also times when I was in conferences with family members that my eyelids would just close. I just could not keep them open. I later found out that this was another symptom of the disease called blephorospasms. I heard myself making excuses to those who were present and explaining to them that I just got to bed late last night. This frightened me. I began to notice whenever I felt fatigued this phenomenon was more likely to occur. Also, my balance began to be affected, obviously, I was more prone to falling. How I got to find out more about my disease was from a nurse practitioner with whom I was working. She asked me one day if I was all right. She said my handwriting was becoming so poor they were having trouble reading it. I told her I had a condition called PSP. She looked heavenward, picked up her briefcase and pulled out an article she was reading for a patient in another facility who had the disease. I copied it, took it to my office, read it, and cried.

That was why I was having trouble eating! That was why I had episodes of choking! That was why I was missing picking up the food on my fork! That was why I was missing the last step! That was why I was finding it difficult to wear high heeled shoes. That was why and the list went on and on.

I went to see another doctor who put me on Sinemet, saying it might improve my writing legibility. I took it for about a month. I began noticing a mood change which frightened me. I started feeling depressed, a dark companion from whose grasp I had recently been released. I walked with that grim traveler for four years—during my mother’s illness, leaving my community and after my mom’s death. I felt as though I could never smile again as though all the color in my life vanished. Being on a Psychotropic Drug

Committee at work, I questioned the side-effects of the medication, one of which was depression. I stopped taking it.

In June 1996, my administrator suggested that I go out on long term disability. This nearly bowled me over. I felt fine. I had not been to a neurologist in three years. I painfully struggled with this concept for a few months. My physician referred me to a neurologist and in August 1996, I went out on long term disability.

My feelings have run the gamut. At times I have felt afraid because I am losing control. I have also felt sad, feeling I am too young to have this disease. I have bargained with my God, asking for a miracle to take it away. But, in the last ten years, I have tried to become friends with this “dragon” whom I have tried to keep locked in the “cellar” of my life. Many times I have gone to the door and have run away from its threatening roar. Slowly, I have not only opened the door, but have actually gone down to pet this fearless monster.

Last weekend, I attended my first conference on PSP. I went alone. It was mainly for caregivers, but I thought I should go further acquaint myself with this disease process. I was fearful of going. When I walked into the conference room and saw so many of my brothers and sisters with the advanced stages of the disease, I felt like running. Again I was little prepared for this. As the day went on, the young woman sitting next to me shared that her father had died of this disease in England a few years ago. During that next session, they asked for a show of hands to indicate how many persons had been diagnosed correctly the first time they went to the doctor. When I raised my hand, she almost fell over.

During the next break, she asked me how long I have known about my diagnosis. I told her ten years. She said I was a medical anomaly. During the conference, I learned the life expectancy is approximately 7 to 10 years after being diagnosed, and that more than half the people who were in attendance at the conference had been misdiagnosed. The question surfaced in my mind: am I a medical anomaly, or was I fortunate enough to have had such an astute physician who recognized early symptoms?

An anonymous friend has enrolled me in the quarterly newsletter, the PSP ADVOCATE, which I have been receiving since I have been on disability. This has been a most informative publication. I have found out that I am not alone. Being a rare disease, affecting 1.4 in 100,000, they have estimated that approximately 20,000 people in the United States have it, although only three to four thousand have been diagnosed. Its’ causes still remain a mystery. No cure has been found.

When I look toward the horizon, I do not know what will be in store for me in the future. So, I am trying to live each day to day. I try not to dwell on my incapacity, but rather live each day to the best of my ability. I have a wonderful family and very dear friends who have been most supportive. I am still able to live independently, and for this I am extremely grateful. And last, but certainly not least, I have God in my life. To Him, with Him, and in Him, I give thanks and praise, knowing He will not abandon me. “For all that has been, thanks; for all that will be, yes!” My prayer is that I may be able to continue to live these words.

(Mary Marino has a B.S Ed./English and a Master’s Degree in Religious Education from Fordham University, NYC. She has lived in religious community for 27 years, working in education, social services and also as director of a retreat center when she left religious community to care for her mother. She became a coordinator for social services in nursing homes. She has been on disability due to her PSP condition since 1996. Now retired on disability, she continues to be active in her parish, volunteering her time to assist in facilitating a women’s group for spiritual development.)

The Society for PSP gratefully thanks generous donors for their gifts to the Society including special contributions to the Annual Campaign.

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We received 750 contributions totaling \$75,000.*

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Memorials given in memory of our special loved ones and friends that were victims of progressive supranuclear palsy as well as other diseases.

August 1, 1998 thru February 1, 1999

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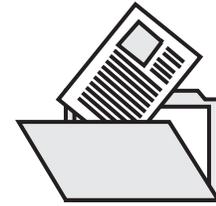
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We are pleased to have a cooperative relationship with our sister organization PSP Europe Association. For information on what is happening in the United Kingdom and throughout Europe contact:

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