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Society for Progressive Supranuclear Palsy

PSP Advocate

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

David and Reba Saks, Founders

AMERICAN ACADEMY OF NEUROLOGY 51ST ANNUAL MEETING
Summary of PSP-Related Presentations

Lawrence I. Golbe, M.D.
Professor of Neurology
Robert Wood Johnson Medical School
Chairman, SPSP Medical Advisory Board

Several exciting research developments in PSP were presented at the 51st Annual Meeting of the American Academy of Neurology held in Toronto, April 17-21, 1999. The AAN is the leading annual venue for the world's researchers in clinical neurology to share their latest findings. The presentations have not yet passed the rigorous peer-review process imposed by journals for publication. However, the methods and results are presented in detail for the audience's scrutiny and the authors are available for direct questioning. The PSP-related presentations summarized below are those that I feel are of greatest potential interest to SPSP members:

Dr. Irene Litvan and Dr. Dennis Dickson discussing his presentation at the AAN

Two presentations reported families with PSP. Dr. Paul J. Tuite and colleagues of the University of Minnesota reported that autopsy in two siblings revealed PSP in one and corticobasal degeneration (CBD) in the other. Both siblings appeared to have CBD, not PSP, during life, although the two diseases can be very difficult to distinguish on examination of the living patient. Brain cells in CBD, like those in PSP, accumulate tufts of fibers called neurofibrillary tangles, which are composed mostly of the protein called tau. The authors conclude that both siblings may have carried a mutation in the gene coding for the tau protein. Although this mutation is probably not one that causes ordinary PSP, where multiple cases in one family are exceedingly rare, working out the genetic code sequence for tau in these two siblings could help us understand how neurofibrillary tangle diseases such as PSP arise.

A similar presentation, from Dr. Ryan Uitti and colleagues of the Mayo Clinic Jacksonville, reported autopsy-proven PSP in two sisters. They have a living brother with mild

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THE HARDER THE BATTLE, THE SWEETER THE VICTORY!

Irene Litvan, M.D., Chief, Neuropharmacology Unit
Defense and Veteran Head Injury Program
Henry M. Jackson Foundation

As Dr. Lawrence Golbe wrote in his recent summary of the 1999 Brainstorming Conference on PSP (The Advocate, Vol. 10, No. 2, 1999), the meeting allowed scientists to review the state of the art of research in PSP and formulate new goals to be accomplished in the near future. New drug trials for people with PSP, the search for PSP-related genes, and the identification of biological markers of PSP were all discussed at the meeting. The chance to meet and discuss these issues stirred new interest in PSP and indicated how research on PSP could influence research in other areas of clinical neuroscience.

PSP is a rare disorder. Rare disorders seldomly attract the attention of companies who are in the business of making money. Since the development of drugs and other interventions are so time consuming and costly, companies tend to focus on disorders that will yield larger profits. Foundations and government institutions provide grants for original research proposals but those proposals are often driven by the scientific atmosphere that is contaminated by that clinical researcher's past scientific interests and by the profit margin motive (new equipment, choosing a topic that allows them to get extra personnel in the laboratory, etc.). So how can a simple meeting inspire more investigators and companies to expend effort on studying and developing treatments for PSP?

The truth is that however successful such a meeting is (and this one was VERY successful), it is only part of a parallel effort that is required to move research on a rare disease forward. And you, the reader, must be part of that effort! How can you help? You can continue to volunteer for research studies in the numbers that you have in the past. This is part of the reason that we are able to move research into PSP forward. You must make your interest in PSP known to local television and radio media who can inform the public about the illness and what is

Continued Page 11

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 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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PSP Advocate

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(In memory of Henry and Jane Ogiba)

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Meeting Jay Troxel, the Society's Guardian Angel

I remember being jolted from a deep sleep by a telephone call in June, 1997 from Dr. Stephen Reich, then the Society's Chairman of the Board. "How would you like a gift of $400,000 to begin a research fund?" I immediately snapped to attention, astonished that such a gift would come unsolicited from an unknown donor who was unfamiliar with the capacity of our organization to utilize this gift. What a momentous call! Now, two years later, I know the motivation of Jay Troxel, an extraordinary person, who jumpstarted our research grants as well as provided for the overall growth of this organization——all in memory of his beloved wife, Eloise, who died from progressive supranuclear palsy in April, 1997.

After two years of talking by telephone with Mr. Troxel, I made the trip to Lakeland, Florida to meet the driving force of the Society. I could not help breaking down in tears as we embraced at the Tampa Airport of July 15

I came to Lakeland to thank Mr. Troxel on behalf of the Society, people with PSP, families, caregivers and medical professionals. Mr. Troxel's gifts are currently funding numerous research grants and the PSP Brain Bank at the Mayo Clinic in Jacksonville. He underwrote the expenses of the Brainstorming Conference for PSP at NIH and furnished our new office as well as provided computers and a computer network. I came with many tokens of thanks-photos, videos, and a plaque.

I met a most extraordinary man; an avid collector and reader of history, religion, poetry, music and philosophy. I loved his endless jokes and his keen wit. I enjoyed a lovely evening with him and his daughter, Karen, who like her father, has a marvelous sense of humor. Savoring a delightful visit with a gracious host, I learned the answer to my question about his gift to the Society.

Mr. Troxel said, "I made my choice quite spontaneously. I just decided to do it one day and I did. It is amazing to me what the Society has done with the funds made in Eloise's memory in such a short amount of time. I recommend any person who wishes to remember a loved one lost to PSP to make their gift to the Society. They will do wonders with your contribution."

Thank you again, Jay Troxel, for all you have done to catapult research efforts and to propel our organization forward. Thank you for being the splendid person that you are!

With deepest appreciation,
Ellen Pam Katz
Director, SPSP

Mr. Troxel with SPSP Plaque of Recognition

Paula John, Friend of the Board, Jay Troxel & Ellen Katz

Mr. Troxel at home with his daughter, Karen Daly

INAUGURAL CANADIAN PSP SYMPOSIUM

Janice Stober
Clinical Social Worker
Center for Movement Disorders
Markham, Ontario

The Inaugural Canadian PSP Symposium was held in Toronto, Ontario on April 18, 1999. There was an overwhelming response with over ninety participants comprised of people with PSP, carepartners, family members as well as health care professionals. Participants came from all across Canada and the United States.

This successful event was co-sponsored by the Society for PSP and The Parkinson's Foundation of Canada. Because this symposium was coordinated in conjunction with the American Academy of Neurology's Conference in Toronto, it allowed us the opportunity to access some of the leading experts in the field of PSP.

A prestigious panel of speakers participated in the inaugural event. Dr. Mark Guttman, The Centre for Movement Disorders, Markham, Ontario, spoke about progressive supranuclear palsy from a medical perspective, focusing on diagnosis and treatment. This overview gave the audience the opportunity to learn about the origins of PSP and current treatments. Dr. David Zee, (Johns Hopkins University School of Medicine), reviewed eye movement problems with people with progressive supranuclear palsy. His interactive presentation enabled the audience to better understand the neuro-ophthalomological signs and symptoms of PSP. Behavioral changes in PSP were presented by Dr. John Growdon, (Harvard Medical School). He discussed his various clinical research concerning the cognitive aspects of progressive supranuclear palsy.

Dr. Dennis Dickson discussed the latest in PSP research as well as the genetic study of people with PSP. Dr. Dickson is from the Mayo Clinic, Jacksonville, FL, conducting research on PSP through the Society for PSP's Brain Bank supported by the

Continued Page 5

Janice Stober, Sandy Jones, Kim Anderson and Ellen Katz - organizers of the Symposium

Persons with PSP - Helen Farlow (Petersbrough, Ont.) and Audrey-Ruth McLaren (Brompton, Ont.) listen to information being presented

Sally Smith Hosner, Kim Smith and Sally Smith family of Jack Smith from Michigan

Janice Stober open the Program

Inaugural Canadian PSP Symposium
Continued from Page 4

Eloise H. Troxel Memorial Fund. A senior physical therapist from Baycrest Centre for Geriatric Care in Toronto, Rebecca Gruber, discussed rehabilitation in PSP. Many audience members had several questions about the accessibility of various community resources and caregiver burn-out.

There was a tremendous amount of information presented in a short period of time. The symposium gave people the opportunity to direct their questions to these leading experts. Perhaps, just as importantly, it provided an opportunity for people related to PSP to meet others sharing similar situations and facing similar challenges.

Being the co-facilitator of the only Canadian PSP support group has been challenging. We have received hundreds of calls from people across Canada wanting to connect with other people whose lives have been affected by PSP. Our mailing list has grown tremendously and the attendance at our local support group continues to grow.

The question remains "where do we go from here?" We have been asking ourselves -how do we reach out to all people in need with PSP in Canada? The need to form "PSP-CANADA" is great and we are currently working on organizing a brainstorming meeting in the fall for those who are interested in becoming involved in currently developing this organization. We will provide feedback in the future ADVOCATES about our Canadian Division of the Society for Progressive Supranuclear Palsy. We look forward to further collaboration with the Baltimore office for future co-sponsored events. On a personal note, My thanks to the SPSP Director, Ellen Pam Katz, and SPSPEditor, Nancy Brittingham, for their enthusiasm and encouragement in helping to organize this successful event.

Ruth Freuhauf, Ardis Barnett, Nance Gondersobn, and Edith Dickinson of Midland, Michigan supporting one another

Pauline McGilvray (Mother), Peggy Graham, Betty McMillan (daughter and person with PSP) and Hilary Gaylor come together to learn all they can about PSP

TAKE FIVE
By Mary Miano
(A Person With PSP)

In my experience as a retreat director, I had the opportunity to host a day for principals of the Los Angeles school district. They were having 20 minute presentations about relevant topics. The organizer for the day recommended that I sit in on the presentation on stress. So, I went and attained some very valuable insights that I would like to share with you.

Stress is defined as the normal wear and tear of life. As soon as we open our eyes in the morning, we are faced with stressful situations. Just to get up in the morning imposes stress. However, what I did not know is that there are different kinds of stress: distress, neustress, and eustress. What I would like to acquaint you with in this article are the differences.

Distress can be compared to a car rolling backwards down a hill and the owner trying to stop it from behind. This is tension-evoking situations over which we have little or no control.

Neutress can be compared to starting a car and reeving up the engine. Translated into our every day experience, it is the time we make to fortify ourselves to "take on the day." Simply calling to mind our breathing can be a form of neutress. Quieting our minds and hearts, getting in touch with our bodies, a "coming home to ourselves, making the time to connect with our "higher power": all of these can be forms of neutress.

Eustress is the beneficial things we do for ourselves: taking a bubble bath, listening to music, watching a television program that we enjoy, going to a social gathering with friends we enjoy, having a good "belly laugh!" There are as many varieties of eustress as there are people. What is it that you enjoy doing? Everything takes effort but the question is "Do we make the time?" It can also be a mini-vacation in your mind. Take five and recall some of the "gold in your memories!" Think of a place that you enjoyed and go there for a while. If it's the seashore, allow yourself to feel the warmth of the sun and the sea breezes blowing against your face. Smell the freshness of the air and listen to the tides rushing in against the pebbles, sounding as an audience in applause. Stay there as long as you want and be refreshed and renewed. Why? Because it will help you to come back and cope with the distressful situations that each of us must face. So, my friends, I invite you all to "take five" and do something good for yourselves!

(Mary Miano has a Master's Degree in Religious Education awarded from Fordham University, NYC. She has lived in religious community for 27 years working in education, social services, and director of a retreat center. Leaving a 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.)*

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.

THE SOCIETY FOR PROGRESSIVE SUPRANUCLEAR PALSY
Presents
THE FIFTH BIENNIAL PSP SYMPOSIUM
FOR PERSONS WITH PSP, FAMILIES AND CAREPARTNERS

November 13, 1999 • 8:45 a.m.-4:00 p.m.

Baltimore-Washington International Airport Marriott
Baltimore, MD

8:00 a.m.-8:45 a.m.	**Registration**
8:45 a.m.-9:00 a.m.	**Welcome from the Society for PSP** George S. Jankiewicz, Jr., Chairman Joanne Armstrong, Vice Chairman Elizabeth Brisson, Chairman of the Symposium
9:00 a.m.-10:00 a.m.	**Where We Are and Where We Are Going: Focus on Research** Dr. Lawrence I. Golbe, Professor of Neurology Robert Wood Johnson Medical School Dr. Irene Litvan, Chief, Neuropharmacology Unit Defense and Veteran Head Injury Program, Henry M. Jackson Foundation
10:00 a.m.-10:30 a.m.	**Eye Problems with PSP** Dr. David Zee, Professor Of Neurology, Ophthalmology & Otolaryngology Johns Hopkins University School of Medicine
10:30 a.m.-11:00 a.m.	**Break with Refreshments**
11:00 a.m.-11:45 p.m.	**Breakout Sessions** A. **"How I Feel"** Persons with PSP will meet with Dr. John C. Steele, Fellow, American College of Physicians, Core Director Micronesian Health Studies. Registration needed. B. A Carepartners Panel Discussion will be facilitated by carepartner, Doris McCray. The panel will include other PSP carepartners' including spouses, children and a person with PSP.
11:45 p.m.-1:00 p.m.	**Lunch** State of the Society and Special Events George S. Jankiewicz, Jr., Chairman Ellen Pam Katz, Director
1:00 p.m.- 2:00 p.m.	**Treatment and Management of PSP** Dr. David Riley, Associate Professor, School of Medicine Case Western Reserve University
2:00 p.m.- 2:30 p.m.	**Swallowing Problems with PSP** Laura Purcell Verdun, MA, CCC Research Speech Pathologist National Institutes of Health Assistant Professor, Johns Hopkins University School of Medicine
2:30 p.m. - 2:45 p.m.	**Break with Refreshments**
2:45 p.m. - 3:30 p.m.	**Ask a Doctor Panel** Dr. Golbe, Dr. Litvan , Dr. Zee, Dr. Riley, Dr. Steele, Dr. Reich and Ms. Verdun will answer your questions.
3:30 p.m.-4:00 p.m.	**Keep a Positive Outlook** Dr. Stephen Reich, Associate Professor of Neurology Johns Hopkins University School of Medicine

A registration fee of $59/person is required; after October 1, registration fee is $69.
Continental breakfast, refreshments, and lunch is included. Limited scholarships available.

FRIDAY, NOVEMBER 12, 1999

Reception
5:30 - 6:30 p.m. (Cash Bar)

Dinner
6:30 - 7:30 p.m.

Support Group Workshop
(OPTIONAL)
7:30 - 9:00 p.m.
$39 per person

Share your support group experiences with one another. Meet new volunteers as well as experienced support group leaders. Discuss helpful tips on starting a support group. All are welcome.

ACCOMMODATIONS
BWI Airport Marriott
1743 West Nursery Rd. • Baltimore, MD 21240
(410) 859-8300 • Fax (410) 691-4555
1-800-228-9290

The Society has reserved a block of rooms at the BWI Marriott Hotel for Nov. 12-13. Special room rates available for $89/double per night. Call (410) 859-8300 to make your reservations. The hotel has a limited number of handicapped equipped rooms. Be sure to make your reservations early and let the hotel know of any special needs. Attendees must provide their own wheelchairs.

SATURDAY, NOVEMBER 13, 1999

The Society for PSP presents
"Visions and Opportunities"

Dinner
5:00 - 7:30 p.m.
No Charge
Reservations Needed

Please help SPSP with your volunteer support. As an SPSP volunteer, you can make a difference for persons with PSP and family members in your community and help the Society expand services throughout the country.

Plan to attend, "Visions and Opportunities", a special dinner and orientation. SPSP is reaching out to volunteers to strengthen the Board, create more public awareness, and raise money for research, medical education, support groups and family services.

The Society has completed a Strategic Plan to begin 2000. The ultimate goal -- to find a cure for PSP. This plan needs volunteer support to be successful. The Society is asking for your assistance.

This evening's special event will give you an opportunity to see and hear how you can help. Whether you actively participate or prefer to just listen and learn, we need you there! Please plan to attend.

Symposium Registration Form Located on page 23

DIRECTIONS

- From Baltimore: Route 295 South (Baltimore Washington Parkway). Take W. Nursery Road exit, turn left. Hotel is on the left - 1½ miles.
- From Washington: Route 295 North (Baltimore Washington Parkway). Take W. Nursery Road exit, turn right at top of ramp. Hotel is on the left - 1½ miles.
- From Interstate 95: Exit onto 195 East to 295 North and follow directions from 295 above.

Location: Five minutes from BWI Airport, 12 minutes from Inner Harbor and downtown Baltimore, 45 minutes from downtown Washington, D.C., 30 minutes from historic Annapolis.

Transportation to Hotel: Complimentary shuttle service to and from BWI main terminal and MARC train station.

"FRIENDS OF THE 1999 SYMPOSIUM" HONOR ROLL

Your gift towards sponsoring the 1999 Symposium will help fulfill our mission of providing vital education and support to Persons with PSP and PSP Families. Our registration fees for the Symposium unfortunately do not cover our costs. Won't you please make a special additional gift to ensure the success of the Symposium? You will be recognized on the Symposium Program and in the ADVOCATE.

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Your gift is TAX-DEDUCTIBLE. A copy of the Society's financial statement is available upon request.

BRAIN DONATION AND HOW IT ADDS TO WHAT WE UNDERSTAND ABOUT THE CAUSE OF PSP

Shamaila Waseem, MD and Katrina Gwinn-Hardy, MD
Mayo Clinic
Jacksonville, Florida

Some of us have heard about brain donation after death in PSP, but have not understood completely why this is done. Some of us have been approached by physicians, or considered for other reasons, whether or not brain donation after death of a person with progressive supranuclear palsy would be worthwhile. Below, some of the issues involved in this are discussed.

Why consider donation of my Brain for the study of PSP?

Neurological disease is the area about which we know the least despite its important consequences. PSP is no exception. Brain donation provides insight into conditions that may clinically masquerade as other diseases. For example, many of the features of PSP are similar to those of Parkinson's disease. Thus, many patients are initially given a diagnosis of Parkinson's disease before all the typical signs of PSP appear. There are many distinguishing signs; however, these may not be obvious early in the course. Many other distinguishing signs are seen upon examination of the brain after death. This allows a more sophisticated understanding of these differences during life. If the diagnosis is wrong, then, what we think we are learning about a given disease might not have anything to do with it after all. This is especially important in family studies. It makes sure that the researchers have correctly catalogued and considered the diseases they are studying. Better treatment can be developed as we continue to collect more information about these disorders. This includes clinical studies (including treatment trials), genetic and other molecular studies, imaging studies of the brain, and direct examination of the brain itself (which can only be done after death).

How can examination of a brain after death give you any more information that examining a person and their blood does when they are alive?

Examination of the brain is the most definitive way to make a diagnosis and to search for a cause. There are classic, reliable features of a given disease, which are seen when the brain is examined. When someone is alive, we use terms, like "Parkinson's disease", "PSP", but we aren't exactly sure until someone has died if the whole picture fits together: the clinical history (the medical records), the examination, and the blood tests are compared to the information obtained from the brain itself.

PSP is a "degenerative" disorder of the brain, affecting certain selected brain circuits. The term, "degeneration" implies that the selected brain cells prematurely age and die. The predominantly affected circuits in PSP are those involved in movement and balance. Why these certain brain circuits degenerate is not known. Other brain areas are spared, such as those involved with vision, hearing and sensation. Because PSP is a disease of the brain, it is important to examine the brain directly in order to learn more about the disease. While MRI scanning and other research methods, such as PET, are useful for looking at the brain, they do not look at each area, nor do these tests look at the circuitry which is in place there, which would show the relationship between those regions. Thus, brain donation allows scientists to continue to learn about what occurs in PSP, and how it differs from what occurs in normal individuals (those without any neurological disease) and how it differs from diseases which have major similarities as well as major differences (such as Parkinson's disease, or lytico-bodig disease of Guam, which it closely resembles in some ways).

What does this mean for the future of patients and their families?

Although donating a brain doesn't help the person who donated it, it hopefully will contribute to helping a large number of other people, many of whom may even be in that person's family. As our knowledge increases, it is clear that some cases of PSP run in families. If genetic tests or other tests eventually become available, it is important to know that PSP is the actual diagnosis. If other family members might be prone to develop PSP this information will be important for early diagnosis and treatment. A single brain donation won't answer all of these questions, but, will add another essential piece of information to our solving of this puzzle.

Does donating my brain mean that I will have to be cremated? Will it be possible to have a normal funeral if the brain has been removed? Is the body taken away?

It is possible to remove the brain without disturbing a person's appearance for a funeral. The family is free to choose any type of service that they might wish even if the brain has been collected. This is because the people who evaluate the person after death are highly trained to do this with care. The person's body is not taken away from their hometown, because the procedure can be done locally and sent to the researchers who are experts in a given disease.

Who evaluates the brain and what happens to the information?

The brain is evaluated by a neuropathologist (a person who is specially trained in making diagnoses from brain material). The case is then discussed with the doctors who took care of the person when they were alive, and with researchers who may have collected blood on a person. This information is taken into consideration to guide further study in a given disease. The information becomes part of the person's medical chart, much in the way an x-ray or CT scan might. The information is also available to the family should they wish it. The information is shared with the family doctor. Also, donated brain material is used for world wide research projects, so that we can all share information and work together towards solving the mysteries of diseases like Parkinson's disease, tremor, and other neurological disorders.

Continued Page 10

Brain Donation Continued from Page 9

Whom should I contact when I have questions about this matter or wish to arrange for me or a loved one to make such a donation?

If you wish to donate your brain once you have passed away, ask your medical doctor to help arrange things in advance, and identify contact people to help as well. Then, if you or a loved one were to pass away, things could happen smoothly and without additional difficulty to the family at a time when there are already enough emotional and personal issues at hand. The PSP Society has a Brain Bank, and the SPSP Office will be very helpful to you in this regard. You can also call 904-953-2439 or email parkinsons@mayo.edu for general information, or for information to be sent to your local physician.

PSP LISTSERVE & DIGEST

By: Bill Reiter, SPSP Volunteer

Perhaps some of you who receive the PSP "Advocate" are not aware that, for those with internet capabilities, there is also a website where those interested can send postings, and receive those posted by any of the other 200 plus members. The Society for Progressive Supranuclear Palsy sponsors a listserve to facilitate communication about PSP. It is not moderated and the Society is not responsible for its content, but a great deal of valuable information can be found there.

The Listserve, or the Digest format, is really a support group electronically; we talk with one another, discuss our problems, solutions to problems, occasionally some humor in a bleak situation, and sometimes even get into "vocal' disagreements. We share what works for us in a caregiver situation, where to find equipment/supplies and just about anything else. And of course, there is the compassion, support and caring for all who join us..... a group in which I am glad to say I have made numerous friends. Most members are/have been caregivers [CG] to a spouse, mother, father etc, but there are a several PWPSP [Persons With PSP], so we have the benefit of all viewpoints available to us. Some people are lurkers' for a period of time, but then feel more comfortable adding their questions, comments etc.. So if you believe it might be of some value to you, come join us.

To subscribe send email to: requests@hydra.welch.jhu.edu
with the following message: subscribe PSP <Your Full Name>

MEET STAN LEVIN
New Society for PSP Board Member

A native of Missouri, Stan has been an active volunteer for more than 35 years within local, statewide and national service and professional organizations. Two of his professional positions involved directing a nationwide research and demonstration project to increase volunteer participation in rehabilitation facilities and managing the Center for the Study of Voluntarism at the University of Maryland where he was an Assistant Professor at the School of Social Work. As a volunteer, Stan has fulfilled leadership positions with the Boy Scouts, the Association of Volunteer Bureaus of America, B'nai B'rith International, the Voluntary Action Center of Central Maryland and American Field Service.

Stan and his wife, Isabel, attended the March 21st family meeting in Baltimore at which Dr. John Steele reviewed the NIH Brainstorming Conference and interviewed PSP families. Stan was elected to the SPSP Board of Directors in May of 1999 and is serving on the Board Development Committee and the Executive Committee. His Master of Social Work degree was awarded by the Ohio State University and he is a long-term member of The Academy of Certified Social Workers. Stan's college-level teaching includes experiences at Youngstown University, Michigan State University and Baltimore Community College. He is currently employed at the Social Security Administration. Welcome to the Board!

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

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

An Interview with George S. Jankiewicz, Jr.
Chairman of the Board of Directors
The Society for PSP

George S. Jankiewicz, Jr. graduated from Towson University, Baltimore, MD, with a B.S. degree in accounting and an MBA from Loyola College in 1988. In 1980, he became a Certified Public Accountant and recently became a Certified Financial Planner. His professional experience includes working as a health care accountant with Blue Cross from 1985 to 1996. He has been employed by Clifton Gunderson LLC since 1996 as a health care consultant and financial planner. George and his wife, Laurie, have two sons, Phillip and Matthew. George is very involved with the Boy Scouts of America as a merit badge counselor and volunteer. He has been very active in his church community serving as treasurer from 1993-1997.

1. How did you become involved with progressive supranuclear palsy and the Society?

My father was diagnosed with PSP in November of 1995. About a year later, I noticed a stack of the Society for PSP brochures on the desk of a co-worker. My co-worker happened to be on a committee with the MD Association of CPA's that was working on promoting volunteerism. I called the number listed and offered to help in any way in this battle against PSP. That was the beginning.

2. How was the Society able to help you during this time?

The Society, especially Ellen Katz, provided me with much appreciated emotional support during the toughest of times. My dad started rapidly declining a few months after I became involved with the Society. Also, the Board of Directors was able to provide me with insight and knowledge of the disease to better equip us in facing the challenges ahead. PSP is a devastating disease and it is a tremendous help to communicate with other PSP families that have faced the same struggles.

3. You have served as treasurer of the Society and was later nominated for its Chairmanship. What prompted you to accept this critical position?

I accepted the chairmanship of the Society because the work of the Society is extremely important to so many people and indications of progress and growth were manifesting. My goal as chairman is to guide the organization in better meeting the needs of people with PSP, their carepartners, and families. I also want to raise the PSP awareness level among health care professionals and work to increase ways to increase support for research in finding the cause and cure for PSP as well as finding better ways to manage the disease at the present.

4. How have you seen the Society grow?

Financially, the Society has had tremendous growth over the past two plus years as contributions have more than tripled and funds expended for research have quadrupled. Daily calls to the office asking for help, information, support and other services are increasing steadily. However, as an organization, we are just scratching the surface of our potential. We need to establish a greater national presence, develop improved support services networks, and continually increase funding for research.

5. How can others help?

Volunteers are needed in many capacities to help establish local support groups (this should be coordinated with our Baltimore office staff). One can volunteer their talents and serve on a committee that supports Society activities. Call the office to obtain a listing of committees and positions available. Be a communicator and share experiences and ideas for the everyday management of PSP. The Society is solely supported by the generous contributions of our PSP friends. Your financial gifts are so needed and greatly appreciated. With your continued help and support, we can reach out to more persons with PSP, their families, carepartners and the health professionals. We must work to find ways to maximize the quality of life for our loved ones as we continue to strive to find the cause and cure for PSP.

"Special Events"

Susan & Harold Bagette win a national award for her Johnathan Book Series.

The Harder the Battle,
The Sweeter the Victory
Continued from Page 1

being done to treat it. Continue to support the tremendous efforts of the SPSP. It is their advocacy for PSP funding that has helped to spur the field of PSP research forward. Tell your congressional representatives how important PSP research is to one of their constituents. Just keep four words in mind: PARTICIPATE, PERSUADE, EDUCATE, AND INSPIRE.

It is well known to you, the reader, that PSP usually strikes a loved one around the time of retirement. Many people put off taking treasured vacations until such time and the onset of PSP can be a devastating and disorienting experience. It is apparent that PSP not only affects the person who suffers the disease, but, also their spouse, children, and friends who can only helplessly watch their loved one becoming progressively more dependent despite our current best research efforts.

Your story could become a powerful resource, use it to inspire and educate others on how this disease has changed your life and hopes as well as those of your loved one. Your stories have certainly inspired me. Despite years of studying this disease in all its manifestations, the stories that my patients and their families tell me about their lives together continue to inspire me to keep fighting for a treatment and cure for PSP. Together, people with PSP, caregivers, physicians and researchers are confronting PSP and we have taken the first necessary steps to identify and understand its clinico-pathophysiology. We will continue to fight for a cure. Don't despair. The harder the battle, the sweeter the victory!

GIVING A GIFT OF SECURITIES

The Society for PSP is a non-profit 501-3(C) organization that exists to promote and fund research into finding the cause and cure for PSP. The Society is exempt from income taxes in the United States. We are able to sell donated securities and use every dollar to enhance our research funding, services for people with PSP and their families, educational programs, and advocacy for all affected by PSP

Transferring listed securities to the Society for PSP is quite easy. You simply have to mail the stock certificate or bond to our office. In a separate envelope, you must mail us the executed stock or bond power. Your generous gift will be valued on the postmarked date for tax purposes. If the stock or bond is with a brokerage account, inform the broker that you want your securities on an account for the Society for PSP. The broker must then call our office and the securities will be transferred by him/her. This usually occurs the same day that you instruct the broker to make the transfer.

Please consider a gift of securities. Each dollar will help people with PSP. We are the largest network of individuals dedicated to helping find the cause and cure for PSP and improving the quality of life for persons with PSP. Please join us in this challenge! Contact our office at 1-(800)-457-4777. Thank you friends of the Society and "ADVOCATES" for those suffering through the hardships of progressive supranuclear palsy.

The Society for PSP Recognizes A Very Special Volunteer

ELIZABETH BRISSON

"Liz" Brisson is indeed an extraordinary SPSP volunteer. Liz became involved with the Society in an effort to raise money for PSP research during the time her aunt, Margaret Parker, was struggling with PSP. Honoring her aunt, Liz was instrumental in developing the Margaret Parker Research Fund in 1997. Liz's husband, Roger, climbed Mt. Aconcaqua to generate international attention to progressive supranuclear palsy as well as raise money. More than $75,000 was raised for PSP research as a result of the "Climb For A Cause."

Now Liz and Roger are preparing another adventure to increase awareness of PSP and increase resources to fund more research. Watch for upcoming news. Roger is going to "Pedal for PSP!" This is a tremendous amount of work for a volunteer!

But, not enough for Liz! This dedicated, energetic gift to the Society is also the Chairman of the November PSP Symposium in Baltimore. Liz and her committee are responsible for planning and coordinating this exciting event. Still there is more. Liz is Chairman of the Development Committee. This committee is responsible for SPSP friendraising and fundraising. This organization's growth has skyrocketed. We must attain the financial resources necessary to provide our services. Liz is working on it!!!!!

And, yes, Liz works full time for New England Financial in Boston as an Officer for Product Management and Sales providing health insurance to small businesses. She has been married to Roger for 19 years. She recently moved to Candia, New Hampshire and continues to commute to her job in Boston.

How does she have the time to help the Society? She makes the time! Despite the passing of Liz's aunt, Margaret, she has continued to remain active with the Society and is driven more than ever to help the Society's mission to find the cause and cure for PSP.

Thank you, Liz!!

Helpful Hints

Dear Editor,

These items have proved very helpful while taking care of my aunt with PSP.

Julian W.

- **EZ-Swallow Pill Crusher**
  This item is designed to crush medications, vitamins, or food supplements in tablet form to aide in swallowing them. Call 605-428-5501 / Price 9.95-7.95
- **Vacuum Feeding Cup (Model K22044)**
  This is a cup with a lid and spout designed to control drinking speeds for people with trouble grasping or swallowing. Call 800-243-9232 / Price 4.69
- **Terry Big Bib (Model K10987)**
  This is a bib designed to prevent spilling of food on clothes for people with swallowing problems. This bib is extra roomy with a vinyl backing-15 by 30 inches.
  Call 800-243-9232 / Price 6.99
- **Extra Wide Walker (Model PC 1769)**
  The Extra Wide Walker is an adjustable height walker that can also be an over-the-toilet support. This walker is designed to support up to 500 pounds. May be suitable for heavier people. Call 800 323-5547 / Price 75.00

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

or
Fax: 757-838-6086
email:
103301.640@compuserve.com

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CAREGIVER INFORMATION

National Family Caregivers Association

The National Family Caregivers Association (NFCA) is a non-profit membership organization dedicated to making life better for all of America's family caregivers. Approximately 25 million people are caregivers focusing on their loved ones' needs. The NFCA places its focus on the family caregivers. The NFCA provides services to its members in the fields of education, information, support, validation, public awareness and advocacy. For more information call 800-896-3650/ email to info@nfcacares.org./Internet: www.nfcacares.org.

"The Educated Caregiver"

An ADVOCATE reader recently wrote to the editor encouraging people to purchase the three-tape video series, "The Educated Caregiver." The cost of the tapes is $39.95. It is a video series designed to improve the quality of life of someone that is caring for a loved one within their home. Caregiving is a mission of love but can also be a thankless job at times.

The video tape series is a guide for caregivers offering ideas and suggestions about Coping Skills, Hands-On Skills, and Essential Knowledge. Education and support help to face the challenges of caregiving. For additional information about these educational tapes, please call 615-781-9494.

"The Resourceful Caregiver" Helping Family Caregivers Help Themselves

By: National Family Caregivers Association

"The Resourceful Caregiver" is a one-of-a-kind guide written by family caregivers for family caregivers. This book contains information useful in helping family caregivers care for themselves as they care for their loved one. Resources are listed for respite care, caregiver support organizations, hotlines, helplines, educational materials and even a shopping section. Personal poems, messages and articles written by caregivers are also included. Call 1-800-667-2968 / $12.95

Well Spouse Foundation

"The Well Spouse Foundation", founded in 1988, is a non-profit, self-help organization which offers support to partners of the chronically ill and/or disabled through local support groups, a bi-monthly newsletter and round robin letter chains. The organization is involved with other groups in educating health care professionals, politicians and the public about the needs of "well spouses," and the importance of long-term care. It sponsors an annual weekend conference for its membership. The organization responds to both mail and telephone inquiries from the public, offers personal outreach through letters and phone calls to its membership, and continuing support for those whose partners have died." Call (212) 644-1241 (Voice), (212) 644-1338 (FAX), (800) 838-0879 (Voice-Toll Free)

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:

ARIZONA
Maxine Faubion
9302 5. Citrus Lane
Sun Lakes, AZ 85248
(602) 895-7646
email: dmaxif@aol.com

Christina Watts, Asst. Coordinator
Gale Kittle, Coordinator
Mohammed Ali Parkinson Research Center
222 W. Thomas Road
Phoenix, AZ 85013
(602) 406-4931

ARKANSAS
Patsy Cunningham
P.O. Box 5554
Fort Smith, AR 72913
(501) 484-0407

CALIFORNIA
Dr. and Mrs. Robert Daft
527 Grovesnor Court
Sacremento, CA 95864
(916) 481-3411

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

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

Mary Marino
2298 Via Puerta Apt. N
Laguna Hills, CA 92653
(949) 855-3872

CANADA
Ms. Kim Anderson and Janice Stober
Parkinson Foundation of Canada
55 Eglinto Ave., E. Suite 400
Toronto, Ontario, Canada M4P 1G8
(416) 932-0315

COLORADO
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Movement Disorder Center
Colorado Neurol. Inst.
701 E. Hampden, #501
Englewood, CO 80110
(303) 788-4600

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Virgie Saltzman
23 Lafitte Drive
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(941) 484-7259

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Quincy, FL 32351
(850) 627-6216

Paula John
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(941) 927-3955

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(715) 362-1777

OUR PSP STORY

July 31, 1999 marked the first anniversary of the death of my dear father, Robert Shoaff Kimball. He died at 6:00 a.m. on that day from complications with PSP. It was, quite honestly, the saddest day of my life. Following is our story:

Daddy was born in 1924 in California and was an active, fun-loving husband, father, grandfather, and pilot. But, things began to change and he was diagnosed (or misdiagnosed) with Parkinson's disease in 1994. What began as subdued concern over Daddy's increasing "tumbles" turned into despair when we learned in 1997 the Dad actually had progressive supranuclear palsy for which there was no cure. The more we read about PSP, the more frightened we became as we watched the progress in textbook fashion-stiffened neck, choking, fixed stare, swallowing problems...you know the rest.

Unbelievably, Daddy remained proud, dignified and accepting of his disease even as my mother, brother, sisters, and I were in a kind of denial that we were soon to lose the most important man in our lives. Eventually, there could be no more denying the obvious. Decisions about his care forced the realities of PSP. It was up to all of us to make certain that we helped our father live the highest quality of life as his condition continued to decline.

An especially hard "tumble" put Dad in the hospital on Thanksgiving Day 1997 with a broken hip. His recovery period was spent in a wonderful, small nursing facility five minutes from home. The staff was dedicated and loving. We welcomed him home on Christmas Day. However, it was not long after when he was admitted again for aspiration pneumonia. In hopes of preventing future aspiration bouts, Dad opted for a feeding tube. This was an incredibly difficult decision because Daddy loved eating-especially peanut butter, hot dogs and cheese! Finally, his aspirations on his own saliva became so frequent and frightening that we arranged for Daddy's care in the same nursing facility where he had spent his short term recoveries. It was an excruciating decision- one that left us with a mixture of relief. He would be professionally cared for but we felt guilty that we were unable to effectively care for our loved one at home.

Daily visits and "wheelchair walks" in the sunshine with his grandchildren leading the way on roller blades were truly a treasure. I can not count the number of times we laid side by side with Dad in the hospital bed holding hands, chatting or napping. Even though his body had failed him he was still the protector and mentor that we all cherished.

Miraculously, all of our family (wife, children, and grandchildren) gathered in our home in Alaska the week before Dad's death. We each spent treasured moments with him. I believe now that as we were all together, Dad had a private discussion with God and asked that He take him home while we were all together. Exactly that occurred. He died peacefully on July 31st. He had a beautiful tranquility about him in death. He no longer displayed the stiff and fixed features of PSP. His skin was smooth and beautiful and he had a sweet mile on his face. His suffering was finally over and ours had just begun.

We continue to pray for all the victims of PSP and their families as they deal with the dreadful realities of this insidious disease. I remind them that there are many who understand their suffering and heartache. We wish them all peace and patience.

Blessings.

Written and submitted by Jenny Olendorff (daughter). On behalf of Helen Kimball (devoted wife), Todd Kimball (son), Mary Leach, Suzanne Modesitt and Lynn Groff (daughters).

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

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.

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National Library Service for the Blind and Physical Handicapped

The Library of Congress
1291 Taylor Street NW
Washington, DC 20542
(202) 707-5100

Facts

Books For Blind and Physically Handicapped Individuals

A free national library program of braille and recorded materials for blind and physically handicapped persons is administered by the National Library Service for the Blind and Physically Handicapped (NLS), Library of Congress. Under a special provision of the U.S. copyright law and with permission of authors and publishers of works not covered by the provision, NLS selects and produces full length books and magazines in braille and on recorded disc and cassette. Reading materials are distributed to a cooperative network of regional and subregional (local) libraries where they are circulated to eligible borrowers. Reading materials and playback machines are sent to borrowers and returned to libraries by postage-free mail.

ELIGIBILITY

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

BOOK COLLECTION

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

MAGAZINES

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

EQUIPMENT AND ACCESSORIES

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

MUSIC SERVICES

Persons interested in music may receive them directly from the Music Section of NLS, The collections consists of scores in braille and large print; textbooks and books about music in brailled and large print; and elementary instruction for voice, piano, organ, guitar, recorder, accordion, banjo, and harmonica in recording form.

INFORMATION SERVICES

This service is available without charge to individuals, organizations, and libraries. Publications of interest to people with disabilities and to service providers are free on request.

FOR FURTHER INFORMATION

Ask your local public librarian for more information about the program and how to apply for service. Information is also available on computer diskette or recorded cassette upon request or on the Internet at http://www.lco.gov/nls. The Library of Congress-National Library Service for the Blind and Physically Handicapped can be reached at (202) 707-5100.

SOME MEDICINES AND FOODS DO NOT MIX

The FDA and The National Consumer's League are advising people to check with their pharmacist for any warnings about combining certain medicines with certain foods. Some interactions include:

Drinking grapefruit juice less than two hours before or five hours after taking certain heart drugs (calcium channel blockers) can cause life-threatening effects.

Individuals taking blood thinning medications such as coumadin should not take Vitamin E. Foods such as broccoli, turnip greens, and spinach need to be avoided as well because they are high in Vitamin K which can reduce the effectiveness of blood thinners.

Caffeine beverages mixed with certain antibiotics can increase stomach irritation and nervousness. Many times it is difficult for consumers to understand information about drug side effects and interactions. Consult your physician and pharmacist if you have questions. There are also several sites to visit on the Internet that provide this information.

- U.S. Food and Drug Administration (FDA)
  www.fda.gov
- World Health Organization
  www.who.org
- U.S. National Institutes of Health
  www.nih.gov
- American Medical Association
  www.ama.assn.org
- U.S. Centers for Disease Control
  www.cdc.gov

Also, most pharmaceutical companies have their own web sites to inquire about the official labeling of their products.

SPREAD THE WORD ABOUT PSP

"Introductory Course in Media Relations"

Angie Gei and Kathleen Holmes

Katherine Holmes & Angela Gei

My father has progressive supranuclear palsy. When he was first diagnosed and I mentioned this to anyone, a lengthy explanation would follow as no one seemed to be familiar with this mystery. The more I learned about the symptoms and complexities of diagnosis, the more I realized how much education and awareness building was required to help PSP sufferers and direct them to the right help and support.

When Janice Stober, Kim Anderson and Sandy Jones decided to organize the first Canadian PSP Symposium in Toronto this past April, I felt compelled to actively participate and start building awareness with and through the media. I was lucky to have a good friend, Katherine Holmes who has her own public relations company, willing to come on board and guide me. When we met Ellen Katz and Nancy Brittingham in Toronto during the Symposium, they suggested we might try to document the journey as this information might be helpful to others in their fight to increase knowledge and awareness of PSP elsewhere. So, here's an introductory course in media relations 101!

Start by using or developing an event in your area (a walkathon, conference or fundraiser)-in our case it was the Symposium. We wrote a press release (see example) containing a "hook" or "angle" to catch the attention of weary journalists who receive tons of releases daily. Make sure to include all the relevant information , or the "5Ws" (who, what, where, when, why) in a succinct, factual style. Make it brief, no longer than one page. Once written, create your media "hit" list. Investigate all the reporters who cover the health, lifestyle and medical beats at your local newspapers, radio, cable and television stations. Call and obtain the correct names of each journalist—it will save you lots of time!

Now the interesting part starts! Fax your press release to the individual journalists and follow-up with a conference call. Be prepared to give a brief "pitch" to convince a journalist why they should write a story on PSP and how it could be relevant to their readers/viewers. Use a personal story to help illustrate the need for broader education and awareness of the disease. Make sure you have an authority, ideally a doctor or healthcare professional, who can speak knowledgeably about the disease to support your story. Get the TV cameras out to your event, set-up radio interviews and create photo opportunities! It may take some time and effort to reach them, as journalists are barraged with a different disease every day. But, remember, once the media ball starts to roll, more and more people will be informed and may discover an answer to their own health concerns.

The neat thing is we've just started building media awareness in Canada and the results have been positive and actionable. Stay tuned, there will be more to come!!

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Sample Media Release

(You can follow this format, personalizing it to your event.)

MEDIA RELEASE
(Include all contacts, addresses, phone #'s)

FOR IMMEDIATE RELEASE
(Date)

(Discuss your upcoming event)
EXAMPLE:

SPOTLIGHT ON PSP AS EXPERTS GATHER
FOR CANADIAN SYMPOSIUM ON
THE "MYSTERY" DISEASE

The Society for Progressive Supranuclear Palsy will host the first Canadian Symposium on progressive supranuclear palsy (PSP) Sunday, April 18, 9:15 a.m.to 3:00 p.m. at the Inn on the Park, 100 Eglinton Ave. East, Toronto, Ontario.

The Symposium will increase knowledge about PSP among people with PSP, their carepartners, families, health care professionals, and friends. World reknown experts in PSP.....

(Continue describing your event)

(Now include the following information)

Progressive supranuclear palsy is a rare, degenerative brain disorder often misdiagnosed as Parkinson's disease. It strikes middle aged adults as well as the elderly affecting 1.4 people in 100,000. In 1963, PSP was described as a distinct neurological disorder by Dr. John Steele, Dr. J.C. Richardson and Dr. J. Olszeski.

Early symptoms of PSP appear as slowness and stiffness of the muscles balance problems causing frequent falls, restricted vertical eye movements, double and blurred vision, swallowing difficulties, reduced volume and irregular explosive quality of speech. There may also be changes in mood, behavior and cognition. People with PSP ultimately become wheelchair bound and require full time care.

The Society for PSP is a worldwide organization that sponsors research, provides information, education, support and advocacy to persons with PSP, carepartners and families. The Society strives to educate physicians and other allied health care professionals on PSP and how to improve patient care. The Society for PSP can be reached at 1-(800) 457-4777, FAX 1 (410) 486-4283, email SPSP @erols.com and website www.psp.org.

For media contact:
(Provide names and contact numbers)

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signs and symptoms suggestive of PSP. The appearance of the disease both during life and at autopsy was typical for PSP except for the family clustering.

Comment: Genetic mutations causing a disease cannot be found from examining one person or even two close relatives with the disease if there is no clue as to where among the 3 billion DNA links on the 23 chromosomes the problem lies. However, for PSP, there is excellent evidence that an important component to the cause lies in the tau gene, on the long arm of chromosome 17. Therefore, pairs of siblings like these can undergo "sequencing" of their tau genes. This is a time-consuming process even for one gene, especially one as large as tau, and is presently under way in several labs. We hope that within the next few months to years, precise defects in the sequence of tau that are associated with PSP will be reported, and that this will provide a clue as to how to undo the abnormal "tangling" that the tau protein undergoes in PSP.

A strong hint that an environmental component helps cause PSP arose several years ago from the work of Dr. Dominique Caparros-Lefebvre of Guadeloupe, French West Indies. She found unexpectedly large numbers of people with PSP on that Caribbean island and hypothesized that consumption of certain native teas might have contributed. Now, the same researcher has analyzed the phenomenon in more detail with the assistance of SPSP Medical Advisory Board members Dr. Andrew Lees of London and Dr. Eduardo Tolosa of Barcelona. They found that of the 90 patients with parkinsonism at the local neurologic clinic, 31 (34%) had PSP. In U.S. or European populations, the expected figure would be about 3% to 4%.

Comment: If there is a genetic component to the cause of PSP, it may operate by rendering the individual vulnerable to the toxic properties of chemical in the air, food, water or workplace. If the relationship of PSP in Guadaloupe to the toxins in the native teas can be worked out, it may shed light on the cause of PSP in the rest of the world and could point the way to prevention of the disease through avoidance of exposure to these substances.

A possible advance in the diagnosis of PSP through the use of positron emission tomography (PET) was provided by Dr. David Kareken and colleagues of Indianapolis. At present PSP can be detected, and possibly differentiated from

Mary Lou Retton representing a product at the AAN exhibits

Dr. Lawrence Golbe and Dr. Irene Litvan at the AAN meeting in Toronto

Parkinson's disease (PD), by injecting radioactive levodopa (the active ingredient in Sinemet) into the individual and allowing the PET machine to creating a map of the brain cells that use the drug. The new research uses a different chemical, radioactive beta-CFT, which is taken up by the "dopamine transporter" on the main brain cells that degenerate in PSP and PD. They found this technique to be quite sensitive to mild degrees of brain degeneration and hypothesize that it may turn out be more useful than radioactive levodopa in differentiating PSP from PD.

Comment: For now, PET in PSP remains a research tool, but if the technique becomes more widely available or if similar, more readily accessible techniques can be devised, the diagnostic value of PET could become a routine part of clinical diagnosis and care of those with PSP. Aside from facilitating the initial diagnosis, such techniques could permit more accurate assessment of treatments designed to slow the progression of the disease.

Two presentations examined the utility of "bedside" techniques for the quantitative assessment of disability in PSP. My own work, performed with the help of most of the other neurologists in my department at Robert Wood Johnson Medical School in New Jersey, evaluated the PSP Rating Scale that I devised a few years ago. I made a videotape of myself examining five patients with PSP using the PSPRS. Each of the other neurologists, none of whom was a movement disorders specialist, then viewed the tape independently and completed the rating form for each patient. I then calculated the degree to which the five agreed with one another. This measure, called "inter-rater reliability," is one aspect of the utility of any subjective rating system. The average "coefficient of variation," a measure of variability where 0% means perfect agreement and 100% means random association, was 7.0%. This means that the PSPRS gives consistent results among neurologists with no previous training in the use of the scale.

The other report, from Dr. Esther Cubo and colleagues from Rush-Presbyterian-St. Luke's in Chicago, applied the Unified Parkinson's Disease Rating Scale to PSP, finding excellent reliability for PSP and delineating several items in the scale that were particularly informative.

Comment: This and the previous study show that PSP can be evaluated reliably with traditional "hands-on" tests, which, for studies that involve large numbers of patients or require frequent evaluations, are more practical than PET or SPECT scans in quantifying the severity of PSP.

National Organization for Rare Disorders, Inc. Announces 1999 Public Policy Agenda: How You Can Help

There are TWO MAJOR public policy issues that NORD will be focusing on during 1999; Funding for the ***FDA ORPHAN PRODUCTS RESEARCH PROGRAM*** for FY 2000, and making the ***Office of Rare Diseases at the National Institutes of Health (NIH) a permanent NIH Center for Rare Diseases with an annual budget.*** These are the primary issues that we will working on and we need your help to accomplish this.

1.**The FDA's Orphan Products Research Grant Program provide**s a small pool of research funds for academic scientists and small companies to support pivotal clinical trials on new treatments for rare diseases: orphan drugs, orphan medical devices, and medical foods. For the past several years, Congress has appropriated only $12 million for this lifesaving program; and the agency has subtracted 8% of theses funds to use elsewhere in the agency.

The track record of the FDA Orphan Research Grant Program has been extraordinary. Since the program was initiated, 20 new orphan drugs and 3 medical devices have been developed with the use of these grants and they have been approved by the FDA for marketing. Obviously, if more money were available to fund more research grants, more products would have been developed. However, $12 million per year is hardly enough to address the research needs of 6,000 rare diseases. Just one clinical trail costs over $1 million per year!

How can you help: Congress needs to understand how important this lifesaving research program is to people with rare disorders. It is a virtual life-line to the treatments and cures that we desperately need. Ask your Congressman and Senators to ***increase the FY2000 appropriation for the FDA Orphan Products Research Grant Program to $20 million.*** The track record of success for this research grant program proves that 23 lifesaving treatments would not have become available to American patients without the support of these funds. Most funds are needed to develop many more breakthrough treatments in future years!

2. ***NIH Office for Rare Diseases:*** This office was created after the National Commission on Orphan Diseases issued its report to Congress in 1989. The Commission recommended that a Center for Rare Diseases should be created to coordinate the rare disease research conducted by many agencies of the federal government in order to avoid duplication of efforts and prevent waste of precious resources. The national Institutes of Health (NIH) reported to the Commission's report by insisting there is no reason a law that would write this Center into a statue ("codify" the office), and that they would voluntarily create an "Office for Rare Disorders" at NIH.

Unfortunately, because the Office is not a "Center" nor is it codified into law, it is not permanent and there is nothing to prevent NIH from eliminating it. Furthermore, without an official permanent status, the Office does not have a permanent line item in the NIH budget, and it has no official authority to actually coordinate NIH's rare disease research activity with other federal agencies such as the Centers for Disease Control (CDC), Department of Defense, FDA, Veterans Administration, etc.

What you can do: In order to assure that the NIH Office for Rare Diseases achieves the **authority, permanence and budget** that it needs, ask your Congressman to codify (write into law) the **"Center For Rare Disease"** and to give it a line item budget of $25 million in FY2000. For FY1999, the Office received less than $3 million and this is inexcusable in relation to the scope of the problem. The NIH estimates that there are more than 6,000 rare diseases affecting more than 20 million Americans! Three million dollars is hardly enough to accomplish anything on behalf of these disorders.

Congress has enacted dozens of "offices" at NIH (e.g. for AIDS, alternative therapies, nutritional supplements, women's health, minority health, etc.) Each of these offices receives tens of millions of dollars annually through congressional appropriations, but the Office of Rare Diseases receives only $3 million primarily because it has not been written into law (codified), and it is not a "center." It is time for Congress to recognize the needs of these medically needy diseases that are desperate for research, especially because Congress recently increased the overall NIH budget by 15% and none of this increase has been aimed at rare disorders.

If you write to your Congressmen and Senators about these two critical issues, please send to the NORD office a copy of your legislators reply to you. (NORD, P.O. Box 8923, New Fairfield, CT 06812) (www.rarediseases.org) 203-746-6518.

REMEMBER THE SOCIETY FOR PSP IN YOUR WILL

Extend your support of the Society's programs beyond your lifetime. No matter what size, large or small, your gifts will continue to support our programs of education, service, support, advocacy and research.

To make a bequest of cash or other property to The Society for PSP, your will or supplemental codicil should state: "I give and bequeath to The Society for PSP, Inc., a non-profit corporation, organized under the laws of the State of Maryland, and having its main office at Woodholme Medical Building, Suite 515, 1838 Greene Tree Road, Baltimore, MD 21208, the sum of $_____ or _____ percent of the residue, rest and remainder of my estate to be used for the general purposes and mission of the organization.

A bequest to the Society is fully deductible for estate tax purposes. To learn more about opportunities for giving, consult your attorney, accountant, estate planner or call our office. Thank you for the gift that keeps giving.

Lynda Blute Appreciation Day
May 2, 1999
"Volunteer Extraodinare"

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

Regular Report of Gifts • May 1, 1999 thru July 26, 1999

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MEMORIALS

Memorials given in memory of our special loved ones and friends that were victims of progressive suprnuclear palsy as well as other diseasees

February 2, 1999 thru July 26, 1999

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Vincent DiMauro
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Robert Donley
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Stratis Doukas
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Mildred Dyke
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Ken Olson
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IN HONOR OF
February 2, 1999 thru July 26, 1999

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Allan Roder
Allen Zerfoss
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Arnold Dahlgreen
Aruna Paun
Badea Abaza
Barbara Konvolinka
Barbara & Donald Wells
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Person with PSP _____ Family _____ Physician _____ Other _____

Name of Family member with PSP _____

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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.

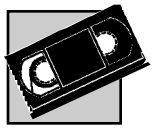
INFORMATION ON PSP AVAILABLE FROM SPSP

Learn more about PSP, its symptoms and strategies for managing them. An informative booklet and several brief folders on PSP symptoms, written in nonmedical language, are available on request. There is no charge for booklets or folders.

Video tapes of symposia for people with PSP, family members and caregivers. They provide scientific information as well as suggestions for day-to-day caregiving.

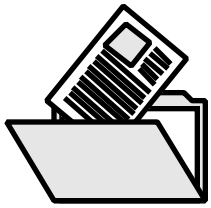
The booklets, folders and video tapes represent SPSP's effort to inform patients, family members, caregivers, and professionals about PSP and its management. **ORDER BY NUMBER at 1-800-457-4777.**

Video Tapes



"The Diagnosis of PSP" (#2)	Made for and sold only to neurologists, neuroscience nurses and similar professionals. The tape depicts presentations on diagnosis of PSP at the international scientific conference in Barcelona. Recommended for clinicians and faculty. VHS format, U.S. $30, prepaid.
1997 Symposium (#10)	Captures the presentations at SPSP's 1997 symposium for patients, family members and caregivers. See and hear Drs. Steele, Golbe, Reich, Zee, Litvan, Growdon and several other experts discuss various aspects of PSP. 3 tapes of complete program. VHS format, U.S. $75 plus $7 shipping outside U.S. $10 shipping.

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.
"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 personalty 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, cargiving 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
Telephone 00 44 (0)1327 860342
E-Mail 10072, 30@compuserve.
Website Http//pspeur.org.uk

"FRIENDS OF THE 1999 SYMPOSIUM" HONOR ROLL

Your gift towards sponsoring the 1999 Symposium will help fulfill our mission of providing vital education and support to Persons with PSP and PSP Families. Our registration fees for the Symposium unfortunately do not cover our costs. Won't you please make a special additional gift to ensure the success of the Symposium? You will be recognized on the Symposium Program and in the ADVOCATE.

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Please list additional guests information on separate sheet of paper and enclose.

RESERVATIONS

Friday Night Activities # _____ guests $39/person $ _____
Reception and Dinner included

Saturday's Symposium # _____ guests $59/person $ _____
Continental breakfast, two refreshment breaks, and lunch included
$69/person after October 1

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Register persons with PSP for "How I Feel"Breakout Session. Name _____

I would be interested in attending a "Planned Giving" Breakout Session. Name _____

Reserve a copy / _____ copies of the videotape of the Symposium. (Approximately $75 for three tapes.)

Special dietary needs _____

Other special needs _____

Wheelchair seating space needed: Yes / No *(Families must provide own wheelchair.)*

Question(s) for the Ask A Doctor Panel _____

_____

_____

Question(s) for Dr. Steele's "How I Feel" session _____

_____

_____

(Use additional sheet if necessary)

ADVOCATE MAILING LIST UPDATE

PLEASE RETURN TO OUR OFFICE BY SEPTEMBER 30, 1999

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