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**INSIDE**

**MORE UPDATES  
ON PSP RESEARCH**

**OCTOBER IS  
PSP AWARENESS  
MONTH**

**"SPECIAL EVENT"  
PLANNER**

**CARING...**  
*Through Education and Support*



*Lecture Series*



*Caregiver's Panel*



*National PSP Support Group  
Leaders*



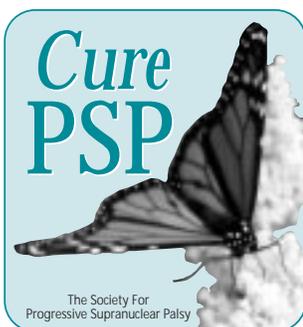
*Workshops*



*Living with PSP*



*Exhibits and Resources*



**The Sixth Biennial National Symposium  
On Progressive Supranuclear Palsy**

MAY 17-18, 2002  BALTIMORE, MARYLAND

# The Society for Progressive Supranuclear Palsy

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Reba and David Saks

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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 fatal degenerative brain disorder that has no known cause, treatment or cure. The Society provides information, education, support and advocacy to persons diagnosed with PSP, their families, and caregivers. The Society educates physicians and allied health professionals on PSP and how to improve patient care.

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

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(In memory of Henry and Jane Ogiba)

Assistant to the Editor: Debra Thompson

(In memory of Lois Croft Davis)

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# Chairperson's Corner

Liz Brissom  
Chairperson, Society for PSP

*"Hope is necessary in every condition. The miseries of poverty, sickness and captivity would, without this comfort, be unsupportable."* Samuel

Let me share with you what I believe is the key ingredient to life with PSP... being hopeful. My message is simple... and one I hope will help you to keep going forward knowing you are not alone. Here are some life lessons that you probably already know or maybe forgot and can reflect upon once again.



By definition, hopeful means: "full of, or manifesting hope: having a hopeful attitude." The definition continues to say: "affording grounds for hope, promising, a hopeful situation."

**H** is for humor, honesty and happiness. It continues to amaze me that those of you afflicted with PSP still have such a wonderful sense of humor despite your many challenges – a lesson from which we can all learn. It's important to be honest about how you are feeling; whether you have PSP or care for someone who does, it's a way to keep everyone in check and to keep your spirit from breaking. By practicing hope, hopefulness becomes a habit and by your acts of caring you will have an impact on people, which brings about happiness.

**O** is for optimism. Keep looking at the bright side of things. It seems to make sense that being optimistic is the best way to look at your situation versus the alternative. As a Society, we are optimistic that researchers will continue their studies in finding a cure for PSP and I'm sure you share that same state of mind.

**P** is for persistence, problem solver, promise, positive thinking and prayer. Often we hear about the power of positive thinking or of prayer and while it is difficult, keeping a positive attitude can help you through tough times and so can praying. No matter what your religion is, praying can be a very powerful tool. As a caregiver, you are a problem solver, looking for ways to keep your loved one comfortable. Hope is always available to us no matter how defeated we may feel at times. When needed, take a deep breath and you can summon up hope.

**E** is for exercise, education and extraordinary. Hopefully, you've acquired some practical advice or gained new information from the PSP Advocate or from support group meetings that you can use for managing day-to-day activities that will help you in coping with PSP. Also, it's important to have some form of daily exercise, particularly if you are a caregiver, as a means of staying healthy and for your overall well-being. Studies have shown that caregivers are more prone to illnesses and injuries as a result of their increased workload and responsibilities, so it is important for you and for the person you are caring for that you stay healthy through a moderate exercise program. Research has shown better sleep patterns and lowered blood pressure can result from exercise. For persons diagnosed with PSP regular

exercises can with the slowness of movement and muscle rigidity. Hopefully you've had a opportunity to meet or speak with many of the extraordinary individuals from the office of the Society, including volunteers, support group leaders and board members that give of themselves unconditionally everyday.

**F** is for faith and forgiveness, a few adjectives to describe how we can nurture the growth of our souls. We tend to look at this disease and want to place blame on ourselves or others or ask how could this have happened. If you haven't read the book written by Rabbi Harold Kushner, "Why Bad Things Happen To Good People," I would highly recommend it for some help in answering those questions. I read this when I learned about my aunt's diagnosis with PSP. As you know, the the Society's logo, the butterfly, represents hope, but it also symbolizes freedom that one day a cure will be found for PSP and the butterfly can spread its wings and fly away.

**U** is for the uniqueness of this disease. As you know, PSP is a rare disease and it is through the "U" in all of Y-O-U-R, efforts that the cause and cure for PSP will be found.

**L** is for love, life and laughter. As I said earlier, I am always impressed with the sense of humor those afflicted with PSP have. Another part of our growth in life is through love by our actions in giving and receiving it. As you are only too well aware, life is very precious, but let us not forget that, where there is life, there is hope. We need to live each day to the fullest, as if it were our last.

Let me end with a quote by Robert H. Goddard: "It is difficult to say what is impossible, for the dream of yesterday is the hope of today and the reality of tomorrow."

So let's be hopeful that a cure for PSP is found soon and the butterfly can fly away. God bless you.



## A SPECIAL THANKS

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

## Director's Doings



The Society has selected the Monarch Butterfly as its logo. We have called it our Butterfly of Hope and have chosen it because of our mission and our passion. Why has the Society selected the Monarch Butterfly? What does it mean to me and most importantly, what does it mean to you?

The Monarch Butterfly signifies the Society's determination to find the cause and cure for

PSP. The Monarch Butterfly is a survivor—it has gone through a metamorphosis of many stages—larva, pupa, caterpillar and chrysalis—before it emerges as one of the most beautiful symbols of nature—a perfect expression of freedom, life, youth, and joy. But it had many hurdles to attain and many natural enemies to thwart its sweet existence—man, disease, other animals and weather. But it has survived, free for us to enjoy.

The Society is dedicated to freeing our world of PSP so that none of us, now or in the future, will know the sorrow and difficulties of the progression of this difficult disease. We want a cure, a treatment and ways to prevent the illness. We want PSP to become extinct and the Society is the only organization dedicated to this end. Statistics warn us that the number of persons will double from 20,000 currently to 40,000 in 20 years. If we do not act, the growing menace of PSP will strike more and more people. We want to offer you now all that we can—information, support, research and most importantly, HOPE for the future and potential future victims.

As an organization, we too are like the butterfly. We began our journey of growth and metamorphosis almost 12 years ago and we have become a formidable force in the fight against PSP. From the small home of founders David and Reba Saks, the idea to form a Society was spawned. We have grown from off the kitchen table with 11 founding members to a strong, nationally based Board of Directors, volunteers and support groups throughout the US and Canada. When I was hired in 1996, there were 3,000 in the database. Now there are 33,000 donors, families and health care professionals. Our income was \$60,000 in 1996 and last year it was \$1.5 million. We have funded 50 research grants totaling 1.3 million dollars—and we certainly are not yet a full-fledged Monarch Butterfly, but we are trying. We want to thank you for helping us grow by your gifts of money, volunteer time, expertise and in-kind donations.

As the Executive Director, I lead a team of fine "Butterfly Collectors and Enthusiasts." It is our job to do the jobs connected with loving and caring for butterflies. We collect, we assemble, we study and do research, and we send the butterflies on their journey to do their important work of cross pollination of flowers and trees, making the world a more beautiful place to live.

We collect—we collect you! That is correct. You are on our mailing list or you have learned about us on the website. You have connected with us and by doing so, you have learned something important—YOU ARE NOT ALONE. Nor should you go through the journey of PSP alone. We are your partners on the journey with PSP. Use us—we are here for you.

Additionally, we study. We study the causes of PSP with the life-saving work of our Medical Advisory Board and many researchers throughout the world. Our most important work is to support the work of PSP research by becoming subjects in studies, by encouraging the government to do research into PSP at the NIH and by giving gracious gifts to advance research. We note that Dudley Moore initiated the Dudley Moore Research Fund. His Bentley was auctioned off at Christie's in New York and half of the proceeds will support PSP research in his name. Thank you, Dudley. We will miss you.

Another thing we do as active "entomologists," we accept your thoughtful gifts with kind thanks. Your support through gifts of cash, stock, planned gifts, in-kind donations and the planning of special events is what keeps us "flying on gossamer wings." You are the wind beneath our wings and we cannot survive without you. Your gracious and generous gifts are sincerely appreciated.

And lastly, we "show off" our butterflies—acknowledging the work of staff, and most importantly, the volunteers who serve on the Board of Directors, on committees and especially the exceptional work of the support group leaders. Our volunteers perform the most fundamental act of citizenship and philanthropy in our Society. They offer their time, energy and skills to improve their surroundings and help others with PSP. Our support group leaders decrease suffering as they reach out to PSP families in their communities. They take their time to listen, to educate and to support. They work tirelessly to improve the lives of others and in return enhance their own.

Thank you for the opportunity to serve you as the leader of a fine team of Butterfly Lovers—staff, volunteers, board and committee members. You fill my life with hope and opportunity to make a difference.

Yes, I have a vision for all of us—that one day, the Butterfly of Hope will set us free and keep us free from PSP. It is a vision that can become a reality. Let's go out and capture the Hope, the Spirit and the Opportunities that each wonderful day brings to all of us.

Sincerely,

A handwritten signature in cursive script that reads "Ellen Pam Katz". The signature is written in dark ink and is positioned above the printed name and title.

Ellen Pam Katz  
Executive Director

## “The Society for PSP Knows Where It Is Going.”

Stephen Hamer  
Vice-Chair, Society Board of Directors  
Special Donors Committee Chairperson

Yogi Berra once said, “If you don’t know where you are going, you probably won’t get there.” I would add a corollary to that. “If you don’t know where you are going, how will you know when you get there?”

Your Society knows where it is going. The growth over the last six years has been nothing short of phenomenal; and it has been happening because of the dedicated and inspired work of many individuals. I became involved with the Society about a year and a half ago because I believed I could have a positive impact. It has been much more than that.

Working with the Society has been one of the most rewarding experiences of my life. To be able to work with and learn from such an outstanding group gives this experience much more meaning than I ever thought possible.

In 1995, the Society was little more than a group around a kitchen table. Now, many wonderful volunteers have joined in the effort. To paraphrase the great Winston Churchill, “Never have so few done so much for so many.” That may seem like a bit of a stretch, but for families with PSP, their battle is no less significant to them than “The Battle of Britain” in 1940. The Society for PSP is a lifeline for these families.

We are part of this battle. We wish to find a cure for PSP, to provide support to those families in need and to educate both the medical community and general public.

We are now beginning to develop our Strategic Plan for the years 2004-2007. This creative process is like “health food” for the soul. When we look at where we are and where we want to be in five years, the feeling is exhilarating. There is nothing like big goals to generate loads of enthusiasm and hard work. It stimulates lots of creativity and innovation. There is no room for complacency.

For your Society to succeed, we need willing volunteers and money. The financial support of our donors has been

outstanding. Each year has brought many pleasant surprises. However, the Board of Directors decided we must be more active in soliciting larger donations on a consistent basis. For this reason, we have formed the Special Donor Committee.

Mario Andretti once said, “If everything is under control, you’re just not going fast enough.” I could not agree more.

The remarkable group that forms the Special Donor Committee is a reflection of the outstanding individuals who work so hard to make the Society for PSP so dynamic. We had our first meeting in March 2002 in Baltimore, as well as several conference calls. It was heart-warming to hear the stories and understand how dedicated each of these people is to eradicate this illness in the long run and give meaningful support to families in the interim. As the conversation and ideas flowed, it was clear everyone was very excited about the future. We must now build on this great momentum.

The special donor committee has begun to flesh out a plan of action. We are committed to making sure that the Strategic Plan for the 2004-

2007 period will be properly funded. We must increase our budget as greater and greater demands are made for services, education, and research funding.

Last year, the Society raised approximately \$1.4 million. This will have to more than triple over the next five years. We know that amount is well within the realm of possibility especially with your generous support. We also still have room for many more volunteers who look forward to making a real difference.

Remember, we will all be winners as the Society reaches each plateau. Perhaps, then, you will not have to explain what PSP is the next time you are talking to an acquaintance, or more importantly, your family physician.



Stephen Hamer (right) with Ken McKusick,  
Society Board Member

### 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:

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Website <http://www.pspeur.org>

### GRANT ANNOUNCEMENT:

The Society for PSP announces its Regular Grant Program up to \$50,000 supported by the Erwin and Pearl Poizner Memorial PSP Research Fund, The Dudley Moore PSP Research Fund, The Eloise H. Troxel Memorial PSP Research Fund and other designated funds.

Deadlines: April 1 and October 1

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

Deadline: October 1

For information contact: Dr. Lawrence I. Golbe, Chairman of the Medical Advisory Board at [golbe@umdnj.edu](mailto:golbe@umdnj.edu) or Fax 732-235-7041.

### 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 PSP

## Meet Jessica Quintilian

*The Society's New  
Director of Outreach and Education*



I joined the Society on May 1, 2002 as the new Director of Outreach and Education, just in time for the Sixth Biennial Symposium. What an introduction it was! I was impacted by the events in many ways, but took two main thoughts back home with me: one, a better understanding of PSP, the needs of those living with PSP across the country, and two, "I really have my work cut out for me!"

Let me share with you how I found this position and the Society. For the past two years, I had been the Education and Training Coordinator for a grant-funded statewide project to increase public awareness on the effects of brain injury. My job included planning and implementing regional conferences and trainings, creating educational materials and modules and co-chairing an education and outreach committee. One of the best parts of the job was the wonderful people I met along the way. I had the opportunity to work with everyone from survivors of brain injury, to neuropsychologists, to police officers. Plus, I had an unbeatable team to work with, and some of my most cherished friendships evolved out of this connection to the world of brain injury. I absolutely loved the work, but for those of you who have any experience with grants, you know that all good things (like funding!) must come to an end.

I was thrilled to see the Society's advertisement for a Director of Outreach and Education in *The Baltimore Sun*. I had heard of PSP, but like most people, did not really know much about the disease. I had investigated other jobs, but nothing really "grabbed" me. This one did. After my initial interview and a meeting with the Outreach and Education Committee by telephone, I thought, *I would love this work... it seems like a perfect fit*. I was pleased to accept the offer a few days later.

Throughout my career, I have served in a variety of roles, including Clinical Coordinator in the Johns Hopkins School of Medicine Department of Neurology, Director of Health and Wellness Education for Quest Fitness, and wearing many "hats" at Health Management Resources, a management and consulting firm near Washington, D.C. When I think back on my career choices and what I enjoy most in my work, the answer is always the same. For me, making a difference in the lives of other people is the most important thing I can do with my life. I enjoy helping people achieve a better quality of life and working in a field that is in harmony with my personal values. Since I have always been fascinated by health and medicine, working as a health educator allows me to combine my passion for health promotion and disease prevention with teaching, communication and creativity. I feel so blessed to be able to do the kind of work I enjoy with another terrific team that I am proud to be a part of. I, like you, want most of all to see an end to this devastating disease. Until that day comes, I am pleased to join you as a partner in the fight against PSP.

Jessica Quintilian, BS, CHES  
Director, Outreach & Education

## Our Sympathy



The Society for PSP extends its sympathy to the Gray and Neagle family for the loss of their loved one, Jim Gray. Mr. Gray is survived by loving wife Dianna, daughter Kari, son Kevin, daughter Jennifer Neagle and son-in-law Denny. Denny, pitcher for the Colorado Rockies, and his wife, Jennifer, established the "Strike Out PSP Research Fund." A few weeks prior to the loss of Mr. Gray to progressive supranuclear palsy, Denny and Jennifer Neagle and The Society for PSP were all recognized by the Colorado Rockies in a pregame activity at Coor's Field in Denver. Joining Denny, Jennifer, and their son Denny Neagle III or Tres, were Jackie Allison, Society Assistant Director; Larry Golbe, MD, Chair of the Society Medical Advisory Board; and Nancy Brittingham, PSP Advocate Editor. Thank you, Denny and Jennifer, for raising awareness about PSP and supporting a fund to find the cause and cure for this disease.



*Jennifer, Tres and Denny Neagle raising PSP awareness  
April 24, 2002 just a few weeks prior to the loss of  
Jennifer's dad, Jim Gray to PSP*

### REMINDER! OCTOBER IS PSP NATIONAL AWARENESS MONTH

October 2002 is designated as our Third Annual PSP Awareness Month. This is the time that we are asking all persons affected by progressive supranuclear palsy to join together nationally and educate others about this devastating disease. Now is the time to start planning your event. Last October, many events were planned around the country and as a bonus, \$18,000 was raised to help support research and the Society's services. Contact the Society office at [spsp@psp.org](mailto:spsp@psp.org) for more information.

# The Society for PSP Thanks Our Special Presenters at the Sixth Biennial PSP Symposium on May 17-18

### **KENNETH ALAN MCKUSICK MD, FACNP, FACR** *"Symposium Moderator"*

Dr. McKusick is certified by the American Board of Internal Medicine and the American Board of Nuclear Medicine. He is a Fellow of the American College of Nuclear Physicians and the American College of Radiology. He is also a retired Associate Professor of Radiology from Harvard Medical School. Now retired from active nuclear medicine practice at Massachusetts General Hospital in Boston, Dr. McKusick is currently president of the Society of Nuclear Medicine Education and Research Foundation, whose mission is to improve health care through the use of radioactive pharmaceuticals.

Having developed some experience with governmental health policy, he continues to be active nationally on those matters that affect the radiology community. He lives on Cape Cod, where he and his wife have become very involved in water resource, health and long-term planning issues.

### **JOHN C. STEELE, MD** *"Describing PSP-A Historical Account"*

Dr. John Steele is a neurologist and a Fellow of the Royal College of Physicians of Canada, the American College of Physicians and a Professor of Medicine at the John A. Burns School of Medicine in Hawaii. In 1972, he came to Oceania as a practitioner and teacher to assist the development of health services for the Trust Territory of the Pacific Islands in Marshall Islands and Ponape. In 1983, he moved to Guam and was challenged to understand an unusual neurodegenerative disease of the Mariana Islands called lytico-bodig. His search for the cause of this geographic isolate of tauopathy has remained his passion for almost 20 years. He is the Director of the Micronesian Health Study II, Physician-Director of the GMH Skilled Nursing Facility, and a neurological consultant for Guam and other Micronesian islands.

Dr. Steele was born in Toronto and graduated from medical school there in 1959. His postgraduate training in medicine, neurology and neuropathology was in Toronto, London, and Marseille. He is best known for his description of progressive supranuclear palsy (PSP), a universal and distinctive tauopathy he characterized with Drs. Richardson and Olszewski in 1963. He is pleased to be the Honorary Chairman of our Society for PSP.

### **IRENE LITVAN, MD** *"Update on PSP Research"*

Dr. Irene Litvan is Chief of the Cognitive Neuropharmacology Unit, Suburban Hospital. She received her medical degree from the University of Uruguay and later completed her neurology residency and fellowship in Neuropsychology and Dementia in Barcelona, Spain. In 1986, Dr. Litvan joined the Experimental Therapeutics Branch, National Institutes of Health (NIH), as a Post-doctoral fellow. After completing a required second residency in neurology at Georgetown University, Dr. Litvan returned to the NIH as Senior Staff Fellow in the Neuroepidemiology Branch of the National Institute of Neurologic Disorders and Stroke. In 1997, Dr. Litvan joined the Henry M. Jackson Foundation where she remained until 1999. She is affiliated with Johns Hopkins University and George Washington University, and is a part-time Consultant at the National Institutes of Health.

Dr. Litvan has published numerous peer-reviewed articles on atypical parkinsonian disorders, in particular progressive supranuclear palsy, and has coedited, with Professor Yves Agid, the first book on progressive supranuclear palsy (PSP) and with Christopher Goetz and Anthony Lang, the first book on corticobasal degeneration. Dr. Litvan is a member of the American Neurologic Association and a Fellow of the American Academy of Neurology and serves on many boards and committees including the Executive Committee of the World Federation of Neurology research group on dementia, the American Academy of Neurology Annual Meeting Subcommittee and the Scientific Issues Committee of the Movement Disorder Society. She is also a member of the medical scientific boards of the Society for PSP and the PSP Association for England and Europe. Dr. Litvan received the NIH merit award for leading international multicenter studies to evaluate and improve the clinical diagnostic criteria of several parkinsonian and dementia neurodegenerative disorders. She is currently working on the search for biologic markers, and symptomatic and biologic therapies to slow the course of these neurodegenerative disorders.

### **MARK WALKER, MD** *"Eye Movements in PSP"*

Mark Walker received his medical training at Johns Hopkins and completed a neurology residency at the University of Michigan in Ann Arbor. He then returned to Johns Hopkins for subspecialty training in neuro-otology. He is currently an Assistant Professor of Neurology. His clinical practice focuses on patients with neurological disorders affecting eye movements and balance. Dr. Walker is a faculty member in the Ocular Motor and Vestibular Laboratory. He has a research grant from the National Institutes of Health to study eye movement disorders in patients with diseases affecting the cerebellum. Along with Dr. David Zee, Society Medical Advisory Board Member, he is also conducting eye movement studies in patients with PSP. He has given lectures to both medical and lay audiences on topics such as dizziness, eye movements, and cerebellar disease.

### **LAURA PURCELL VERDUN, MA, CCC/SLP** *"Helpful Hints for Swallowing in PSP"*

Laura Purcell Verdun has been a certified and licensed speech pathologist for more than 10 years. She completed her graduate training at Saint Louis University, and clinical fellowship with the Johns Hopkins University Department of Otolaryngology-Head & Neck Surgery. During her eight-year tenure at Hopkins she had the opportunity to develop clinical expertise in motor speech, voice and swallowing disorders associated with neurodegenerative diseases, developing a particular interest in PSP. She completed an 18-month tour with the Laryngeal & Speech Section of the NINDS/NIH. She is now in private practice in Northern Virginia with Otolaryngology Associates, P.C.

### **SUSAN IMKE, RN, MS** *"Family Adjustments to Chronic Disease"*

Susan Imke, RN, MS, is an advanced nurse practitioner holding dual certification in gerontology and family health-care. She earned a Master of Science degree in Community Health Education from The University of North Texas and maintains a geriatric consulting practice in Ft. Worth, TX.

## Special Events

Ms Imke serves on the board of The Parkinson Alliance in Princeton, NJ, and is an educational consultant to the National Parkinson Foundation in Miami, FL and the Southwest Region of the American Association for Retired Persons. She has authored numerous publications for families living with chronic neurological disease and lectures widely to healthcare professionals and support group audiences on topics related to movement disorders and health maintenance. Susan has recently become a member of the Society Board of Directors.

### **PAUL FISHMAN, MD** *"An Overview of PSP"*

Dr. Fishman is professor of neurology at the University of Maryland School of Medicine, and Director of the Division for Neurodegenerative Diseases.

He received his Ph.D. from Yale University and his M.D. from The Johns Hopkins University School of Medicine. His training in neurology was completed at Columbia-Presbyterian Medical Center. He is the founder of the Alzheimer's and Parkinson's Disease Clinic at the University of Maryland, as well as the Medical Advisory Board of the Alzheimer's Association of Maryland.

He is the former chair of the Institutional Review Board for the supervision of human research at the University of Maryland, Baltimore. His current research is supported by the Department of Veterans Affairs, where he also chairs the review group for Neurology, as well as the NIH (NINDS) and the Society for PSP. He has a longstanding interest in experimental therapies of neurodegenerative diseases with a research program devoted to the development of vectors to deliver therapeutic proteins to neurons.

### **HEATHER J. CIANCI, PT, GCS** *"Mobility Issues in PSP"*

Heather J. Cianci received her Bachelor of Science degree in Physical Therapy from the University of Scranton, in Scranton, PA. She is currently working in the Master's program for Gerontology at St. Joseph's University in Philadelphia. Heather has been practicing at Pennsylvania Hospital in Philadelphia since 1994. Heather began specializing in the treatment of movement disorders in 1998 and became a Board-Certified Geriatric Clinical Specialist in Geriatrics in 1999. In 2000, she began practicing at The Dan Aaron Parkinson's Rehab Center at the Penn Neurological Institute, which specializes in treating movement disorders. Cianci is co-leader of the Philadelphia area PSP Support Group.

### **GWYN M. VERNON, MSN, CRNP** *"Caregiver Panel Moderator"*

Gwyn M. Vernon is a neurology nurse practitioner in private practice with a physician colleague, Stephen M. Gollomp, MD, at the Lankenau Hospital near Philadelphia, PA. Gwyn has 25 years of nursing experience, 14 of which have been in neurology and movement disorders. In addition to nursing practice, Gwyn is on the faculty of the Graduate School of Nursing at the University of Pennsylvania. She has authored or co-authored over 20 articles published in the nursing and medical literature on care of patients with neurologic disorders and related research projects. Gwyn is a member of the Society Board of Directors.

### **LAURIE S. FRANK, ATTORNEY AT LAW** *"Business EVERYONE Needs to Take Care of"*

Laurie S. Frank graduated from the University of Maryland School of Law and holds a Master's degree in Social Work and a certificate in Gerontology from the University of

Maryland School of Social Work. Before joining the Law Office of Jason A. Frank in 1995, she was a Housing Specialist with the Maryland Department on Aging, with a focus on Medicaid issues. She has taught courses on elder law for the University of Maryland University College and the Maryland Institute for Continuing Professional Education of Lawyers. She is a member of the Elder Law Section of the Maryland State Bar Association, the National Academy of Elder Law Attorneys, and the National Association of Social Workers.

### **WENDY M. RESNICK, RN, MS, CS** *"Support Group Leadership Training"*

Wendy M. Resnick, RN, MS, has facilitated the organization and development of The Depression and Related Affective Disorders Association (DRADA), a voluntary health organization for persons with depression and manic depression, family members, and mental health professionals.

Since 1987, she has been employed by DRADA as the director of its very active Support Services Program. The program has been successful in assisting individuals with this illness and family members in the community to develop mutual help support groups for persons affected by these disorders. Ms. Resnick provides ongoing consultation and leadership training to group leaders facilitating all types of groups. Her training workshops are nationally renowned.



*Paul Fishman, MD*



*Laura Purcell Verdon, MA, CCC/SLP*



*Laurie Frank, Attorney At Law*



*JoAnne Armstrong, Mary Anne Memminger & Charlotte Tripet at the Symposium*

## Special Events

# Thank You

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# Special Events

## Thank You Rena, Brian & Dudley

Saturday, May 18, 2002 was a wonderful evening of friendship and dining. The Society for PSP hosted this special event to honor and thank Rena Fruchter, Brian Dallow, Dudley Moore and Music for All Seasons, Inc. for raising awareness of PSP internationally and establishing the "Dudley Moore PSP Research Fund." Music for All Seasons provided the evening's lovely musical entertainment by the Diva Duo. Several other special guests were recognized by the Society, including Provident Bank for their generous gift to support the Symposium.



Rena



Dudley



Brian



Stephen Hamer, Liz Brisson, Brian Dallow, Rena Fruchter and John Steele at the evening program.



Janet Shock from Provident Bank presents a gift to Liz Brisson, Society Chairperson

The Society is pleased to announce that it has received a gift of \$56,000, half of the proceeds from the sale of Dudley Moore's Bentley at the Christie's auction on May 18, 2002. The car sold for \$125,000.

Music For All Seasons received the same amount. It is wonderful that Dudley Moore made this magnanimous gift to the "Dudley Morre PSP Research Fund" before his death. Thank you, Dudley.

## SIXTH NATIONAL BIENNIAL PSP SYMPOSIUM VIDEOTAPE ORDER FORM

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# 54th Annual Meeting of the American Academy of Neurology

## Five Original PSP Research Presentation Summaries

Lawrence I. Golbe, MD  
Chairman, The Society for PSP Medical Advisory Board  
Professor and Acting Chairman  
Department of Neurology  
UMDNJ-Robert Wood Johnson Medical School  
New Brunswick, NJ

Five original research presentations on PSP were given at the 54th Annual Meeting of the American Academy of Neurology held in Denver from April 13 to 20, 2002. The AAN meeting each year is the world's leading venue for early communication of clinical research in neurology. Presentations here typically precede their appearance in journals by months to a year or more.

### SLEEP DISTURBANCES

Dr. Isabelle Arnulf and colleagues from Paris performed polysomnography (monitoring of many brain and body functions during sleep) in 15 patients with advanced PSP to study the problem of excessive daytime sleepiness. Patients averaged 52 arousals from sleep per hour. One patient averaged 127 arousals per hour. Most nighttime arousals were caused by obstructive sleep apnea. About half of the patients with obstructive sleep apnea were receiving benzodiazepines, a popular class of sleeping pill that includes lorazepam, diazepam and temazepam. About a third had periodic leg movements, a common nighttime abnormality in the parkinsonian disorders. This work suggests that use of some bedtime sleeping pills may actually impair nighttime sleep by interfering with breathing, producing daytime drowsiness, although cause-and-effect was not demonstrated. It also suggests that treatment of periodic leg movements could improve daytime drowsiness.

### GAIT DISTURBANCES

Another group from Paris, this one led by Dr. Marie-Laure Welter, analyzed the gait abnormalities of PSP, Parkinson's and healthy people of similar age using an electronic "force platform." They found that the gait difficulty of PSP, far more than that of PD, results from defective braking of the fall of the center of gravity at the end of each step. This abnormality responded poorly to levodopa not only in PSP but also in PD. However, in PD, there were also abnormally short strides and slowed velocity, which did respond to levodopa.

### BEHAVIORAL DISTURBANCES

Continuing the strong showing for the French, a group led by Andrea Slachevsky from Paris evaluated the diagnostic

value of the "applause sign" in PSP. This is where the patient is instructed to clap three and only three times. An inability to inhibit the action after the third clap indicates frontal lobe difficulty, which eventually occurs in nearly all patients with PSP. They found the applause sign to be present in all 42 patients with PSP tested. Thirteen of the 42 did more than 10 claps. Only one of 18 patients with PD showed the sign. Surprisingly, none of 24 patients with frontotemporal dementia (a condition very similar to PSP, but affected thinking more severely than PSP and movement less severely) had the sign despite the fact that both PSP and FTD produce a "frontal lobe dementia." They conclude that the "subcortical" damage of PSP is necessary to produce the applause sign and that it can be used to differentiate PSP from FTD and PD.

A team from Norway and the US led by Dr. Dag Aarsland performed detailed psychological testing on 60 patients with "dementia with Lewy bodies" (a variant of Parkinson's disease that affects thinking as the first and worst symptom) and 35 with "Parkinson's disease dementia" (Parkinson's disease that eventually produces dementia), comparing them with 49 similarly tested patients with PSP. They found that the patients with PSP did better on memory tasks than the other groups but less well on "conceptualization" (tasks such as describing similes) and "construction" (tasks requiring spatial reasoning). This study is larger than most previous ones and helps delineate just which parts of the brain are not working normally in PSP.

### MRI IN PSP DIAGNOSIS

Dr. Hillary Ross led another international team from Bethesda, Maryland and Tel-Aviv, Israel that performed MRI scans in 41 patients with PSP and 19 with corticobasal degeneration (CBD), a condition that is similar to PSP. The patients had been diagnosed by neurologists who interviewed and examined them. They analyzed many MRI measurements by sophisticated statistical methods and formulated a "model" to differentiate the two disorders solely by those MRI measurements. They found that if the diameter of the midbrain (the seat of the most intense damage in PSP) was less than 16.6 mm, or if that diameter was 16.6 mm or more, but the height of the corpus callosum (a band of tissue connecting the two halves of the cerebrum) was more than 4.4 mm, PSP was the diagnosis. All patients of the group of 60 who satisfied this criterion had PSP and 78% of the patients with PSP satisfied the criterion. The next step will be to test the value of this MRI criterion in distinguishing the difficult cases that cannot be diagnosed by other means.



## More Updates on PSP Research

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

### TWO PSPS?

PSP, like any disease, varies from one sufferer to another with regard to the speed of progression and prominence of the various symptoms. At the microscopic level, too, PSP varies with regard to which part of the brain is affected first and worst. Nevertheless, this variability is no wider than occurs in most other diseases and PSP is therefore considered to be a single disease. But in the April 2002 issue of the prestigious British journal *Brain*, a team of neurologists and neuropathologists led by Dr. Huw R. Morris and Dr. Tamas Revesz of University College and the Institute of Neurology in London report observations at the biochemical and genetic level suggesting that what we call PSP may actually be more than one disease.

The scientists used 26 brains that had been donated by PSP sufferers to a research brain bank similar to the one run by the Society. They analyzed the tau protein, which is vital to the function of normal brain cells and forms abnormal blobs called neurofibrillary tangles in cases of PSP. They also analyzed the tau gene for the "H1 haplotype," which had previously been found to be present in about 90% of people with PSP but in only about 60-70% of the rest of the population. They also examined those patients' neurologists' records with regard to the pattern of symptoms during life.

All 26 brains were confirmed to have PSP at autopsy. The patients who had donated their brains were then divided, based on their neurologists' office notes, into those with "typical" and "atypical" PSP symptoms. Some of the atypical group of 15 patients resembled patients with Parkinson's disease, others had normal eye movements, some had only mild balance difficulty and one had what appeared to be corticobasal degeneration. The atypical group had a slightly longer duration of illness although the age at symptoms onset was no different from the typical group.

The crucial observation was that relatively few members of the atypical group carried the H1/H1 genotype (that is, each of the two copies of chromosome 17 carrying the H1 haplotype at the tau gene position) – 76% compared to 100% of the typical group. Also, only 33% of the atypical group had a tau "doublet," compared to 73% of the typical group. This means that most of the typical PSP patients had only two major forms of tau protein in their brains rather than a greater number of forms (four to six) seen in the atypicals and in healthy people.

The authors conclude, "Our data indicates that several discrete clinicopathological entities may lie within the spectrum of pathologically diagnosed PSP." That means that PSP may be more than one disease. The traditional definition of PSP has relied most strongly on the abnormal appearance of the autopsied brain under the microscope. This new research shows that those microscopical brain abnormalities can have different genetic and biochemical changes underlying it and different sets of clinical symptoms resulting from it.

We await confirmation of these observations using a larger set of patients and perhaps different ways of grouping the abnormalities at each level - genetic, biochemical, pathologic

and clinical. If PSP does prove to be more than one disease, then prevention or treatment, once available, could differ from one form to another. However, until then, there is little or no reason to attempt to determine which type of PSP one has, even if there were some test that could be readily applied in the living person.

*Morris HR, Gibb G, Katzenschlager R, Wood NW, Hanger DP, Strand C, Lashley T, Daniel SE, Lees AJ, Anderton BH, Revesz T. Pathological, clinical and genetic heterogeneity in PSP. Brain vol 125, pp969-975, 2002.*

### NEW DATA ON THE PSP CLUSTER ON GUADELOUPE

Previous issues of *The PSP Advocate* have reported the progress of research on the unusual concentration of "atypical parkinsonism," including a PSP-like illness, on the Caribbean island of Guadeloupe. There, PSP is at least three times as common as in industrialized countries. Other forms of parkinsonism unresponsive to levodopa (Sinemet) are also quite common on Guadeloupe. Neurologists led by Dr. Dominique Caparros-Lefebvre have previously found that PSP sufferers on Guadeloupe are more likely than patients with typical Parkinson's disease on the same island to have consumed two native tropical fruits, sweetsop and soursop. These fruits harbor chemicals toxic to brain cells.

The new article reports autopsy results in three Guadeloupean patients with PSP. Under the microscope, all three brains had the features considered typical of PSP, but one had some atypical features. In addition, all three brains showed the types of tau protein typical of PSP – a "doublet" of two nearly identical forms of tau with only minute quantities of other types. (Normal brains and most other tau-related brain disorders have more than just two major types of tau.)

It is important to note that the form of brain degeneration seen among natives on the island of Guam, which also superficially resembles PSP, does not have the PSP doublet. Therefore, at the level of the tau protein "signature," Guadeloupean PSP closely resembles western PSP and not the Guamanian "parkinsonism dementia complex."

It is also important that Dr. Caparros-Lefebvre and colleagues found no mutations in the tau gene in their Guadeloupean patients and found all of their patients to carry the H1/H1 tau genotype. In these respects, they are identical to patients with typical western PSP. This means that the Guadeloupean disease, like western PSP, cannot be explained by a simple genetic defect.

The significance of the new research is that discoveries related to Guadeloupean PSP may apply closely to western PSP. If a specific culprit food toxin, for example, is found on Guadeloupe, then similar toxins may help explain all PSP. Experiments financially supported by the Society are now under way in which extracts from sweetsop and soursop are being injected into the brains of mice in an attempt to reproduce PSP. This could help us understand the development of the disease and find new treatment. This is a very exciting and promising development.

*Caparros-Lefebvre D, Sergeant N, Lees A, Camuzat A, Daniel S, Lannuzel A, Brice A, Tolosa E, Delacourte A, Duyckaerts C. Guadeloupean parkinsonism: a cluster of PSP-like tauopathy. Brain vol 125, pp801-811, 2002.*



Lawrence I. Golbe, MD

## Research

### The Sara Koe PSP Research Centre at the Institute of Neurology, London

Reprinted from PSP Europe Bulletin  
Spring 2002, Vol. 9, No. 24

The Sara Koe PSP Research Centre at the Institute of Neurology, London, England, has been set up to provide a focal point for medical research into PSP in Europe. The five-year program grant from the Europe PSP Association will permit funding for an administrator, a senior laboratory technician and a clinical research fellow. The Centre will be linked with the Queen Square Brain Bank for Neurological Disorders. Donated brain tissue from patients and their relatives will be diagnosed and prepared for research in the Sara Koe Centre and in other research laboratories located throughout the world.

The Movement Disorder group at the National Hospital for Neurology and Neurosurgery, Queen Square, London, will be involved in the care and clinical research of patients with PSP under the direction of Professors Niall Quinn and Andrew Lees. A multidisciplinary dedicated PSP clinic is planned. Clinical projects will include trials or new experimental treatments, research related to neuron-imaging, and studies to determine improved methods for early diagnosis.

The Sara Koe Centre will also provide a current clinical database of patients with PSP for researchers and a comprehensive list of all research projects being conducted throughout the world. This formation will build and encourage a vibrant research co-operative within the University College London for PSP research as well as strengthen the excellent collaborations already in place with other researchers. The Sara Koe PSP Research Centre will educate others about PSP and, hopefully, encourage more government funding and support.



*The Plaque Unveiled*

*Prof. Lees, Sir Michael Carleton-Smith, Digby Koe,  
Simon Koe, Michael Koe, HRH.*

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### The Society for PSP Sponsors Research Symposium

A PSP Research Symposium is being presented Saturday, November 9, 2002 in Miami Beach. International PSP researchers are being invited. This will be an ideal opportunity for these experts to share ideas and results in the field of PSP and to discuss future avenues of PSP research. The format for the meeting is that each PSP research grant recipient since 1997 will present a brief review of his/her results and other relevant material. There will then be formal discussion from an invited discussant and question and answer sessions from the audience. The Society Medical Advisory Board will be present as well.

### 54th Academy of Neurology Annual Meeting

Jackie Allison, Society Assistant Director, and Nancy Brittingham, *PSP Advocate* Editor, represented the Society for PSP at an informational exhibit at the American Academy of Neurology Meeting in Denver, Colorado, April 13-20, 2002. "Since 1947, the AAN Annual Meeting has celebrated the scientific achievements of neurologists and neuroscience professionals. It's the largest international meeting of neurologists and garners the best and brightest researchers. With more than 1,300 platform and poster presentations, the Annual Meeting delivers a comprehensive collection of the latest advances in neurology. With more than 200 educational programs, the Annual Meeting is the epicenter of continuing medical education for neurologists. The weeklong meeting covers a wide range of topics including the latest in disease treatment and prevention, practice management, and hands-on skills workshops. Each program is led by expert faculty recognized as leaders in the field of neurology. In addition to a wealth of scientific presentations and educational programs, the Annual Meeting offers a variety of original programs to encourage involvement in AAN activities and projects."

### Society for Progressive Supranuclear Palsy Brain Donation Program

*For Diagnosis of and Research on PSP*  
Society for PSP Brain Bank

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

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

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

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

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

## Integrative Medicine: The Combination of Conventional and Alternative Therapies

Amy Mandlman  
Speech and Language Pathologist  
Member of the Society Board of Directors

When someone you care about is first stricken with a debilitating illness, the majority of your time may be spent visiting doctors to identify a diagnosis, testing out various medications to see if they will help the symptoms and educating yourself so you can help this person maintain his independence for as long as possible. PSP is not the only chronic illness where diagnosis and treatment often seem light years apart.

When this happens, we rely on medical professionals to guide us in our search for answers. While we can rely on medical professionals in this way, we can also look to other resources to obtain a broader awareness of options. A Holistic Approach is a non-medical therapy approach that often enhances the treatment of a person with PSP. Since PSP does have the advantage of being an illness where patients often can find comfort in Holistic Medicine, you may ask your MD how a holistic approach can help and whether or not it is right for you (indications). He may be familiar with some of the more common therapies and be able to recommend one, or he may have a specific reason for advising against this (contraindications).

However, during the long process of PSP diagnosis and treatment, you will face this hard question, "What kind of quality of life do I want?" or "What kind of quality of life does my loved one want?" For example, you may want to prolong functional use of and flexibility of muscles or promote relaxation through touch. Holistic medicine may provide another

option for you to achieve a better quality of life.

Holistic medicine covers many ideologies. Below is a list of some of the most common ones, however, it is not all-encompassing.

- Massage
- Homeopathy/Naturopathy
- Myofascial Release
- Healing Touch
- Watsu
- Nutrition
- Reflexology
- Reiki
- Acupuncture

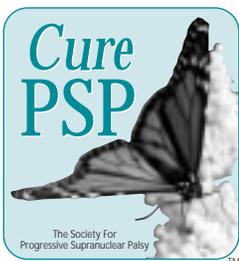
In my series of upcoming newsletter articles, I or a holistic healer, will discuss these treatments and how they may help people with PSP. Remember, "The answer is to question" (whether or not this can add to your quality of life).



Massage can relieve sore, stiff muscles by improving circulation of the blood through the body part.



Massage can also affect rate and quality of blood flowing through the circulatory system.



## "The PSP Butterfly Pin of Hope"

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

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## Communication and PSP

Problems with cognition and communication vary in nature and severity from person to person. Although there are commonalities, no two persons diagnosed with progressive supranuclear palsy are exactly alike. As the disease progresses, the variability continues. The following list summarizes problems that persons diagnosed with PSP may experience throughout the course of the disease.

### COMMUNICATION PROBLEMS

- ◆ Diminished rate control (talking too slowly)
- ◆ Dysarthria (muscular weakness, slowness, or incoordination of the lips, tongue, throat, and jaw)
- ◆ Apraxia (disruption in programming and sequencing muscle movements for speech)
- ◆ Poor voice quality (hoarse/harsh, breathy, volume too low)
- ◆ Word-finding difficulties
- ◆ Short length of utterance (person only responds with one or two words)
- ◆ Lack of initiation (inability to initiate conversation)
- ◆ Perseveration (person gets "stuck" on certain words or phrases, repeating them often and at inappropriate times)
- ◆ Discoordination of breathing and voice

It should be emphasized that most people diagnosed with PSP are receptively intact. Even during the end stages of the disease, they can understand what is being said to them.

### HOW THE SPEECH-LANGUAGE PATHOLOGIST CAN HELP

A speech language pathologist can be helpful at all stages of the disease. Early involvement and intervention with therapeutic professionals is best because people can learn compensatory strategies more successfully during the early stages of PSP, then can apply them throughout the course of the disease.

A speech language pathologist can evaluate a person's ability to use augmentative or alternative communication devices and techniques. These can be as simple as a word/picture board or an electronic device that speaks for the person. Once a person's level of ability for using such techniques has been determined, the SLP can personalize the technique or method of communication.

### SUGGESTIONS FOR IMPROVING COMMUNICATION

Although alternative methods of communication are available, people with progressive supranuclear palsy generally prefer to attempt verbal communication for as long as possible, even if their speech becomes hard to understand. The SLP and family members can often help by encouraging the speaker to:

- ◆ Speak more slowly
- ◆ Say one word at a time
- ◆ Repeat the word or sentence when necessary
- ◆ Rephrase the sentence
- ◆ Exaggerate the sounds
- ◆ Speak louder (take deep breath before speaking)
- ◆ Describe what he/she is trying to say if he/she can't think of the word
- ◆ Indicate the first letter of the word
- ◆ Use gestures
- ◆ Keep sentences short
- ◆ As a supplement to speech, use alternative communication techniques such as word boards, alphabet boards, picture boards, electronic devices

### SOME SUGGESTIONS FOR THE LISTENER ARE:

- ◆ Eliminate distractions and reduce background noises (TVs, radios, large groups of people, close the door)
- ◆ Keep questions/statements simple

- ◆ Ask one question at a time
- ◆ Stick to a topic for a while. Avoid shifts from topic to topic
- ◆ Use yes/no question format as much as possible
- ◆ Be an active listener. Pay attention to gestures and facial expressions/changes
- ◆ If you do not understand what is being said, don't pretend that you do. Ask for clarification, or repeat what you think was said in the form of a question, such as, "Did you say?"
- ◆ Try to keep to familiar topics
- ◆ Encourage the speaker to use his/her specific compensatory strategies
- ◆ Allow enough time for the person to convey his/her message
- ◆ Give the person choices to ease decision making "Do you want coffee or tea?" Rather than "What do you want to drink?"
- ◆ Most importantly, be patient

### MY VOICE IS VERY SOFT BUT I CAN STILL SPEAK, IS THERE ANYTHING I CAN USE TO MAKE MY VOICE LOUDER?

When the muscles involved with voice production and breathing may be weakening, speech amplifiers can increase the loudness of speech. This also minimizes the strain and fatigue associated with speaking. Issues in selecting amplifiers include: a) the quality of the amplifier, b) whether the device will be cost effective c) portability d) how and where to mount or carry the microphone.

### HOW CAN I FIND SOMEONE TO RECOMMEND A DEVICE?

The first step in device recommendation is an evaluation to determine which device best meets the needs and abilities of a person diagnosed with PSP. Evaluations usually are conducted by a team of professionals including a speech pathologist that specializes in augmentative communication and an occupational therapist specializing in assistive technology. Other professionals may include a physical therapist and a rehabilitation engineer.

These teams usually work in centers specializing in assistive technology or augmentative communication, located mainly in hospitals, university clinics or not-for-profit organizations. The centers typically have a variety of equipment available to them so that the PSP person can try a number of devices that might meet his/her needs. An individual evaluation is conducted and a set of recommendations is developed which may be for no technology at all, for simple devices or techniques, for sophisticated technology, or most commonly, for a combination of low-tech and high-tech solutions to the problems identified during the evaluation process. The evaluation center usually does not sell or provide these products, but rather gives information on recommended products and where to procure them.

It is essential that a person diagnosed with PSP receives an evaluation, rather than directly contacting a vendor of communication devices, although a vendor may also be involved in the process. An evaluation by objective professionals will allow one to make an informed choice from firsthand experience with a variety of devices. Only so much can be learned from a catalog description or from a demonstration by someone who sells a product.

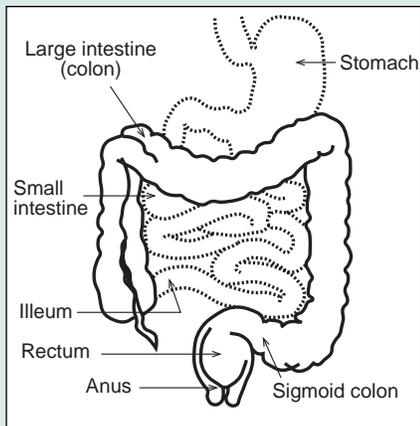
Referrals to professionals who specialize in augmentative communication can be obtained from the following organizations:

- ◆ The American Speech-Hearing-Language Association (ASHA) [www.asha.org](http://www.asha.org) 800-638-8255.
- ◆ ISAAC (The International Society for Augmentative and Alternative Communication) publishes a directory of members and lists them by country and state within the United States. [www.isaac-online.org](http://www.isaac-online.org) (416) 385-0351
- ◆ RESNA - Technical Assistance Project [www.resna.org/taproject/index.html](http://www.resna.org/taproject/index.html) (703) 524-6686

## Constipation And PSP

As we age and our metabolism slows down, so does our process of elimination. Constipation is a frequent symptom of persons diagnosed with chronic neurological disorders such as Parkinson's disease and progressive supranuclear palsy. Constipation is the passage of small, hard, dry stool, usually fewer than three times a week. People who are constipated may find it difficult and painful to have a bowel movement. Other symptoms of constipation include feeling sluggish, bloated and uncomfortable. Often, people think that they are constipated when their bowel movements are regular. There is no right number of daily or weekly bowel movements - normal can be three times a day for some and three times a week for others.

Normally, food is liquefied in the stomach by the digestive juices and then moves through the small intestine in liquid form. Nutrients are absorbed in the small intestines. Muscle contractions called peristalsis propel the remainder along into the large intestines where water is reabsorbed from the left-over waste product, leaving fecal material or stool which is moved along and passed out of the body in a bowel movement. In PSP, the rigidity and slowness that affects other muscles can affect one's bowels. This is called "bradykinesia of the bowel." Because the bowels are moving slowly, the stool moves slowly and the fluid that is in the stool often dries out, making the stool hard. The longer the stool takes to pass through the bowel, the harder it may become, causing more difficulty for it to pass out. Constipation problems can also be complicated by the effects of some of the medications used to manage some of the symptoms of PSP (such as levodopa and others.)



### Early Intervention

#### DIETARY FIBER

A diet low in fiber can cause constipation by decreasing the size and water content of the stools produced. Most persons eat about 8 to 10 grams of fiber per day. At least 25 to 30 grams of fiber should be eaten each day. Fiber is the part of fruits, vegetables and grains that the body cannot digest. Soluble fiber dissolves easily in water and takes on a gel-like texture in the intestines. Insoluble fiber passes almost unchanged through the intestines. Thus, the bulk and soft texture help to prevent dry, hard stools that are difficult to pass. Dietary fiber is found in plant foods. This includes whole grains such as whole grain pasta and brown rice, whole grain breads, cereals, fruits, and vegetables. Try to include beans, peas, raspberries and broccoli. Reduce red meat and dairy/milk products. If swallowing/choking problems occur, these foods can be pureed into a smoother consistency. For example, add cream of broccoli soup to the broccoli and then puree in blender. Add fruit juice to raspberries and puree.

Cream of mushroom soup could be added to beans or peas prior to blending. Be creative.

#### FLUID INTAKE

Liquids like water and juice add fluid to the colon and bulk to the stools. It is recommended that a person drink six to eight 8-ounce glasses of water or juice per day. Beverages containing caffeine and alcohol can be dehydrating and should not be substituted for the recommended 6-8 glasses of water per day. If swallowing/choking problems occur, thickening agents may be added to the liquid. Example - Simply Thick (see Helpful Hints, page 20). Fruit smoothies can be a favorite. Try frozen juice bars such as Welch's. Frozen flavored ice can also add to liquid intake.

#### EXERCISE

Lack of exercise can lead to constipation. Constipation often occurs after an accident or during an illness when one must stay in bed and cannot exercise. Mild exercise such as walking 20 minutes three times a week can keep your bowels moving. If balance problems occur while walking, try crawling. Mild exercise in a swimming pool will help while the water helps support you.

#### TREATMENT OF CONSTIPATION

If you are getting ample fiber and fluids, but still need additional help to achieve normal bowel movements, the following remedies may be considered in consultation with a physician.

- **PRUNE JUICE COCKTAIL** - Mix 1/2 cup applesauce, 2 tablespoons miller's bran and 4-6 oz. prune juice. Keep in refrigerator. Take one tablespoon per day initially and gradually increase to find out what works best.
- **WEAK TEA OR HOT WATER** - 6 oz. (3/4 cup) of weak tea or hot water with lemon juice on waking each morning.
- **DIETARY FIBER SUPPLEMENT** - Dietary fiber can be supplemented with methyl cellulose (Citrucel) and psyllium (Metamucil) but 6 to 8 glasses of water must be consumed throughout the day.
- **STOOL SOFTENERS** - Stool softeners such as Solace Equality or Tracheal can be used regularly.
- **"SENNA PASTE"** - "Senna Paste" is a folk remedy. Take a 4 oz. package of Senna Tea. Senna tea is a traditional medicinal called Smooth Move. Put the Senna tea in 3 cups of boiling water and steep for 5 minutes. Pour tea into a pot and add 1 pound of pitted prunes, 1 pound of raisins and 1 pound of figs. Boil tea and fruit for five minutes. Remove from heat and let cool. Add 1 cup of lemon juice. Use a blender to mix to a smooth paste. Place in a glass container and store it in the freezer. Do not worry—the paste will not freeze. Use 1 or 2 tablespoons daily.

#### CAN CONSTIPATION BE SERIOUS?

Although it may be bothersome, constipation itself usually is not serious. But, occasionally, it can lead to complications. These complications include hemorrhoids caused by straining to have a bowel movement or anal fissures (tears in the skin around the anus) caused when hard stool stretches the sphincter muscle. Constipation may also cause hard stool to pack in the intestine and rectum so tightly that the normal pushing action of the colon does not expel the stool. This is called a fecal impaction, also known as bowel impaction. Bowel impactions can be very painful and may require hospitalization.

# Abnormal Eye Movements in PSP

Mark Walker, M.D.  
Department of Neurology  
Johns Hopkins University

Abnormal eye movements are a prominent part of progressive supranuclear palsy. They are important to patients because they impair vision and to physicians because they help make the diagnosis of PSP.

Problems with vision are common in patients with PSP and are often among the first symptoms. In fact, these patients may present first to an eye doctor, thinking that they need new glasses, but when their vision is checked with an eye chart, it seems to be normal, and a change in glasses is not needed. However, visual disturbances in PSP do not result from an inability of the eyes to focus (something that could be corrected with glasses) but rather from a failure of the eyes to move properly. Eye movements are important because they help us to see. For example, to read quickly and easily, we must be able to move our eyes accurately across and down a page of text. When walking or driving, we must be able to move the eyes to scan the visual scene quickly. It is also important that the two eyes be lined up properly; when they are not, we see double, and depth perception is impaired.

Several types of eye movements are affected by PSP. The most characteristic abnormality is the loss of the ability to make normal saccades. Saccades are the rapid eye movements that we make to look from one point to another, for example, during reading. Patients with PSP have trouble making saccades; particularly vertically, that is, they have difficulty looking up and down voluntarily. At first, saccades can still be made but are slower than normal. With time, this may progress to the point that patients may be nearly unable to make saccades at all. The loss of saccades makes reading difficult. It also explains why PSP patients cannot use bifocals: they are unable to move the eyes down to look through the close-up part of the lenses. Thus, PSP patients should have separate glasses for distance and for reading, rather than bifocals.

Patients with PSP also have trouble keeping the eyes aligned. These eye movements are called vergence. Because of difficulty crossing the eyes, double vision may occur when looking at something that is relatively close to the eyes; for example, when reading. This can be helped by covering or patching one eye and sometimes by prisms in the glasses.

Other types of eye movements are also impaired. For example, smooth pursuit, the ability to keep the eyes fixed steadily on a moving object, is reduced. Not only is there trouble moving the eyes, but it is also difficult to keep the eyes still. Square wave jerks are small involuntary back-and-forth eye movements often seen in PSP.

Control of the eyelids is also impaired in PSP, and, like eye movement problems, this may present significant problems to patients. Because the frequency of spontaneous blinking is markedly reduced, the corneas can dry out. The cornea is the clear part of the front of the eye. Normally, blinking spreads

tears to keep the corneas moist. When they become too dry, there is discomfort, and vision can become clouded. For this reason, anyone diagnosed with PSP should have an examination of the cornea by an eye doctor for signs of over-drying and irritation. This problem is commonly treated by frequent use of artificial tears and eye ointment to replace the deficient lubrication. Although blinking is reduced, once the eyes are closed, it is sometimes difficult to open them voluntarily. This problem is called apraxia of lid opening. There may also be an involuntary closure of the eyelids, which is called blepharospasm.

So, why is the eye movement disturbance in PSP called a supranuclear palsy? Supranuclear means "above the nucleus." It refers to the fact that the weakness ("palsy") of eye movement is not due to a failure of the eye muscles or even the nerves that control them, whose cells are in the nuclei of the brainstem. Instead, the problem is with higher (supranuclear) eye movement control areas that generate the commands to make saccades and other types of eye movements. Thus, in PSP, some types of reflexive eye movements may be preserved (or even enhanced) even when voluntary eye movements (such as saccades) are lost.

## Ask the Doctor

Lawrence I. Golbe, MD  
Chairman, The Society for PSP Medical Advisory Board

*"My husband underwent emergency surgery after a car accident. He did not appear to have any symptoms of PSP prior to that. After surgery, strange things started to happen to him. Two years later, he was diagnosed with PSP. I have read this same experience numerous times on the PSP Listserv. Could trauma have caused the onset of symptoms and the disease to manifest itself?"*



Many chronic, progressive illnesses such as diabetes, Alzheimer's disease, or coronary artery disease produce their first symptoms immediately after an episode of unrelated trauma, illness or emotional stress. PSP is no different. The stressful event was not the cause of the PSP, but it may have caused its symptoms to appear a bit sooner than they would have otherwise. The long-term outcome of the PSP in these cases is probably no different, but adequate data on that are lacking. You must also realize that many people suffer illnesses, injuries and stresses and naturally tend to suspect a causal relationship to any subsequent illness. There are no statistics on whether people who experience onset of PSP are more likely to have had a very recent trauma than people who do not experience onset of PSP. (But those who don't develop PSP don't write to the PSP listserv!)

# Support Groups As Of June 15, 2002

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

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416-227-9700  
*Let us post your support group news and announcements in the PSP Advocate. Deadline dates are Feb. 10, May 10, Aug. 10, Nov. 10. Please send your support group news/photos to The PSP Editor at NancyB501@cs.com or to the Society office.*

## Houston Support Group "Sinful Saturday Sweet Buffet"



The Houston support group celebrated its second anniversary with what may become a traditional "Sinful Saturday Sweet Buffet" to mark the occasion each year. Offerings included chess pie, magic cookie bars, marshmallow fudge cake, chocolate chip cookies, fudge brownies, assorted pastries, Death-by-Chocolate cake, and a special sheet cake on which a pinch-hitting cake designer valiantly tried to reproduce the Cure PSP pin in butter cream. Take-out containers were provided for a dessert exchange so that no goodie need be left behind.

### SAVE-THE-DATE! California Regional Symposium on Progressive Supranuclear Palsy

An Educational Conference for Persons Diagnosed with PSP, Families and Caregivers.

Saturday, October 12, 2002 9am - 3pm

(Registration: 8:30 am)

Doubletree Hotel Westwood

10740 Wilshire Boulevard, Los Angeles, CA 90024

(800) 472-8556

Speakers to include:

- Dr. James Sutton, California Neuroscience Institute
- Dr. Neal Hermanowitz, Director of Movement Disorders, University of California, Irvine
- Dr. Giselle Petzinger, Assistant Professor of Neurology, University of Southern California

For more information or to register, contact:

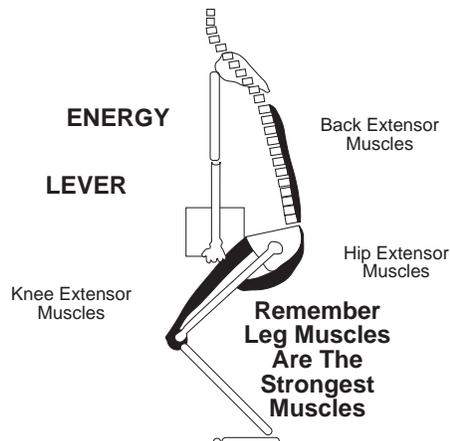
Jessica Quintilian, Director of Outreach & Education  
at (800) 457-4777 or Carolyn Cheek (310) 534-8623

### WALL OF HOPE

At the California Regional Symposium on October 12, we want to honor our PWPSP (Persons with PSP) with a hope for the future by displaying a picture of your PWPSP alone or with family (5X7 preferred). Please send to Carolyn Griffith, 18202 E. 17th St., Santa Ana, CA 92705. We are sorry that we cannot return the pictures.

## Body Mechanics for Caregivers

The job of a caregiver requires much bending and lifting while attending to the needs of a person diagnosed with progressive supranuclear palsy. Caregivers can minimize risk of injury and make their work easier by using proper body mechanic principles.



- **BEND KNEES**—Bending your knees rather than your back will make the legs do the work instead of the back.
- **KEEP BACK STRAIGHT**—Keeping your back straight minimizes the risk of injury. The muscles that support the back work optimally in this position.
- **WIDE BASE OF SUPPORT**—Spread your feet during transfers because a wide base of support will make your stand more stable.
- **LIFT WITH YOUR LEGS**—The muscles of your legs are strong and should be used for lifting. If you use your legs, it will be easier to maintain a straight back. Bend your knees when lifting.
- **ADJUST THE HEIGHT OF THE WORKING SURFACE**—If your loved one is in a hospital bed; raise the bed to an optimal height so that back stress is minimized.
- **MOVE YOUR FEET WHEN YOU TURN**—If you turn without moving your feet; you are twisting your back causing wear and tear on your discs.

Dear Nancy:

In the last Advocate a writer mentioned the name of a product made by Mobility, Inc.—the Airlift Toileting System. This product, which was demonstrated at the Sixth Biennial PSP Symposium in Baltimore, is available in both a freestanding bedside unit and in a model that attaches to a toilet. The cost ranges from \$300 to \$400, depending upon accessories selected. The Airlift Toileting System operates with a hydraulic lift device that aids the user in getting on and off a toilet with minimum effort and supports weights to 300 lb. The bedside model is Medicare approved and is adaptable for use on a conventional toilet. Mobility, Inc. can be reached at 866-456-8121.

Karen Kennemer

Continued Page 20

## Helpful Hint

Dear Editor:

My mother who has PSP lives in a small midwestern town where my brothers look after her with some outside help. Mom is beginning to need some aids for walking, and I know that she will need many more aids as time goes on. Earlier my brothers seemed resigned to relying on what was available at the local medical/surgical supply store where the offerings were very limited. However, because I live in a large urban city, I was already aware there was much more available out there than could be found in our small hometown.

As a starting point, I called all the companies listed under Corporate Sponsors in the current Advocate to request product literature and catalogs. I had it all sent to Mom's address so my siblings and the part-time caregiver could see it. My brothers in particular were surprised to learn there are so many products that will help Mom right now and in the future, too. Even though our mother's needs are not great yet, we realize she may need many types of assistive equipment as time goes on, and we already have a growing file of product descriptions and catalogs to help us find what she needs when she needs it. It is not necessary to limit the search for helpful products to that local store where (as in our case) the only wheelchair available was from a prominent company but was a model that had already been superceded by two more recent models not available at our store. Please remind PSP Advocate readers there are many types of aids available from reputable companies by mail order and through the Internet. And it is always best to have this information on hand before the need is critical.

K. D., Los Angeles

Dear Nancy,

I have found a great thickening agent. I picked up samples at the PSP Symposium and tried it. It works very well. Here is their information.

Carol P.

New Jersey

### SIMPLYTHICK™

SimplyThick™ is the next-generation food and beverage thickener designed specifically for people who have difficulties swallowing. This thickening agent offers a solution to the problems patients, their families and healthcare professionals raise with products currently serving the dysphagic population.

#### FEATURES:

Flavorless

Gel Formulation

Quick-Mixing Formula

#### BENEFITS:

- unaltered taste
- better patient acceptance
- no undissolved particles
- smooth texture
- better patient acceptance
- one-step preparation
- no waiting to serve
- minimized prep time
- no thickening over time

- Individual Serving Packets
- no measuring
  - consistent thickness every time
  - identical honey and nectar preparation
  - simplified training needs

#### Hot and Cold Uses

- one product for all liquids
- can be used in ice
- simplified inventory

#### Using SimplyThick™

SimplyThick™ thickens all liquids, hot and cold, including water, juice, soda, milk, coffee, tea, soups, purees, beer, wine and mixed drinks. SimplyThick™ unique gel formulation mixes quickly and completely by hand to make clear solutions. There are no undissolved or unappealing particles to detract from a liquid's appearance or flavor.

Addressing healthcare professionals' desire for simple preparation, SimplyThick™ comes in two different packages. Each is designed for use in a four-ounce (120 ml) serving to produce either a nectar or honey consistency.

Using a packet of the desired consistency, shake or stir the contents into the liquid. No measuring spoons or special containers are necessary. Liquids are ready to drink as soon as mixing is complete. For purees, add the desired amount of SimplyThick™ and reblenderize the liquid.

Where pudding consistency is required, use two honey packets for each four-ounce (120 ml) serving.

To order call: 1-800-205-7115

Fax: 800-508-2990 • e-mail: info@simplythick.com

## Congratulations, Liz Brisson, Chairperson of the Society Board

Liz Brisson was recognized by New England Financial for her many hours of volunteer work (especially for the Society for PSP, thanks, Liz). Liz was awarded a CARE Grant and received \$1000 to be given to the charity of her choice.



*Donna Ailard, Dale Ferris, Debra Shapiro, Vice President, Volunteer Resources, United Way of Massachusetts Bay and Liz Brisson.*

## Community Resources

Community care options care services and programs vary in different states, counties and communities. They also differ in services available and their eligibility requirements.

Information and Referral (I & R) helps you identify your local resources. Call the National Area Agencies on Aging (AAAs), senior centers or community mental health programs to learn about potential services.

### ELDERCARE LOCATOR

Phone: (800) 677-1116

Website: [www.eldercare.gov](http://www.eldercare.gov)

The Eldercare Locator helps older adults and their caregivers find local services including health insurance counseling, free and low-cost legal services and contact information for Area Agencies on Aging (AAAs).

### TRANSPORTATION SERVICES

The Americans with Disabilities Act requires transit agencies to provide curb-to-curb transportation service to persons who are unable to use regular public transportation. To learn more about this transit in your community, contact Project Action which has a national database or call your local Agency on Aging.

### Project ACTION

700 13th St., NW, Ste. 200, Washington, DC 20005

Phone: (202) 347-3066 • Website: [www.projectaction.org](http://www.projectaction.org)

### CASE MANAGEMENT SERVICES

Case Management Services can help locate services and provide hands-on management of these services. Case managers help determine eligibility for entitlement programs. If you meet eligibility requirements, you can obtain free case management services through federal, state or county programs including Medicare or Medicaid. Hospitals, mental health programs, home health agencies, and social service agencies (e.g., Catholic Charities, Jewish Family Services) can sometimes provide free case management service. A geriatric case manager can also be professionally hired.

National Association of Professional Geriatric Care Managers

1604 N. Country Club Rd., Tucson, AZ 85716-3102

Phone: (520) 881-8008 • Website: [www.caremanager.org](http://www.caremanager.org)

Medicare and Medicaid phone: (800) MEDICARE

Medi-Cal (California's version of Medicaid)

Phone: (800) 952-5253 • [www.medi-cal.org](http://www.medi-cal.org)

### NUTRITION PROGRAMS

Nutrition Programs usually provide lunch within a group environment. If an individual is homebound, individuals meals can be delivered at home. There are programs such as "Meals-on-Wheels" that provide meals on weekdays leaving sufficient food for the weekend. Nominal fees are sometimes charged.

Meals-on-Wheels Association of America

1414 Prince St., Ste. 302, Alexandria, VA 22314

Phone: (703) 548-5558 • Website: [www.projectmeal.org](http://www.projectmeal.org)

### ADULT DAY CARE

Adult Day Care offers attendees opportunities to socialize with their peers in a safe environment. Adult day care services include supervision, group and individual activities, exercise, educational programs and nutritious meals.

National Association of Adult Day Services

c/o National Council on the Aging

409 Third St. SW, Ste. 200, Washington, DC 20024

Phone: (202) 479-1200 • Website: [www.ncoa.org](http://www.ncoa.org)

### RESPIRE CARE

Respite Care offers relief for caregivers from caregiving demands. Respite care includes home care services and adult day care. Some organizations provide offer volunteer respite workers who provide companionship and care. Your Agency

on Aging can provide this information. Home care provides health care and services for the homebound sick and disabled persons. Services, and the level of health care needs professionally accessed and approved by the physician. Home health care services include medication assistance, nursing and physical therapy. Fees vary. Medicare, Medicaid (Medi-Cal in California) and some private insurance policies provide for limited home health care services. Many times, the family has to pay out of pocket. Contact your local AAA.

Visiting Nurses Associations of America

11 Beacon St., Ste. 910, Boston, MA 02108

Phone: (888) 866-8773 • Website: [www.vnaa.org](http://www.vnaa.org)

### HOSPICE CARE

Hospice Care provides services for individuals who are terminally ill allowing them to remain at home. The hospice team works together to meet all daily living needs of the patient and regularly make scheduled visits as well as round-the-clock care when needed. Insurance coverage care is provided through Medicare, Medicaid and some private insurance plans. For information, contact Hospice Foundation of America.

Hospice Foundation of America

2001 S. St. NW #300, Washington DC 20009

Phone: (800) 854-3402 • [www.hospicefoundation.org](http://www.hospicefoundation.org)

Contacting the resources can be confusing and time consuming. It may be necessary to make endless phone calls and referrals before you find the service or person to help you. Do not get discouraged, keep working.

## A Bundle of Energy

By Carolyn Cheek, Los Angeles Support Group Leader

Amy Mandlman is a bundle of curly haired energy. Amy is a member of the Society Board of Directors and leads the St. Louis Support Group. I've seen her name and exchanged e-mails with her for a long time so imagine how pleased I was to meet with her. She e-mailed me that she would be in LA on a certain day and could I meet with her. Could I!

We met at a local restaurant for brunch and stayed 4 1/2 hours. Neither of us being short of PSP ideas, conversation just spouted out of us. Not sure I can even remember the details. But, I was able to get a better grasp on the Society structure from having my questions answered by Amy. Things like "how big is the office" and so forth. We exchanged ideas on support group leadership. Very interesting since her group has speakers and my group is a casual informational exchange. And yes, we cry and laugh lend each other wheelchairs and whatever else. Amy had a zillion ideas for speakers, good for us since we are trying to steer our group a little more in that direction.

The St. Louis group is putting together a resource directory for PSP families—all about walkers, wheelchairs, doctors and services. What a great idea! I've been mulling over how that could be done in LA - we are so much bigger than St. Louis. However, the seed has been sown.

I told Amy about how we had organized our Walk that has been a success for two years. The key there is, of course, get acquainted with someone who has done it, and most of your questions are answered.

After our meeting, I came home exhilarated and ready to start in a million directions at once. The one that really turned me on, was to ask Amy to come and speak to my support group - two days hence. She really wowed them.

Our people loved her. And so do I.

# Support - Our PSP Stories

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

## Our Journey With PSP

Doris Thornton-caregiver and spouse of Arvie Thornton  
Georgia

Our journey began in 1991 when Arvie noticed he could not verbalize the words he wanted to say even though he knew what was in his mind. This was very important because Arvie was an active Baptist minister for 44 years, serving many churches in Georgia. Our plan was for him to retire at 65 years of age at the end of the year 1993.

As his words got slower and softer and his movements slowed, our regular doctor diagnosed him with Parkinson's disease. Arvie was sent to a neurologist who prescribed Sinemet and told him to come back in two weeks. We made many trips to this neurologist but no medicine seemed to help. An MRI, brain wave test and brain scan were ordered. The tests ruled out what he did not have (brain tumor, etc.) but PD was still the diagnosis. Arvie's problems continued with slow gait, speech problems, handwriting difficulty, vision and equilibrium problems and trouble getting up from a chair. We were referred to a neurologist that specialized in movement disorders. By the end of 1992, he had to retire at the age of 64.

Arvie began to have increasing balance problems and had more falls by the end of 1994. The doctor at the movement disorder clinic tried many medications, but nothing helped. He had speech therapy and physical therapy on two different occasions. The movement specialist began to say that Arvie might be suffering from PSP or some other neurological problems. Artane and a few other medications helped some of the side effects. In 1996, I decided to take Arvie to the Mayo Clinic in Jacksonville, as he was progressively getting worse. With the cooperation of his doctors, reports were given to me to take to Mayo Clinic. The diagnosis was PSP and we were told to return to our former neurologist. We were given information about how to contact the Society for PSP. Through the years, the Society has been helpful with information.

Arvie digressed from a walking stick to a walker and to a wheelchair in 1997. He lost his coordination and could not feed himself, shave, brush his teeth or do many of the menial tasks for himself. I was his full-time caregiver. He still wanted to go to church, shopping or just any place I would take him with the help of my daughter. By now, he could only speak a few words. He was content most of the time and never complained.

As his swallowing worsened in 1999-2000, we were advised to put in a feeding tube and we did. Arvie continued to lose weight and in June of 2000, it was necessary for me to move Arvie into a nursing home because I could not take

care of him any longer. My children were very supportive of what I had to do. He accepted the care of the nursing home and was a good patient. I went to see him everyday and I believe he always looked forward to seeing me. Arvie was in the hospital several times with pneumonia during that year. On May 13, 2001, he died of aspiration pneumonia—a major complication of PSP. He died in peace and I felt relieved that he did not have to suffer anymore. I knew I had done all I could. Arvie and I had over 50 years of a wonderful marriage before his death.

Our journey with PSP lasted for 10 years. I have become a spokesperson for PSP to anyone who will listen. I hope a cure will soon be found.

## In Memory of Ruby P. LeBleu

I am very sad to say my precious little "mom" lost her battle with PSP on Tuesday, February 19, 2002. She passed on in her sleep, which was a blessing. She was the most loving, caring and giving person. I am so blessed and happy that she was mine. She will be missed terribly.

As sick as she was, she never stopped worrying about others—never herself! She never complained even one time about the horrible disease that took a piece of her every day. She loved life and everyone who came into her life.

I only hope that during my lifetime, I can be the slightest bit as special as she was. That would be an absolute honor.

Here is a picture of our last Christmas together with her. Please keep fighting to find the cure! Thank you.

Pam Hussey  
Texas



Ruby and her family

GIVE A GIFT ONLINE

[www.psp.org](http://www.psp.org)



**“Love Is The Condition  
in which the happiness of another person  
is essential to your own.”**



Mrs. Lorna Sagendorph Trowbridge, age 68, for whom I have acted as a companion/caregiver for three years, has probably been suffering with progressive supranuclear palsy for almost 14 years, although the positive diagnosis as PSP was not made until a year ago.

It is the joy of my life to care of her rather intensive many needs as her voice is so faint, her eyesight practically zero, her balance very poor and her state of mind often depressed, mostly because she feels so useless after an earlier life of raising four wonderful children followed by a 14-year career as archivist/librarian for *Yankee* magazine which she still owns. Lorna now has eight grandchildren, while I have eight great-grands.

Lorna and I met eight months after my beloved wife of 62-1/2 years died in 1998 from inflammatory breast cancer and that is a story unto itself. You can imagine that I was immersed into the caregiving business in a big way during my wife's last years. Lorna and I found that we had a lot of mutual interests, many friends in common, and sort of a crazy, optimistic outlook on life. My answer to those who question my constant devotion to Lorna is that we are still madly in love, and as Robert Heinlein says in his wonderful book, *Stranger in a Strange Land*, "Love is the condition in which the happiness of another person is essential to your own." If you save one life, you are saving the world. Right? Fortunately, at 89 (will be 90 next December), my health is still good, my optimism still out of control, though I am formidable. Lorna and I are good for one another—each giving and receiving new strength and hope when together. We ask the Lord above to give us just a few more years together.

Frank Knowlton, Jr.  
Florida

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



## Our Father, Our Inspiration

By Bart Battista  
Rockaway, NJ

I come from a family of seven: five kids, our Mom and Dad. Our father, Angelo Battista, suffered from progressive supranuclear palsy. Although he was diagnosed with this horrible disease only 2 years ago, he had been showing symptoms and progressing for the worse for over seven years. Our father passed away on May 13th, 2002 as an indirect result of PSP. He was 71 years old and too young to leave us. I would like to share his story with you.

Our father was a hardworking man who raised a large family with only a high school education. He was a U.S. Marine veteran with an incredible work ethic. As his kids got older, he needed to find a way to support us, and that would involve working two jobs. You see, he was an old-fashioned man with old fashion morals and ideals. My mother stayed at home with the kids and my father worked to provide for all of us. The worst part about that, for him, was that the work would keep him away from his family. His family was the single most important thing in his life and he would do anything to give his children the opportunity to succeed in life. That included giving all five of us the opportunity to go to and finish college, something he never had a chance to do.

He was the most honest, trustworthy person that I knew, and he loved his family with every bit of his heart and more. He was simply a true family man. That is what made his bout with PSP even more difficult for him. He took care of his family his entire life, without even giving it a second thought. During his battle with PSP, the thing that hurt him the most (and I know because he told me on numerous occasions) was that he now had to depend on us. He was so hurt and depressed about the fact that his wife and kids had to see him deteriorate in front of them and that he could not do anything about it.

He was such a strong man his whole life and PSP was overpowering him. About seven or so years ago, my father began to complain that he didn't feel well. He just wasn't feeling himself. He would go to doctor after doctor, only to get the same diagnosis. They all told him that there was nothing wrong with him and that he was fine. He once fell and hit his head and a few days later experienced Global Transit Amnesia where he did not remember where he was for approximately six hours. His symptoms slowly got worse over the years and doctors never gave him a clear diagnosis. There were a lot of "possible" problems, but nothing definitive. One doctor would say he may have had a stroke, another would say it could be Alzheimer's disease, and the list goes on.

It was extremely frustrating for my family and even more so for my father. He didn't know what was happening to him and nobody else did either. In the fall of 1999, my sister noticed an article in the NY Post about Dudley Moore. It was amazing the similarities in symptoms that my Dad had compared to what they said Dudley Moore was experiencing. They talked of his loss of balance, his slurred speech, his coughing, etc., all things that my father was going through. A few days later, a special 20/20 on Dudley Moore aired and my family and I watched in amazement and sadness. We

*Continued Page 24*

# Support - Our PSP Stories

Continued from Page 23

## Our, Father, Our Inspiration

were watching my father on TV. Everything about the way Dudley Moore looked, acted, and talked, was an exact replica of how my father was.

In early 2000, my family took my dad to see a movement disorder specialist and he was finally diagnosed with PSP. Although we were saddened by the result, it was a bit of a relief for us to finally know what was wrong with him. My father was put on medications to help slow the progression, but he had already gotten to a point where he had trouble getting himself around. He walked with a walker and when we brought him out of the house, we put him in a wheelchair. My Dad eventually had to move into the bedroom downstairs that was on the same floor as the TV room and bathroom, because stairs became impossible for him to use on his own. We helped to make him as comfortable and safe as possible in his own house because we did not want to have to put him in a nursing home. That wasn't an option we wanted to explore. We chose, rather, to take care of him to the best of our abilities.

Our father died at home, a place that he worked so hard to build for his family. After his death, I have tried to think of comforting thoughts to get me through the pain. My faith that he is in a better place and no longer suffering is one of my ways of dealing with our loss. The other thing that I take solace in is the fact that my father died of a heart attack, before he could progress to the later stages of PSP, which would have caused him much more suffering and pain.

Through it all, my father never lost his sense of humor. Never lost his love for his family. Never lost his faith. And, most amazingly, he never complained or blamed anyone for his misfortune. When he got frustrated or angry, he made it perfectly clear that he was frustrated and angry with himself and no one else. Speaking as my father's oldest son, I have to say that if I can become even half the man my father was, I will be 100% satisfied with who I am as a person. He is my mentor, my motivation, my inspiration. He is my father and we will miss him dearly.



Angelo Battista and family

## My Husband Bob

Robert Webster ended his struggle with PSP (progressive supranuclear palsy) on Wednesday evening, May 29, 2002.

Although barely able to speak, about four weeks earlier, he had made it clear that he wanted and needed to return to New Hampshire. His daughter, Cathy,

and her fiancé, Mike, were visiting us in Foley, Alabama at the time, and they invited us to come stay in their home in Nashua. This all sounded wonderful to me because his care was becoming so demanding and physically strenuous that I was unsure how much longer I could do it alone, even though we did have hospice assistance.

Cathy and Mike went home and completely rearranged their house for us, building a long ramp and moving half their furniture and personal possessions to storage. Our Alabama hospice transferred coverage to New Hampshire and made all arrangements. I frantically wrapped things up in Foley and packed for a trip of unknown duration.

Then son Rob and his wife Peggy flew in from Elkton, MD to accompany us on the long drive "home." They loaded my Dodge Caravan with Bob's lift chair, oxygen, nebulizer, wheelchair, catheter and diabetic supplies, etc. Boxes of clothes and other incidentals were shipped. The four of us crammed ourselves into the van and we set off on the pilgrimage of a lifetime.

The trip took us four days, with two motel stays and one stay at Rob and Peggy's. We arrived in Nashua on May 13, exhausted but elated to have reached our goal. Bob saw his other three sons and all four grandkids the first week back. He watched his grandson play saxophone in a Memorial Day parade, and he was there when a very premature granddaughter was buried—the important stuff, never doubt it.

But his condition was declining dramatically. All of a sudden, he couldn't sip through a straw, or blow his nose, or swallow even yogurt or scrambled eggs; then, not even ice cream mixed with Boost. The last two days, he developed a fever which was impossible to bring down and his breathing became rapid, irregular and loud.

Bob died in his daughter's home, surrounded by loving family members. He let us all visit and have dinner together, then as people were saying good-bye, his breathing finally quieted and slowed, and he peacefully slipped away. Everyone there will be forever touched by his courageous struggle and by his wisdom and determination in choosing when, where and how he would die. Bob is my all-time hero. Exhausted and broken-hearted as I am, what will keep me going right now is my wish to become more and more like Bob day by day.



Robert Webster visiting grandsons Brenan (L) & Jordan (R) in Derry, NH summer of 2000

# Caregiving

## CAREGIVING WEBSITES

- Caregiver Survival Resources  
<http://www.caregiver911.com>
- Family Caregiver Alliance  
<http://www.caregiver.org>
- Family, Friends Caregiver Support  
<http://www.restministries.org>
- John Hopkins Health Caregiver Resources  
<http://www.intelihealth.com>
- National Alliance for Caregivers  
<http://www.caregiving.org>
- National Federation of Interfaith Volunteer Caregivers  
<http://www.nfivc.org/default2.htm>
- National Family Caregivers Association  
<http://www.nfcacares.org>
- National Partnership for Women and Families  
<http://www.nationalpartnership.org>
- Today's Caregiver Magazine On-Line  
<http://www.caregiver.com>
- Well Spouse Foundation  
<http://www.wellspouse.org>

## BOOKS ABOUT CAREGIVING

Brandt, Arverne, L. - *Caregiver's Reprieve: A guide to Emotional Survival When You're Caring For Someone You Love* - Impact Publishing

Brown, Denise - *Caregiver's Handbook* - Visiting Nurses Association - DK Publishing

Carter, Rossalyn - *Helping Yourself Help Others: A Book For Caregivers* - Random House

Davis, Maggie - *Caring In Remembered Ways, The Fruit Of Seeing Deeply* - Heartsong Books  
<http://heartsongbooks.com/carebook.html>

Dolan, J. Michael - *How to Care For Your Aging Parents - and Still have a Life of Your Own* - Mulholland Pacific

Grollman, Earl A. - *Caring and Coping When Your Loved One is Seriously Ill* - Beacon Press

Heath, Angela - *Long Distance Caregiving: A Survival Guide for Far Away Caregivers*

Hodges, Houston - *Circle of Years: A Caregiver's Journal* - Moorehouse Publishing

Haymon, Sandra. W., Ph.D. - *My turn: Caring for Aging Parents & Other Elderly Loved Ones, A Daughter's Perspective* - Magnolia Productions Inc

Karpinski, Marion, R.N. - *Quick Tips For Caregivers- Healing Arts Communications* - [www.homecarecompanion.com](http://www.homecarecompanion.com)

Kuebelbeck, Julie and O'Connor, Victoria - *Caregiver Therapy* - Abbey Press

Love, Joy - *The Complete Elder Care Planner: Where to Start, Questions to Ask and How to Find Help.* - Hyperion

McLeod, Beth Witrogen - *Caregiving: The Spiritual Journey of Love, Loss, and Renewal* - John Wiley and Sons, Inc.

McGonigle, Chris, Ph.D. - *Surviving Your Spouse's Chronic Illness* - Holt & Company

McPhelimy, Lynn - *In The Checklist of Life, A Working Book to Help You Live and Leave this Life* - AAIP Publishing Company <http://www.checklistoflife.com>

Mienville, Dr. Lisa and Robeson, Dr. Bonnie L. - *Elder Care For The Millenium, A Practical and Compassionate Guide For Caregiving* - <http://www.eldercareplanning.com>

Ray, M. Catherine - *"I'm With You Now" A Guide Through Incurable Illness for Patients, Family And Friends* - Bantam Books

Samples, Pat, M.A. - *Daily Comforts for Caregivers* - Fairview Press

Samples, Pat, M.A. - *Self-Care For Caregivers, A Twelve Step Approach* - Hazelden Publishing

Schomp, Virginia - *The Aging Parent Handbook, The Baby Boomer Dilemma, How to Take Care of Your Loved Ones* - Harper Collins Publishers

Sheehan, Pauline J. - *Hugs For Caregivers* - WinePress Publishing

Warnock, Sheila & Capossela - *The "Funny Family" How To Care for Someone Who is Seriously Ill (Without Killing Yourself)* - Fireside Publishing

## Report of Gifts

### FROM THE EXECUTIVE DIRECTOR:

The Report of Gifts will not be included in this issue of the PSP Advocate due to technology conversions. The complete Report will be in the next issue of the PSP Advocate, 3rd Quarter, 2002.



## MINNESOTA SUPPORT GROUP

The Minnesota Support Group will be having a dinner on Thursday, October 3, 2002 at the Mayflower Community Church, 106 East Diamond Lake Road, Minneapolis, Minnesota. A neurologist will be speaking on current PSP research and treatment for PSP. The dinner will be at 6:00 PM. For reservations or information, please contact Charlotte Tripet at 763-546-1694.

## BECOME A PSP COMMUNICATOR

Become a PSP Communicator which means you give permission to release your name to other PSP families in your state. Just call the office and be placed on the Communicator's List. Ask for a Communicator's List for your community/state. You can contact others whether or not you add your own name to the list.

The Society for PSP, Woodholme Medical Building, Suite 515, 1838 Greene Tree Road, Baltimore, MD 21208  
1 (800) 457-4777 • 1 (410) 486-3330 • In Canada 866-457-4777  
PLEASE MAKE ALL CHECKS/GIFTS TO "THE SOCIETY FOR PSP."

Send me copies of:

- #1 PSP Some Answers (Overall guide To PSP)
- #2 Aids for Daily Living Catalogs/Thickening Agents/Personality Changes/Helping the Helpers - four page pamphlet.
- #3 2002 National Symposium Video Tapes - 3 Pack \$75, plus \$7 shipping in US and \$10 outside the US.
- #4 The PSP Advocate Newsletter
- #5 Thickening Agents
- #6 Swallowing Problems
- #7 Personality Changes
- #8 Helping the Helpers Who Care for People with PSP
- #9 Eye Movement Problems with PSP
- #10 1999 National Symposium Video Tapes - 3 Pack \$75, plus \$7 shipping in US and \$10 outside the US.
- #11 PSP Fact Sheet (1 page summary can be duplicated and distributed)
- #12 Aids for Daily Living Catalogs Listing
- #13 Medical Professional's Journal Review/PSP Advocate
- #14 Brain Bank Information Packet
- #15 Physician Referral Cards
- #16 Giving Envelopes
- #17 The Society for PSP/National Institutes of Health PSP Brainstorming Conference/Dr. John Steele meeting with the Maryland Support Group \$25, plus \$3 shipping in US and \$5 outside the US.
- #18 Beautiful Acknowledgment Card to someone special for any occasion and will personalize your message. By donation only.
- #19 Planned Giving Information
- #20 Information About PSP translated in Spanish
- #21 I Have Been Diagnosed with PSP
- #22 Challenges in the Management of PSP
- #23 Support Group List

Mail to: \_\_\_\_\_

\_\_\_\_\_

Fax to : \_\_\_\_\_ Email to: \_\_\_\_\_

FOR PHYSICIANS ONLY:

- #2 Video "The Diagnosis of PSP" (Recommended for clinicians and faculty) \$30 + \$4 shipping in US and \$7 outside
- Medical Professional Packet (Grant Award Information/PSP Rating Scale/copies of all other info.)

.....  
 I no longer wish to receive the PSP Advocate and by sending this will save expenses for the Society.

My new address is: \_\_\_\_\_

\_\_\_\_\_

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

Name \_\_\_\_\_

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City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_ Country \_\_\_\_\_

Fax \_\_\_\_\_ Email \_\_\_\_\_

Person w/PSP  Family  Physician  Other \_\_\_\_\_

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

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

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone/Fax/email \_\_\_\_\_

Check/Charge to:  Visa  Mastercard  American Express

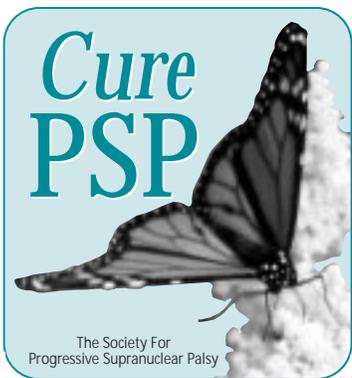
Card number \_\_\_\_\_ Expiration Date \_\_\_\_\_ Signature \_\_\_\_\_

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

26 .....

PSP Advocate, Second Quarter 2002

# How Can We Serve You Better?



## PLEASE FAX OR MAIL THIS TO:

Nancy Brittingham, PSP Advocate Editor  
 The Society for PSP  
 1838 Greene Tree Road, Suite 515  
 Baltimore, MD 21208  
 FAX: 1 (410) 486-4283

To help us make this newsletter as useful to you as possible, please take a moment to answer the short questions below and fax or mail your completed survey to us within the next 10 days.

### PLEASE CIRCLE YOUR ANSWERS TO QUESTION 1-4:

1. How much of the newsletter do you usually read?	0%	25%	50%	75%	100%
2. How many other people do you typically share this newsletter with?	0	1	2	3	4+
3. How would you rate the overall value of the newsletter articles to you? (5 excellent)	1	2	3	4	5
4. How would you rate the overall look and feel of the newsletter?	1	2	3	4	5

### PLEASE WRITE IN YOUR SUGGESTIONS:

What topics are you most interested in reading about? \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

How can we make this newsletter more useful to you? \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

How can the Society be of assistance to you? \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

Yes, I would like to save the Society production and mailing expenses and receive this newsletter by email.

Name \_\_\_\_\_

Current Home Address \_\_\_\_\_

Phone \_\_\_\_\_ Email address \_\_\_\_\_

Relationship to PSP \_\_\_\_\_

### WHAT CAN YOU DO TO BE OF SERVICE?

1. Contribute to the Society regularly and when possible use the newsletter's giving envelope.
2. Send the editor your PSP Stories, Helpful Hints, and Support Group News to NancyB501@cs.com or mail to Nancy Brittingham, 6 Bramston Drive, Hampton, VA 23666.

*Thank you, Mr. Jay Troxel of Florida, for funding the production of the PSP Advocate for the third consecutive year in memory of his beloved wife, Eloise H. Troxel.*

2000-2010  
*The Decade of Hope*

## *Guide To Planning Special Events*

OCTOBER IS PSP AWARENESS MONTH

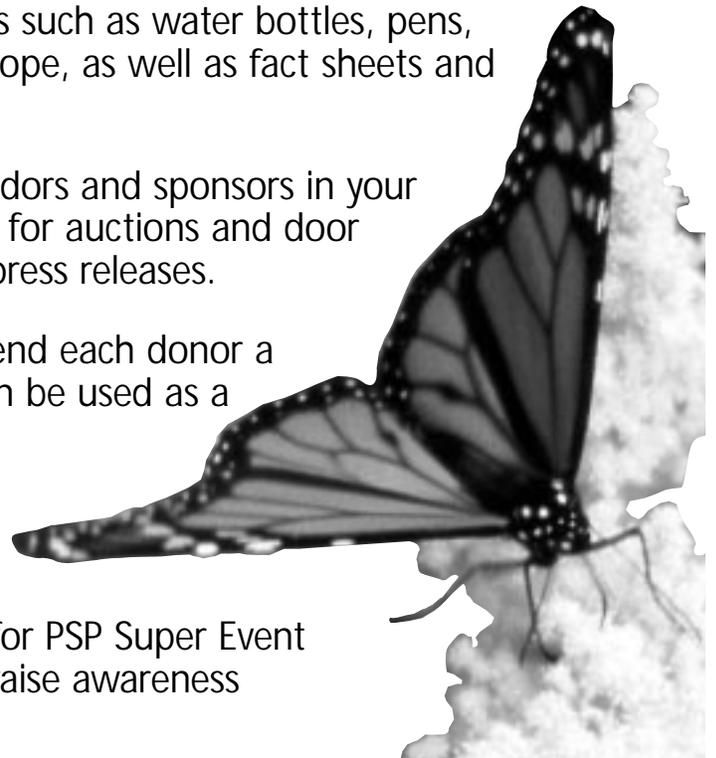
Raise PSP Awareness

Raise Funds

Promote the Society for PSP's mission to provide support/education and fund research.

### *How the Society for PSP can help with your event:*

-  Many special events require liability coverage and or/permits for the time and location of the event. The Society can assist with those items.
-  The Society can assist in the planning of your event and how to promote it.
-  We can design flyers and mail them to our mailing list in your state or city.
-  We can advertise your event in our newsletter and on our website.
-  We can provide advertising specialties such as water bottles, pens, carrying bags, PSP Butterfly Pins of Hope, as well as fact sheets and brochures on PSP.
-  We can provide sample letters to vendors and sponsors in your community so they can donate items for auctions and door prizes. We can also provide sample press releases.
-  We can process the donations and send each donor a personalized thank you letter that can be used as a tax-deductible receipt.
-  We can follow up with pictures of your event in our newsletter.
-  We can recognize you as a "Society for PSP Super Event Planner" for taking the time to help raise awareness and funds for PSP.



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# PLANNING A SPECIAL EVENT

## *Special Event Critical Success Factors*

### PRE-EVENT EVALUATION

1. DETERMINE PURPOSE AND GOAL
  - What do you want to achieve? Do you want to raise funds?*
  - Do you want to increase the Society's visibility within the community?*
  - Do you want to gain a broader base constituency?*
  - What are the type of factors you may want to consider so that the type of event will compliment the values of the organization?*
2. IDENTIFY YOUR AUDIENCE
  - Who is your audience?*
  - Who are people, groups or other organizations that you have access to contact?*
  - How do you connect with a specific group?*
  - Who are the business and personal friends and families of your audience?*
3. WHAT ARE THE STRENGTHS OF YOUR HUMAN RESOURCES?
  - Who are the volunteers and how will they be involved in the day to day details implementing the event?*
  - How much time will be needed?*
  - Is there a working committee?*
4. CONSIDER THE MISCELLANEOUS IMPLICATIONS
  - What time of the year do you want to hold the event? How much time is needed to prepare for the event?*
  - What is the projected income?*
  - What percent of gross income will be expenses?*
  - Do you have a job description for: the Chair, Co-Chair, and committee responsibilities?*
  - Have you determined how you will monitor the committees with benchmarks?*
  - How will the event be evaluated?*
  - How will you measure the success of the event: by money raised, participants, publicity?*

### HOW TO PROCEED

5. ESTABLISH A STRONG WORKING COMMITTEE
    - Who will be the Chair/Co-Chair?*
    - How many people will serve on the Special Events Committee?*
    - How often will the committee meet?*
  6. PREPARE PROPOSALS OUTLINING TYPES OF POSSIBLE EVENTS
    - Research various types of appropriate events*
    - Compile the particulars*
      - Name of the event*
      - Objectives*
      - Number of participants*
      - Projected financial goals*
      - Facility*
      - Location*
      - Entertainment sponsorships*
    - Present particulars to the committee for approval*
  7. PREPARE A WELL-THOUGHT-OUT PLAN BEFORE MAKING ANY FINAL DECISIONS
    - Timeline*
    - Budget*
    - Detailed checklists*
    - Committee structure and job descriptions*
  8. ESTABLISH SUB-COMMITTEES
    - Entertainment*
    - Catering and menu selections*
    - Invitations*
    - Logistics*
    - Publicity*
    - Ticket sales*
    - Finance*
    - Decorations/favors*
    - Miscellaneous fundraising activities/raffles, auctions, ad-book etc.*
- .....

# WALKATHONS

Walkathons are special events that will raise money and will educate the community about an organization, cause, and mission. Currently, there are millions of women, men and children of all ages who like to walk. The number continues to grow as the current emphasis on fitness continues to increase public awareness of this excellent recreational activity.

Individuals, friends and families are all potential participants for this type of event. Walkers solicit pledges based on the number of miles they walk. Everyone has the opportunity to participate and win prizes.

Walking is an activity that is easy for many. The only equipment you need is you! Children and parents can participate together. It is an ideal activity for the entire family to participate in together.

The following committee structure is designed for a Walkathon; however, the event should be adapted to the organization/group objectives and capabilities.

The Walkathon Chair is responsible for coordinating the event and sees that the committee members carry out the operational assignments. The Chair helps to recruit committee members and assigns specific responsibilities to each member of the committee.

Committee responsibilities include: walker recruitment, registration course, logistics, prizes, sponsorships, safety and first aid, publicity and finance.

A walkathon can have one route or more than one route. Routes may vary in length from 1 mile to 25 miles. The routes and prizes should be determined in advance so that the information can be printed on the materials.

Example of prize winners — person who finishes 1st, 2nd, 3rd in specific age groups; person who raises the most money etc.

There are a number of variables that have to be considered when estimating income and expenses. As a rule, expenses should not exceed 25%; keeping in mind that first-time events have a higher cost and expenses will become less as the event continues to grow.

These variables should be discussed with the committee to determine the human resources and time necessary to implement the event.

The number one rule to remember is have a “first class event” — if you do it right the first time — participants will come back the next year — will bring their families and friends—and sponsorships will increase — the event will grow!!!!

WALKATHONS ARE BASED ON THE FOLLOWING CRITICAL SUCCESS FACTORS:

- ◆ # of routes
- ◆ # of miles per route
- ◆ # of participants
- ◆ # pledged per mile
- ◆ # of corporate sponsorships, sponsorship levels and dollars sponsored
- ◆ overall sponsor
- ◆ route sponsor
- ◆ sponsor's along the route

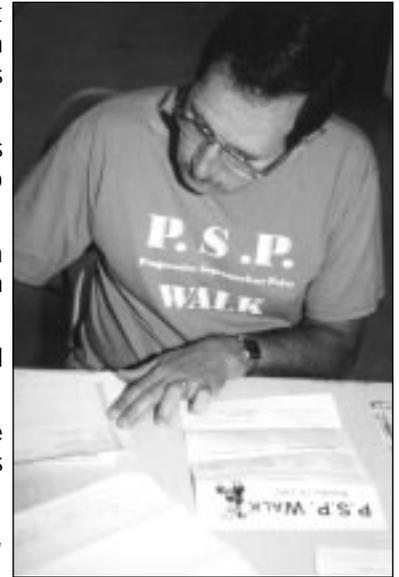
The potential for income can expand depending upon the number of miles, the number of routes, the number of participants, the number of corporate sponsors.

Mileage may vary upon logistics and committee decisions. Routes can be from 1 mile (a kiddie walk) to 25 miles or more. Routes are usually 5, 10, 15, and 25 miles.

ONE EXAMPLE OF A WALKING ROUTE CONSIDERING THE CRITICAL SUCCESS FACTORS:

- ◆ Overall sponsor for the event - \$5,000
- ◆ Walking route - 5 miles
- ◆ Number of participants - 200
- ◆ \$100 raised per participant - \$20,000
- ◆ Sponsors along the route (5 sponsors each paying \$100) - \$500
- ◆ Gross income - \$40,000
- ◆ Expenses 25% - \$10,000
- ◆ Net Income - \$30,000

As stated above, there are many variables to consider. The example presented is “food for thought.” Carefully addressing the “critical success factors” will enable the committee to determine a detailed plan that includes income potential and expenses.



## FUNDRAISING IDEAS

### SILENT AUCTION

Acquiring tangible and intangible items from retailers at no cost or a nominal fee to display for bidding.

### DINNER DANCE

Providing an atmosphere for a fine sit-down or buffet dinner followed by an evening of dancing. A theme is often used to attract an audience such as a 50's or 60's dance, square dancing, etc.

### SHOWS

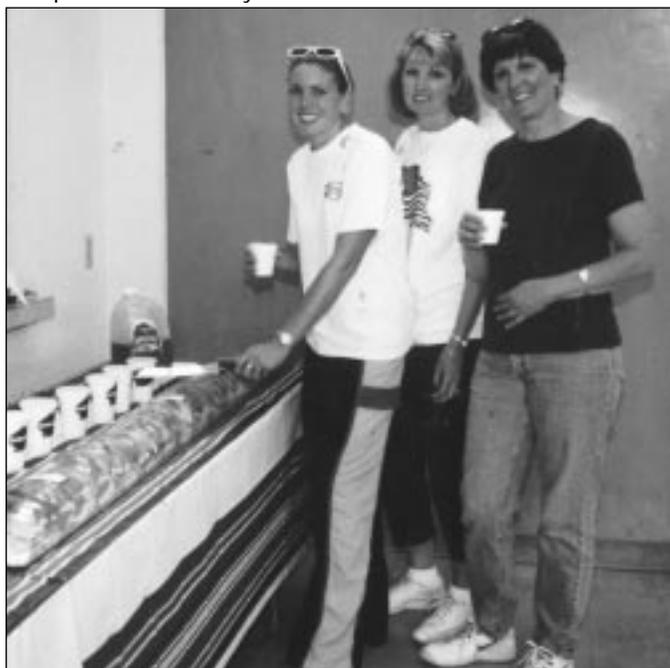
Purchasing a block of tickets to a show at a local theater and selling them to constituents. A reception may be held in conjunction with the theater experience.

### LAS VEGAS NIGHT

Providing games for gambling and various stations for winning prizes. Guests have the opportunity to "play at the casino" for the evening. A dinner may accompany the plans for this type of event.

### MOVIE PREMIER

Publicizing a movie and enlisting guests to watch the movie on a designated evening or afternoon in which proceeds benefit your cause.



### CONCERT

Hiring a talented, either nationally or locally known celebrity/singer or a group to perform. Arranging the event on the opening night of a celebrity concert is one option. Sometimes the performer may donate their services.

### MARATHONS

A walk-a-thon or dance-a-thon recruits generally large numbers of people to participate in a physical activity

that brings in funds through pledges made in advance.

### FOOD FESTIVALS

Lining up vendors to provide food that either relates to a specific theme such as an international food event, chocolate festival, etc.

### CRUISE

An evening or full day on a boat in the harbor filled with activities on the boat can provide an exotic setting for an event.

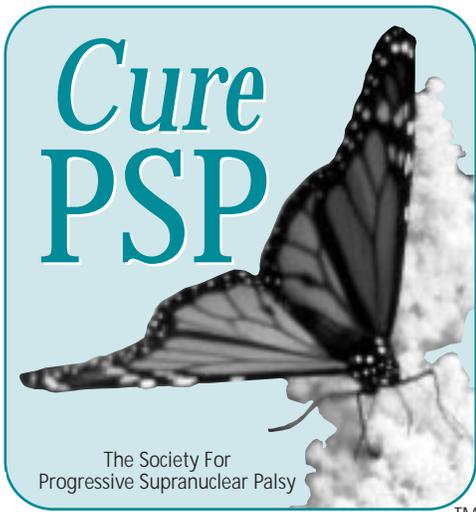
### CARNIVAL, STREET FAIR, COUNTY FAIR

A family event with an assortment of booths, featuring arts and crafts, food, music: (appearances by school choirs, orchestras, and marching bands) along with races and other activities for the children and adults

### GOLF TOURNAMENT

Golf tournaments offer many opportunities for fundraising while participants enjoy spending the day playing the most popular corporate sport in the United States.

Please contact the Society office and let us know about your special event. Let us know how we can assist you.  
(800) 457-4777 • (410) 486-3330 • [www.psp.org](http://www.psp.org)



Dear Friends,

While the stock market has plummeted, the Society's income has fallen considerably. During this difficult financial period, we are committed to maintaining our role as a lifeline to everyone impacted by PSP.

We recently sent an appeal letter requesting a contribution. We are in need of your thoughtful support TODAY to assist with the programs and research planned for 2002. Please give what you can. It's easy to give—go on line and click on “Annual Campaign”, call the office with your credit card (1-800-457-4777) or make a pledge to be paid over time. An envelope is also enclosed with this newsletter.

**PSP Families NEED YOU, EACH OTHER AND THE SOCIETY!  
WE ARE COUNTING ON YOU TO KEEP OUR  
ORGANIZATION VIABLE!**

THE SOCIETY FOR  
**PSP**  
Progressive Supranuclear Palsy

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

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