Synapse

Winter 2005

Serving the Primary Lateral Sclerosis Community since 1997
Welcoming the SP Foundation since 2003

What's in Your Walker?

During a Holiday visit with my youngest grandson, we discovered a novel way to go for a walk. The rollater seat is a perfect perch for a toddler to have a ride. How do you use your assistive devices for fun and/or work? Please send your picture for the next issue as an email attachment to: synapsePLS@comcast.net
The editor, Thurza Campbell

SPF SPASTIC PARAPLEGIA FOUNDATION, INC.
Research / Education / Support
Lead Sponsor of the Synapse Newsletter

The Spastic Paraplegia Foundation is dedicated to finding the cures for Primary Lateral Sclerosis and Hereditary Spastic Paraplegia through research funding, information and support programs.

http://www.sp-foundation.org ✦ email: info@sp-foundation.org
Phone: 703.495.9261

Our thanks to the SP Foundation - now the lead sponsor of the Synapse Newsletter.

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SP Foundation News

HSP Research Grant Awarded to Two British Doctors

Vincent T. Cunliffe, Ph.D. and Jonathan D. Wood, Ph.D.received a two-year, $90,000 grant for their proposal entitled "Modeling the neurodegenerative processes caused by mutation of the SPG4 gene in zebrafish and development of strategies for pharmacological intervention". Drs. Cunliffe and Wood are from the Centre for

Developmental Genetics and the Academic Neurology Unit of the University of Sheffield, Sheffield in the United Kingdom. Dr. Cunliffe explains that zebrafish embryos develop outside of the mother, allowing a unique opportunity for research: "The high optical clarity of the embryos enables detailed visualization of fluorescent molecular probes and internal structures in both living and fixed specimens." The researchers will seek to determine the role of mutant Spastin in the neurodegeneration that leads to HSP. They will then develop drug strategies to reduce the severity of the condition. Funds for this grant were raised by the SP community in 2003.

Two SPF Board Members Retiring

The Spastic Paraplegia Foundation announced that two of its Board members, both of whom are also officers of the corporation, will be retiring from the Board effective March 12, 2005. The two members are Kathi Geisler and Marlene Doolen.

"Kathi Geisler is a co-founder of the SPF and has been an organizer extraordinaire, said Mark Weber, President of the SPF. "She has been a key organizer for several TeamWalk efforts including chairing the 2003 and 2004 weekend events. As a communications professional, she also created and maintains our web site and she has also been involved in community projects such as the SPF cookbook. It is no exaggeration to say that the SPF wouldn't be where it is today without Kathi Geisler leading the charge."

"Marlene Doolen has also been a workhorse for the SPF", said Weber. "Her work has primarily been behind the scenes - doing mailings, keeping records and filing reports with government agencies, which has been critical to the launching and ongoing success of the SPF. She also organizes community events in Texas and promotes various fundraising efforts and community projects."

"Both of these individuals will be sorely missed", said Weber. "In addition to the countless hours of their time that they gave to our cause, they were wonderful to work with. And they provided wise advice during Board meetings. I wish we could clone them", said Weber.

SPF Announces Five New Members to the Board of Directors

The Spastic Paraplegia Foundation announced the addition of five new members to its Board of Directors effective at the Annual Meeting in Nashville, Tennessee on March 12, 2005. The five talented individuals will join five current board members.

New Board members:

Kris Brocchini was the top TeamWalk fundraiser for the SPF for 2004. She has worked in numerous volunteer positions in the past, as well serving on her local School Board for 13 years. Kris was recently diagnosed with PLS. A graduate of the California Polytechnic State University, she has four children and lives in Ripon, California.

Jean Chambers, R.N., is an operating room nurse. She has been the Head Nurse/Manager of a private plastic surgery clinic for the past fifteen years. Jean has served on various committees of her provincial and national Operating Room Nurses associations. She has organized several SPF Connections. Jean has an R.N. diploma and is the mother of two sons. She has HSP and lives in West Vancouver,British Columbia, Canada.

Frank Davis is the President of Pittman & Davis, a direct marketing catalog company specializing in the sale of perishable food items. He also serves as the President of the National Association of Perishable Shippers and has served in an advisory capacity to the US Postal Service. Over the past two years, Frank has donated his services to the SPF by doing several large mailings for the Foundation. He has Bachelors degrees in business administration and sociology from Trinity University. He lives in Harligen, Texas with his wife. Frank and his daughter have HSP.

Rick Pallas served as an executive with several major companies (including Perot Systems, and EDS Corporation) during his nineteen year career in the automotive parts manufacturing and information systems industries. He was also the President and Lobbyist for the Washington Association of Community College Students. He brings extensive management and consulting experience to the Board. Rick graduated from Olympia Technical College where he majored in Computer Science and Accounting. He lives in Ypsilanti, Michigan with his wife and two children and was very recently diagnosed with PLS.

Jim Sheorn is a sales representative for Sankyo Pharma Incorporated (a pharmaceutical company), and has over fourteen years of experience in customer relations and sales. He was previously a Field Director for the American Heart Association where his work led to large increases in fundraising. Jim has is actively involved organizing SPF Connections in Nashville. Jim holds a bachelor's of science degree in marketing from the University of Tennessee at Chattanooga. He lives in Brentwood, Tennessee with his wife and has had HSP for over ten years.

Current Board Members

These five outstanding individuals will be joining current Board members who are completing terms or have been elected to a new, two-year term. They are:

Paul Brockman joined the Board in 2003. He is the owner and President of Midwest Medical Equipment and has over fifteen years of business experience. He has previously raised monies for a capital improvement program with his Parrish, Immaculate Conception in Columbus, Ohio. Paul has been active on the fundraising committee of the SPF, and has provided the Board with his business experience. He holds a Bachelor's Degree from Ohio State University and lives in Columbus, Ohio with his wife and two sons. His wife and a son have HSP.

Linda Gentner joined the Board in 2003. She has held several volunteer positions over the past fifteen years, including President of the Washington Hospital Service League. She also serves on the Board of Directors of the Washington Hospital Foundation. Linda has been active organizing SPF Connections, organizing special projects and organizing the first California TeamWalk. She also assists with and attends numerous SPF events around the country and frequently lends her knowledge, experience and compassion to others on the SPF's email support groups. Linda graduated from the Southern Ohio College. She has been diagnosed with PLS, and lives in Fremont, California.

David Lewis is an SPF incorporating board member and served on the foundation steering committee. He also serves as the SPF's Treasurer. David is the chief financial officer for Pezold Management Associates, Inc. and has twenty years of various business experience. David holds a Bachelor of Science degree in Commerce & Business Administration and earned a CPA license in 1982. He developed HSP as a child. He and his daughter live in Fortson, Georgia.

Annette Lockwood is an SPF incorporating board member and served on the foundation steering committee. She works for ExxonMobil, and has more than twenty years experience in sales, management, pricing, marketing, administration and procurement.

Annette is active in the SPF community organizing various fundraising initiatives including the SPF portion of the Exxon /Mobil Employee Giving Program. Annette holds a Mechanical Engineering Degree and a Professional Engineers License. She has adult-onset HSP. She has two children and lives with her husband in Fairfax Station, Virginia.

Mark Weber is an SPF incorporating board member and co-chaired the foundation steering committee. He is an attorney with eleven years experience as an Assistant Attorney General and Assistant District Attorney. Formerly, he served in several environmental issues advocacy positions. Mark was an active PLS community leader, launching and managing a PLS support/information email List, serving as editor of a quarterly informational/support newsletter and organizing and assisting in fundraising initiatives. Mark holds a BA in economics and psychology and a JD. He was admitted to the Massachusetts Bar in December 1986, and was diagnosed with PLS in 1997. He lives with his wife and two sons in Sherman, Connecticut.

MEDICAL UPDATES

Is PLS Part of the ALS Spectrum – or Not?

By Gail McBride

Neurology Today: November, 2004

The article reports on the first ever international meeting on PLS. The meeting was held in Santa Clara in June, 2004. The question of whether PLS is part of ALS drew an international group of investigators to meet for the first time. After two days of presentations, intense discussions, and disagreements on the clinical attributes of PLS meeting participants met in five subcommittees to work out new criteria either for diagnosing or getting more information about PLS. The subcommittees are clinical criteria, neurophysiology, neuroimaging, neuropathology and genetics.

The Role of the Spastin Protein in House flies (Drosophila)

http://www.pubmedcentral.nih.gov/articlerender.fcgi

?tool=pubmed&pubmedid=15562320 PLoS Biol. 2004 Nov 30;2(12):e429

Drosophila Spastin Regulates Synaptic Microtubule Networks and Is Required for Normal Motor Function.

Sherwood NT, Sun Q, Xue M, Zhang B, Zinn K.Broad Center, Division of Biology, CA Institute of Technology, Pasadena, California, United States of America.

The most common form of human autosomal dominant hereditary spastic paraplegia (AD-HSP) is caused by mutations in the SPG4 (spastin) gene, which encodes an AAA ATPase closely related in sequence to the microtubule-severing protein Katanin. The Drosophila neuromuscular junction is a glutamatergic synapse that resembles excitatory synapses in the mammalian spinal cord, so the reduction of organized presynaptic microtubules that we observe in spastin mutants may be relevant to an understanding of human Spastin's role in maintenance of axon terminals in the spinal cord.

PLS with Parkinsonian Symptoms

Mabuchi N, Watanabe H, Atsuta N, Hirayama M, Ito H, Fukatsu H, Kato T, Ito K, Sobue G. Department of Neurology, Nagoya University Graduate School of Medicine, Nagoya, 466-8550 Japan. sobueg@med.nagoya-u.ac.jp : J Neurol Neurosurg Psychiatry. 2004 Dec;75(12):1768-71

http://jnnp.bmjjournals.com/cgi/content/abstract/75/12/1768

We encountered three patients with primary lateral sclerosis (PLS) showing bradykinesia, frozen gait, and severe postural instability, as well as slowly progressive spinobulbar spasticity. Cranial magnetic resonance (MR) imaging showed precentral gyrus atrophy. Central motor conduction was markedly prolonged or failed to evoke a response. Positron emission tomography (PET) showed significant reduction of [(18)F]fluoro-2-deoxy-d-glucose uptake in the area of the precentral gyrus extending to the prefrontal, medial frontal, and cingulate areas. No abnormalities were seen in the nigrostriatal system with PET using [(18)F]fluorodopa or [(11)C]raclopride or with proton MR spectroscopy. Thus, widespread prefrontal, medial, and cingulate frontal lobe involvement can be associated with the parkinsonian symptoms in PLS.

Drug Effective in Combatting Inappropriate Laughing/Crying: Treatment of pseudobulbar affect in ALS with dextromethorphan/quinidine: a randomized trial.

Neurology. 2004 Oct 26;63(8):1364-70.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=15505150

Brooks BR, Thisted RA, Appel SH, Bradley WG, Olney RK, Berg JE, Pope LE, Smith RA; AVP-923 ALS Study Group. University of Wisconsin, 600 Highland Ave., Rm. H6/563 CSC, Madison, WI 53792-5132, USA. brooks@neurology.wisc.edu

BACKGROUND: Patients with ALS commonly exhibit pseudobulbar affect. METHODS: The authors conducted a multicenter, randomized, double-blind, controlled, parallel, three-arm study to test a defined combination of dextromethorphan hydrobromide (DM) and quinidine sulfate (Q) (AVP-923) for the treatment of pseudobulbar affect in ALS CONCLUSIONS: AVP-923 palliates pseudobulbar affect in ALS. Overall benefits of treatment are reflected in fewer episodes of crying and laughing and improvements in overall quality of life and quality of relationships.

Early onset Autosomal Dominant Spastic Paraplegia Caused by Novel Mutations in SPG3A.

Neurogenetics. 2004 Oct 28;

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=15517445&dopt=Abstract

Abel A, Fonknechten N, Hofer A, Durr A, Cruaud C, Voit T, Weissenbach J, Brice A, Klimpe S, Auburger G, Hazan J.

Molecular Genetics Section, Clinic for Neurology, JW Goethe University, House 26, Theodor-Stern-Kai 7, 60590 Frankfurt, Germany.

More than 20 HSP loci and 10 spastic paraplegia genes (SPG) have been identified to date, including the genes responsible for the two most frequent forms of autosomal dominant spastic paraplegia (AD-HSP), encoding spastin (SPG4) and atlastin (SPG3A), respectively. To date, only eight mutations have been described in the atlastin gene, which was reported to account for about 10% of all AD-HSP families. We investigated 15 German and French AD-HSP families. Overall, the comparison of the clinical data for all SPG3A-HSP families reported to date failed to reveal any genotype/phenotype correlation as demonstrated for other forms of AD-HSP. However, it confirmed the early onset of this form of HSP, which was observed in almost all affected individuals with a mutation in the atlastin gene.

Early Onset Alzheimer's with Spastic Paraparesis

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=15534188&dopt=Abstract Arch Neurol. 2004 Nov;61(11):1773-6.
Ataka S, Tomiyama T, Takuma H, Yamashita T, Shimada H,
Tsutada T, Kawabata K, Mori H, Miki T.
Department of Neurology, Osaka City University Medical School, Osaka, Japan.
OBJECTIVE: To describe a novel mutation in the PSEN1 gene associated with early-onset Alzheimer disease with spastic paraparesis. . RESULTS: We found a novel mutation (Leu85Pro) in PSEN1. This mutation influenced the production of Abeta, resulting in a 2-fold elevation of Abeta42 production and of the Abeta42/40 ratio.
CONCLUSION: To our knowledge, this is the first report of very early-onset Alzheimer disease with spastic paraparesis and with the visual variant form of the disease, which is associated with visuospatial cognitive disorder.

Regrowing Motor Neurons

Proc. Natl. Acad. Sci. USA, 10.1073/pnas.0406795101
http://www.pnas.org/cgi/content/abstract/0406795101v1
Jinhui Chen *, Sanjay S. P. Magavi, and Jeffrey D. Macklis Departments of Neurosurgery and Neurology and Program in Neuroscience, Massachusetts General
Hospital-Harvard Medical School Center for Nervous System Repair, Harvard Medical School, Massachusetts General Hospital, Boston, MA 02114
Communicated by Richard L. Sidman, Harvard Medical School, Boston, MA, September 15, 2004 (received for review March 17, 2004)
The adult mammalian CNS shows a very limited capacity to regenerate after injury. However, endogenous precursors, or stem cells, provide a potential source of new neurons in the adult brain. Experiments have demonstrated that endogenous precursors can differentiate into even highly complex long-projection CSMN in the adult mammalian brain and send new projections to spinal cord targets, suggesting that molecular manipulation of endogenous neural precursors in situ may offer future therapeutic possibilities for motor neuron degenerative disease and spinal cord injury.

Neurotransmitters – the background

Contributed by Frank Reyerse
http://faculty.washington.edu/chudler/chnt1.html
Communication of information between neurons is accomplished by movement of chemicals across a small gap called the synapse. Chemicals, called neurotransmitters, are released from one neuron at the presynaptic nerve terminal. Neurotransmitters then cross the synapse where they may be accepted by the next neuron at a specialized site called a receptor. The action that follows activation of a receptor site may be either depolarization (an excitatory postsynaptic potential) or hyperpolarization (an inhibitory postsynaptic potential). A depolarization makes it MORE likely that an action potential will fire; a hyperpolarization makes it LESS likely that an action potential will fire.

Arimoclomol Drug Trials for ALS to Commence in 2005

CytRx Corporation has acquired all the clinical and pharmaceutical assets and related intellectual property of Hungary-based Biorex Research & Development RT. a privately held biotechnology company focused on the development of novel small molecules with broad therapeutic applications in neurology, diabetes, and cardiology. This acquisition dramatically accelerates CytRx’s entry into clinical testing for amyotrophic lateral sclerosis (ALS; Lou Gehrig’s Disease), with an anticipated initiation of a Phase II clinical trial for the drug arimoclomol during the second quarter of 2005.
Dr. Robert H. Brown, Jr., Professor of Neurology at Harvard Medical School, founder of the Cecil B. Day Laboratory for Neuromuscular Research at Massachusetts General Hospital, and a recognized authority on ALS and member of CytRx's Scientific Advisory Board said, "The preliminary data makes arimoclomol an extremely important ALS drug candidate because of its demonstrated safety profile and the potential to treat both sporadic (spontaneous) and familial (inherited) forms of ALS."

Originally developed to treat diabetic complications, arimoclomol was recently discovered to significantly inhibit progression of ALS in an experimental animal model of the disease (Kierin et al., Nature Medicine, April 2004, Vol. 10(4), 402-5).
The company's RNAi approach seeks to prevent the production of a toxic protein that causes disease in a subset of ALS patients that have inherited a mutation in the superoxide dismutase 1 (SOD1) gene. CytRx believes that arimoclomol would not only target the SOD1 protein, but also additional toxic proteins that may be involved in the more common ("sporadic") form of ALS as well. Arimoclomol would thus dramatically increase the number of treatable ALS patients, compared with the RNAi approach. "We plan to continue development of our RNAi approach to ALS concurrently with developing arimoclomol, but if both drugs prove to be effective, we would focus any immediate clinical development activities on the orally available arimoclomol, since it addresses a broader patient population," said Dr. Barber.

Neurology : Journals Links

Ed. Note:Below is a comprehensive listing of world wide neurology journals. Click the name while holding down the Control button to go to each site.

European Journal of Paediatric Neurology - The official journal of the European Paediatric Neurology Society, successor to the long-established European Federation of Child Neurology Societies. 6 issues per year plus supplements.

African Journal of Neurological Sciences - Published in french and english. Access to full text articles.

Archives of Neurology - Journal published by the American Medical Association. Published monthly.

Brain - A journal of neurology. Free access to already published articles.

European Neurology - Journal covers clinical aspects of diseases of the nervous system and muscles, as well as their neuropathological, biochemical, and electrophysiological basis. Published by Karger.

The Journal of Neurophysiology - Tables of contents and abstracts available to non-subscribers; subscribers can view articles in PDF format and/or receive updates and regular searches via email. An American Physiological Society publication. This journal publishes articles on all levels of nervous function from the membrane and cell to systems and behavior.

Autonomic Neuroscience - Journal published by International Society for Autonomic Neuroscience (ISAN) for publication and dissemination of original investigations on the autonomic nervous system. Published by Elsevier since 2000.

Clinical Neurology and Neurosurgery - Papers and reports on the clinical aspects of neurology and neurosurgery. It is an international forum for papers of interest to Neurologists and Neurosurgeons world-wide. The journal complements the renowned Handbook of Clinical Neurology.

Clinical Neurophysiology - Journal of research and other information on all aspects of the field, both normal and abnormal, including human physiology and pathophysiology of both the central and the peripheral nervous system, and applications of neuroimaging and other techniques.

Clinical Neuroscience Research - Official journal of the Association for Research in Nervous and Mental Disease. The focus is on basic neuroscience and clinical investigations of cognition, mood, behavior and motor function of both normal and abnormal brain function.

Neuromuscular Disorders - Official Journal of the World Muscle Society, covers all aspects of neuromuscular disorders in childhood and adult life. Online archive covers all issues since 1997.

Parkinsonism and Related Disorders - Results of basic and clinical research contributing to the understanding, diagnosis and treatment of all neurodegenerative syndromes in which Parkinsonism, Essential Tremor or related movement disorders may be a feature. Useful for all neurologists specialising in Parkinson's Disease and other movement disorders.

Sleep Medicine - Journal primarily focusing on the human aspects of sleep, integrating the various disciplines that are involved in sleep medicine. Published by Elsevier Science since 2000.

Nervenarzt - German neurological journal; 12 issues per year. Abstracts available both in german and english. Online archive since 1997. Fulltext in pdf format available on subscription.

Experimental Brain Research - Journal publishes original contributions related to experimental research of the central and peripheral nervous system. It was founded in 1966.

Neuroradiology - Official Journal of the European Society of Neuroradiology. Organ of the Japanese Neuroradiological Society.

Acta Neuropathologica - Official journal of the Research Groups for Neuropathology, Comparative Neuropathology, and Neurooncology, and for the World Federation of Neurology. Publishes work on diseased and experimentally altered nervous tissue. Free access to abstracts.

Journal of Neurology - Official international journal of the European Neurological Society. It publishes original communications on clinical neurology and related basic research.

European Spine Journal - The official publication of the Spine Society of Europe focuses on spine surgery and all related disciplines, including functional and surgical anatomy of the spine, diagnostic procedures, and neurology.

Neurogenetics - Journal publishes findings that contribute to a better understanding of the genetic basis of normal and abnormal function of the nervous system. Indexed in Current Contents and Index Medicus.

Neurological Sciences - Continuation of The Italian Journal of Neurological Sciences. Covers contributions in both the basic and clinical aspects of the neurosciences, in English. Online archive since 1999.

Journal of Headache and Pain - Journal covers all aspects of headache and pain, including theory, methodology, clinical practice and care.

Lancet Neurology - Neurological version of Lancet started May 2002. Many papers available for free download.

Stroke - Journal on cerebrovascular diseases published by American Heart Association. Abstracts and sample issue available online. Full text available for subscription.

Developmental Medicine and Child Neurology - Covers a wide range of clinical topics concerning the neurological diseases and disabilities of children.

Associated Disorders - Journal focuses on Alzhiemer Disease and related disorders. Published monthly. Full-text content, online-only content available upon subscription. Published by LWW.

Neuroscience BiblioAlerts - Customized scientific and technical information reports delivered immediately on a fee per paper basis.

BMC Neurology - BioMedCentral Neurology publishes original research articles in all aspects of the prevention, diagnosis and management of neurological disorders, as well as related molecular genetics, pathophysiology, and epidemiology. BMC Neurology is indexed by PubMed. Full text content available online for free.

Headache: The Journal of Head and Face Pain - Official journal of the American Headache Society publishing original articles on head and face pain, including clinical and basic research, diagnosis and management, epidemiology, genetics, and pathophysiology.

Cephalalgia - Journal of the International Headache Society provides an international forum for original research papers, review articles and short communications.Published monthly by Blackwell Publishing.

Acta Neurologica Scandinavica - An international forum for the dissemination of information advancing the science or practice of neurology and neurosurgery. It represents a high scientific quality of original clinical, diagnostic and experimental work in those fields.

European Journal of Neurology - Official journal of the European Federation of Neurological Societies. Published monthly by Blackwell Publishing.

Brain Aging - International journal published by "Ana Aslan" Academy of Aging attempts to explain in a clear and scientific language the latest news from all over the world related to brain aging. Fulltext contents available for free in *.pdf format.

BrainLINC - Case-based continuing medical education journal focused on insights into the different courses of Multiple Sclerosis. Published by Elsevier. Full access to Abstracts. Free registration required.

The Canadian Journal of Neurological Sciences - Official journal of the Canadian Congress of Neurological Sciences (CCNS).

Journal of Clinical Neurophysiology - Official journal of the American Clinical Neurophysiology Society.

Current Opinion in Neurology - Website provides access to full-text content, online-only content, features and services, author submission materials and title-specific information. An LWWonline partner.

Continuum - CME journal published by the American Academy of Neurology. 6 issues per year. Subscribers get ACCME accredited self-study materials that reflect key clinical and scientific developments in neurology.

Current Neurology and Neuroscience Reports - Provides the views of experts on current advances in neurology and neuroscience and selections of the most important papers. Free access to abstracts; full text requires subscription.

Experimental Neurology - Publishes the results and conclusions of original research in neuroscience with a particular emphasis on novel findings in neural development, regeneration, plasticity, and transplantation.

Brain and Cognition - Coverage includes, but is not limited to: memory, cognition, emotion, perception, movement, or praxis, in relationship to brain structure or function.

Journal of Neurological Sciences - Official journal of the World Federation of Neurology focusing on clinical neurology and the basic sciences.

NeuroImage - Focuses on publishing research on imaging and mapping strategies to study the brain's structure, function and the relationship between the two, from the whole brain to the tissue level. Abstracts available since the first issue, full-text articles require subscription.

Neurological Research - International peer-reviewed journal publishing original and fundamental studies as well as clinical research in areas of neurology, neurosurgery and neurosciences. Full text access from January 2001 issue available upon subscription via Ingenta Select service.

Functional Neurology - Provides a medium for the publication of scientific contributions dealing with all aspects of functional neurology. It focuses on the interaction of the nervous system with the environment. Includes author instructions, and subscription details.

Journal of Clinical Neuroscience - The official journal of Neurosurgical Society of Australasia Australian Association of Neurologists.

Neuropeptides - Original research and reviews dealing with the structure, distribution, actions and functions of peptides in the central and peripheral nervous systems.

Seizure - International forum for the publication of peer-reviewed papers on topics related to epilepsy.

Journal of Molecular Neuroscience - The journal presents original papers on all aspects of macromolecular neuroscience research. It covers a broad range of subjects, from genomics to proteomics or genes to behaviors. Published by Humana Press.

Polish Journal of Neurology and Neurosurgery - Official Journal of Polish Neurological Society. Access to the list of past issues starting from 1990, abstracts and selected full text supplements, published since 1997.

Muscle and Nerve - Journal for EMG related research. Registration required to access.

Annals of Neurology - Official journal of the American Neurological Association and the Child Neurology Society. Full-text content available upon subscription.

Movement Disorders - Official journal of the Movement Disorders Society.

Internet Journal of Neurology - Peer reviewed journal published and archived by Internet Scientific Publications LLC and recognized by The Library of Congress Catalog of Publications. Free access to full text articles.

Journal of Alzheimer's Disease - International multidisciplinary journal to facilitate progress in understanding the etiology and pathogenesis of Alzheimer's disease and is dedicated to providing an open forum for original research that will expedite our fundamental understanding of Alzheimer's disease. Published by IOS Press.

Metabolism - Website provides access to full-text content, online-only content, features and services, author submission materials and title-specific information. An LWWonline partner.

Journal of Neuro-Ophthalmology - Official publication of The North American Neuro-Ophthalmology Society.

Journal of NeuroVirology - Official journal of The International Society for NeuroVirology provides a forum for researchers and clinician scientists involved in the study of neurovirology. Published bi-monthly by Taylor and Francis Group.

Journal of Neurology, Neurosurgery, and Psychiatry - A journal in clinical neurological practice, published from Europe. Currently, the online version has some full text articles and all abstracts.

Journal of Turkish Neurological Sciences - On-line peer-reviewed and quarterly published e-journal. Official publication of the Aegean Neurological Society. All abstracts (Adobe .pdf format) are in English. Full-texts are either in English or in Turkish. Free to access.

MedBioWorld Neurology and Neuroscience Journals - Directory of links.

Acta Neurologica Belgica - Published by Royal Association of Belgian Medical Scientific Societies. 4 issues a year.

Surgical Neurology - Journal provides comprehensive peer-reviewed coverage of the latest developments in neurosurgery. Audience includes neurosurgeons, neuroscientists and physicians specializing in medical imaging (especially CAT scanning).

Journal of the Neurological Sciences - Official Journal of the World Federation of Neurology provides the interface between clinical neurology and the basic sciences. Emphasis is placed on sound scientific developments which are or will soon become relevant to the clinician. Published by Elsevier.

Epilepsy Research - Journal focuses on experimental and clinical epileptology. Principal emphasis of the research is concerned with brain mechanisms in epilepsy.

Development - Journal devoted to publishing review articles and papers in the field of Child Neurology and related sciences. Online issues available since 1999.

Pediatric Neurology - Journal publishes peer-reviewed clinical and research articles covering all aspects of the developing nervous system, the latest advances in the diagnosis, management, and treatment of pediatric neurologic disorders.

Neuropsychiatry, Neuropsychology, and Behavioral Neurology - Official journal of the Behavioral Neurology Society. Each quarterly issue presents original research articles on basic brain processes, critical review articles, case reports, and brief reports on preliminary studies and pertinent clinical issues.

Neuroacta - Online fulltext, in multiple languages.

Neurologic Clinics of North America - Journal provides comprehensive, clinical reviews of timely subjects, including diagnosis and therapy, new materials, and new equipment. Each issue contains invited reviews (usually 10-14 per issue) on a single topic in neurology and is presented under the direction of an experienced guest editor.

Neurology - Official Journal of the American Academy of Neurology (AAN).

Neuron - Neuroscience journal published by Cell press. Abstracts since 1988 available for free. Fulltext issues available for 1996-current issues.

NeuroReport - Access to tables of contents and abstracts, instructions for authors, related web links, subscription information. Subscription is required to access full-text content.

NeuroRx - Official journal of the American Society for Experimental NeuroTherapeutics (ASENT). Published quarterly since January 2004. Each issue provides critical reviews focused on a single important topic relating to the treatment of neurological disorders.

NeuroMolecular Medicine Online - Research articles and critical reviews on the molecular and biochemical basis of neurological disorders.

Practical Neurology - Practical, up-to-the-minute digest of all the important developments in neurology. Published by Blackwell since 2001. Fulltext papers available on subscription.

Revista de Neurología - Spanish journal on clinical and experimental neurology. Spanish abstracts available. Full text available after subscription.

Spine - Bi-weekly peer review journal of spine surgery. Access to contents, abstracts, author, and subscription information.

Child's Nervous System - Official journal of the International Society for Pediatric Neurosurgery (ISPN). Covers all aspects of the pediatric neurosciences.

Brain Tumor Pathology - Official journal of the Japan Society of Brain Tumor Pathology published since 1983. It focuses on research and topical debate in all clinical and experimental fields relating to brain tumors.

Journal of Stroke and Cerebrovascular Medicine - Deals with management of stroke.

Neurocase - Journal of both adult and child case studies in neuropsychology, neuropsychiatry and behavioral neurology. Published by Swets and Zeitlinger (6 issues per year).

The Clinical Neuropsychologist - Professional journal hosted in The Netherlands.

Aphasiology - Journal concerned with all aspects of language impairment and related disorders resulting from brain damage. It provides a forum for the exchange of knowledge and the dissemination of current research and expertise in all aspects of aphasia and related topics, from all disciplinary perspectives.

Brain Injury - Research journal of the International Brain Injury Association, covering all aspects of brain injury from basic science, neurological techniques and outcomes to rehabilitation and outcome.

Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders - Official journal of the World Federation of Neurology Research Group on Motor Neuron Disease publishes clinical and experimental reasearch on motor neuron disorders. Published 4 times a year by Taylor & Francis Health Sciences.

Neurologist, The - Website provides access to full-text content, online-only content, features and services, author submission materials and title-specific information. An LWWonline partner.

Current Treatment Options in Neurology - Provides views of experts on current treatment options in neurology and selections annotated by experts of the most interesting papers from original publications. Free access to abstracts, full text only by subscription.

World Neurology - Newsletter published by World Federation of Neurology in cooperation with Elsevier Science. Fulltext contents in *.pdf format available since October 1999 issue.

LIVING WITH PLS/HSP

Becoming Smart about your Medications

Contributed by Dolores Carron

The December 2004 issue of Money magazine has a worthwhile article about recent concerns of new drugs and their safety and side effects. Many were devastated to learn of the adverse effects of Vioxx on the heart. We wonder how this can happen. One problem is that the clinical trials that lead to government approval of drugs are conducted in relatively idealized populations and only for a limited time. So when a drug hits the general population, the variations among us--race, gender, age, weight, health conditions--can bring to light previously undetected side effects. On top of that are all the other drug interactions you need to be aware of in an increasingly medicated age. Now, more than ever, it's important to take an active role in understanding the risks of your medications. A study of 548 new drugs approved by the FDA between 1975 and 1999 showed that the worst adverse side effects weren't known for about seven years. It's easy to be impressed with a new remedy, but often, the older more established medicines will do just fine with less risk.

Of course, you can't turn yourself into a physician or pharmacologist, but you can follow a few prudent practices and use a growing number of online resources to find the right questions to ask before popping those pills. Here is a checklist of things to ask your doctor whenever he or she recommends that you begin a new drug.

Why do I need this drug?

Are there non-drug therapies that I can try instead?

How will it interact with medications I am presently taking (including over the counter medication, vitamin, and mineral supplements)?

What are the risks and side effects of this drug?

How is this an improvement over existing drugs?

Can I take a lower dose?

Can I discontinue another drug?

Most of us can't name a complete list of what we are taking--name of drug, dosage, strength, etc. To prevent potential drug interactions, you should have a printed list, including over the counter medications, and take it to every doctor you consult. You can find a sample medication record sheet at www.citizen.org/eletter/drugworksheet.htm . If you can't do this, put all your pills in a bag and bring them to your doctor(s).

Gather as much information about the drug as you can. Some suggested websites are: www.pdrhealth.com , www.clinicalstudyresults.org , www.fda.gov/medwatch , www.medlineplus.gov , and www.worstpills.org . Don't rely on just one reference; get as much information as you can. Each site is unique in the type of information it gives.

World Community Grid

Contributed by Mark Weber

http://www.worldcommunitygrid.org/index.html

World Community Grid's mission is to create the largest public computing grid benefiting humanity. Our work is built on the belief that technological innovation combined with visionary scientific research and large-scale volunteerism can change our world for the better. Our success depends on individuals - like you - collectively contributing their unused computer time to this not-for-profit endeavor. Click on the above link to learn more.

Angelo Sciulli, PLSer: Giving ALS One Big Shiner

by Gary Wosk, ALSA Staff Writer

November 3, 2004

Nearly seven years since learning he had a rare form of ALS -primary lateral sclerosis - Angelo Sciulli, someone "Rocky Balboa" would be proud of, is still going strong.

The indefatigable Sciulli never goes down for the count, tries to prevent others with ALS from doing so, and is as passionate as ever about "eliminating the disease from the face of the Earth." He's made quite a name for himself as a wildlife and nature photographer, is mad as hell about ALS and is not going to take it anymore. This means stepping in the ring against the disease 24/7.Open this link to see some of Angelo's photographs http://www.alsa.org/news/article.cfm?id=530 A personification of determination, Sciulli has gone so far as to even attempt arranging a meeting with President Bush to discuss stem cell research. He's quick to point out, however, that he could not maintain the momentum and positive attitude without his wife for 37 years, Janet, who he calls a "saint."

His emphatic messages to people with ALS are subliminally conveyed through the beautiful images he takes of wildlife and nature, and motivational writings. The overall themes are stand tall, get involved and never give up. Anecdotes about the ravages of ALS are peppered with wry, witty observations that are funny and comforting to all. For instance, ask him what he's up to these days and he replies, "Six-feet, 243 pounds, but why do you ask?" or when asked what his age is, "Let's just say in dog years, I'm dead."

The doctors told the former director of chemical research for Spring Industries, a home furnishing company, that he would not survive for more than four years. That was in 1998, one year after he embarked on a second career as a professional photographer. And here he is, still basking in his 15 minutes, more like 30 minutes, of fame. "When I was diagnosed with ALS I was upset initially. My photography gave me a reason to get up and do `stuff.' The only difference was that ALS changed my focus to writing solely for ALS and disability awareness.

Sciulli's photos have appeared in numerous publications and have been chosen for exhibits, including the National Press Club and the International Photography Hall of Fame and Museum. He downplays personal glory and prefers shining the spotlight on the potential of all ALS patients."Each of us has a different talent and each of us can use those talents to the fullest," he pointed out. "Not everyone can be a pro athlete but that doesn't mean we cannot play recreationally. People can go and travel just like I do and take photographs. Because they don't publish and write doesn't mean they do not experience the same natural beauty as I do."

Each section of "Challenging Nature Photography," which the Midwest Book Review called "exceptionally well written and very highly recommended reading," describes a photography trip he made after the diagnosis and details the mental, physical and spiritual challenges he faced pursuing his passion.When I go to `work' with my camera, time ceases to exist for me. I can be exhausted after a day of shooting yet completely rejuvenated."

The Stretching Handbook

Contributed by Sue Me

This book has 100 photos for stretching every major muscle in the body. It is meant for people doing sports, but might be helpful for us, too. If you order both the book and video, you save money. http://www.thestretchinghandbook.com/products.htm

Welcome to Holland

By Emily Perl Kingsley

I am often asked to describe the experience of living with a disability -
to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this:

When you are finally "out on your own" it's like planning a fabulous vacation trip-to Italy. You buy a bunch of guidebooks and make your wonderful plans: the coliseum, the Michaelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting. After months of eager anticipation,-the day finally arrives. You pack your bags and off you go.

Several hours later the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland? You say." What do you mean, Holland?" I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there has been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place. So you must go out and buy new guidebooks. And you Must learn a whole new language. And you will meet a whole new group of people you never would have met.

It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts. But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, “Yes, that's where I 'was supposed to go. That's what I had planned.”

The pain of that will never, ever, ever go away, because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very 1ovely things about Holland.

Accessible Journeys

Travel agency specializing in individual and group trips and cruises for individuals with mobility problems and in wheelchairs. Visit www.disabilitytravel.com or call 800-846-4537. This site has valuable links from trip planning to wheel chair rentals, to ATM worldwide location.

On Peoples' Reaction to Someone Handicapped

Contributed by Galen

. . .One of the really neat things about this is never knowing how people will react. And you thought being sick was enough on your plate! Wait. There's more. Some folks will see you as a reminder of just how uncertain their own lives are, and may react with fear and sometimes even hate. Others may see you as an object to be pitied, rather than the person you are. Some will see you as just a hinderance, or some burden to bear. Now and again however, you run into folks that treat you like a human being, and somehow that makes all the grim stuff bearable.

Season of Sharing

Prepared by Synapse Ed. from a story written by Jane Kay, Staff Writer for the SanFrancisco Chronicle

Four years ago, lawyer Lynn Holmes had a nice life -- rollerblading in Manhattan Beach, spoiling her nieces and nephews with presents and traveling to Europe and Asia to negotiate customer contracts for a big semiconductor company. She was a frequent speaker on online privacy issues for the California Bar Cyberspace Law Committee and was busy going out for fun with friends and family.

Now, at 50, still with her mischievous smile and chestnut hair, she's in an electric wheelchair, speaking through a computer voice program and struggling to adapt to a rare degenerative nerve disorder. Three years ago, Holmes was diagnosed with Primary Lateral Sclerosis. Her life began to change after she decided to leave her position at International Rectifier in Los Angeles and opened a solo law practice in Sonoma County on copyright, trademark and contracts, focusing on Internet businesses and privacy.

She moved back to the family house in Forestville, where she grew up, down the hill from her younger sister, Tina Montgomery, and her family. One day, when Holmes and Montgomery were running, her sister noticed something odd. "She just wasn't picking up her left leg very well." Holmes made an appointment with an orthopedic sports physician, and finally at the ALS Center at UCSF with the director, Dr. Catherine Lomen-Hoerth. She began receiving medicines to relieve stiffness, emotional stress and other symptoms.

Her condition deteriorated, first limping, then unsteadiness and falling when bumped -- even falling when sneezing. She started with a cane, then a walker and a manual wheelchair. She started on the talking computer six months ago and in the power wheelchair in August.

Holmes' greatest struggle is trying to remain as independent as possible in her own home. She uses her love of math and machines to help her out. "I'm a geek at heart," she said. "I use the Internet for everything." Safeway delivers her groceries, and she researches and orders creative new tools to adapt. Holmes stays in touch with her family through e-mails. "I look at everything as a multipurpose tool," she said. "A reacher or grabber can also be used to get your pants over your feet while sitting. The bottom of a hospital bed can be raised to help me stand up." She would very much one day like to have an "assistant dog," one that can open doors, turn on lights, pick up objects "and snuggle."

A grant from The San Francisco Chronicle Season of Sharing Fund will help modify a Ford van that her Uncle Raul Arellano in San Jose found on eBay.

Her biggest boost comes from her large family. She has three sisters."We have a very large family," one sister said. "We have annual family picnics, and growing up, we had all the aunties in the kitchen making tamales. They love Lynn dearly. She definitely holds a special place on the family tree." Lynn and her sister are so close that they can often communicate without the use of the voiced

computer."We're sisters," she said. "There is some understanding without words."
www.seasonofsharing.org.E-mail Jane Kay at jkay@sfchronicle.com.

Have you ever laid awake at night?

by Gary Lockwood (son of Annette, SP Board member)

Just thinking about those few people,
Those few people you can't do without.
How many of those times have you,
the next time you saw them,
Honestly told them what they mean to you?
Insecurities aside,
Open your minds, open your hearts,
Open your souls.
One man is no one,
Without love,
Without the passion that leads him,
Leads him to within.
Where he finds portraits of friends,
Portraits of family.
Look within yourself and find those people.
And tomorrow,
and the next day,
Tell them how much they mean to you,
Tell them you love them.

Tips for Living with Bulbar PLS

Contributed by Thurza Campbell

1. Learn the American Sign Language alphabet. http://where.com/scott.net/asl/abc.html Your caregiver and close family and friends will need to learn it too. As your speech diminishes, certain sounds are hardest for others to understand. My husband and I have found that often hand spelling one word makes a sentence clear. Now that I use a computer to "talk" I still use hand spelling often, as in many places I can't get in a position to use the computer. It's also fun with grandkids to "talk" across a room! "g" was the first sound to go.
2. Make plans through your neurologist to get an Rx for a voiced computer before you are desperate. My local ALS chapter pointed me the right direction. The rehab specialist wrote the request to the insurance company. A voiced computer does not make communicating perfect, as you learn that most people are not "active listeners". However, mine is my lifeline which keeps me from being "locked in" and lets me continue my design business.
3. Buy a waterpik for brushing your teeth. Since food doesn't move around in your mouth properly, much of your meal ends up between your teeth. Since spitting and even brushing are difficult, the waterpik with a rinse mixed into the water keeps your mouth as clean as possible.
4. Cut your food, or have some kind caregiver cut up everything into very small pieces – about ½"x ½" at the most. This size can be swallowed easily, especially with the help of applesauce, mashed potatoes, oatmeal, au gratin sauces, etc.
5. Give up lettuce. I've found it sticks to the roof of my mouth. For those B vitamins you need, drink V-8.
6. Buy a small electric grinder/whisk. I bought a 200 watt Braun device which is wonderful. http://www.yourdelight.com/braun_mixers.htm It's called a Hand Grinder and Chopper. I refer to my pureed steak with mushrooms, "Zen steak". Why? Because I get the essence of whatever food I grind – the taste! I also use the whisk attachment for beating eggs (a tip for those whose hands don't do what you need them to do.)
7. Drink from wide mouthed cups and glasses. Best shape is with a flare out. In a restaurant, request any drink be put in an old fashioned glass.
8. Tuck your chin when you swallow. Try turning your head to one side. This helps, too.
9. I've found that Bounty paper towels are my best friend. They do not disintegrate like tissues do, leaving specs on your lips. I buy the rolls of half sheets, and keep them with me at all times. Since I can't keep my lips closed when eating, I've found that a neatly folded paper towel pressed against my lips when I eat helps quite a bit to have food or drink go where you want it rather than into your lap or down your front.
10. The meds for saliva reduction help some, but cause constipation. They do make your mouth dry while drooling – charming! The anti-constipation paste is a mainstay of my diet.

Anti-Constipation Fruit Paste

Contributed by Bobbi Woodward, PLS

1 lb. Prunes, pitted
1 lb. Raisins
1 lb Figs
1 c. lemon juice
1 c. brown sugar
4 oz. package of Senna Tea (From health food store)

Steep tea in 3-1/2 c. boiling water
Strain to 2 c.
Add fruit and boil until all fruit is soft
Add sugar and lemon juice
Puree in food processor. Add more tea if needed.
Freeze.
Take 2-3T each day.

Job Opportunity to Work from Home- Medical Transcriptionist

Contributed by Sharon Neumann

There is an opportunity for two people who have some medical and/or legal transcription experience and would like to be able to work from home.

Transcription equipment will be provided; you need to have your own computer with Word and be able to e-mail the completed transcripts which must be sent within 30 days of receipt of the dictation.

We do medical-legal reviews and advocacy for injured persons as well as in wrongful death cases. This often includes matters on a wide variety of rare disorders, including HSP and PLS, etc. The work is very interesting and meaningful while allowing you to be working from the comfort of your home.

If you would like to be considered for this opportunity, please reply with your letter of interest and resume.

Sharon Neumann, Paralegal
SMITH & JOHNSON ATTORNEYS PC
603 Bay Street
P.O. Box 705
Traverse City, MI 49685
231-946-0700
sneumann@smith-johnson.com
(mailto:sneumann@smith-johnson.com)
http://www.smith-johnson.com
(http://www.smith-johnson.com)

Living for Today, Locked in a Paralyzed Body

From an article by John Schwartz and James Estrin
From the NY Times, November 7, 2004

Dr. Jules Lodish welcomes visitors to the downstairs bedroom of his Bethesda, Md., home with a robotic greeting that bursts from his computer's speaker. Ten years of living with amyotrophic lateral sclerosis, or A.L.S., a progressive, paralyzing disease, have stilled nearly every muscle; he types with twitches of his cheek, detected by a sensor clipped to his glasses.

But ask him how he feels about his life, and Dr. Lodish, his eyes expressing the intensity denied to his body, responds: "I still look forward to every day."

With adequate medical care, patients often can live for years relatively free of physical pain from the disease itself. "It's more a sort of existential, psychic sort of pain," said Dr. Leo McCluskey, a neurologist in Philadelphia who treats many people with the disease.

As a result, patients and their families are forced, on a daily basis, to take stock of the meaning and quality of their lives and to make repeated decisions about how much is too much.

Those patients who do best are those who have insurance that covers nursing and medical care, allowing them to avoid some of the major health risks associated with the disease, and family members who can cover the hours when expert help is unavailable.

Many patients, Dr. Ganzini said, have deep religious beliefs that help sustain them, and they are able, "to find hope in the future, find meaning and tolerate the daily ongoing losses that they are experiencing."

As Dr. Davis put it, "Quality of life becomes a moving target - what was one day an unacceptable quality of life becomes an acceptable quality of life."

Dr. Lodish's body sits limp in a wheelchair and his tongue lolls; a machine breathes for him through a tracheostomy tube in his throat. He lost the ability to talk more than three years ago, he says, then jokes, "but not the ability to be annoying."

He continues to provide medical consultation, and now advises patients with A.L.S. and their families on how to organize their own care and use the communication devices he has mastered.

"One irony is with many people I communicate more now than when I was well," Dr. Lodish said.

By holding on, he said, he has been able to see many of life's milestones, including the marriages of two of his three children.

When his older daughter, Elizabeth Lester, became pregnant with the first grandchild, she asked her father to make the official family announcement.

"He still plays the same role for me," she said, "I still consult him on financial matters and other kinds of things."

Dr. Lodish said that his own determination to live comes, in part, from his long experience in treating cancer patients, who often feel that a diagnosis is a death sentence.

"I spent my career getting people to live with their illnesses until they died," he said, "if they weren't cured."

Now, he says, "My illness has validated my approach to my caring for people." His wife, Carolyn, says she and her husband draw comfort from each other and from family jokes that have worn thin with repetition and age.

"We all say he's a better dancer than he used to be," Mrs. Lodish said with a tired smile.

"Do you know what happiness is?" Dr. Bach says, citing a survey that showed patients on ventilators tend to rank their level of satisfaction with life at 5.1 out of a possible score of 7; the average person in the same surveys has a score of 5.5. "Happiness is reality divided by expectations."

Meaning for Others

Finding meaning in life is not only the fundamental challenge for A.L.S. patients, said Dr. Adele Zinberg, a psychiatrist who works with the homeless and who has lived with the disease for seven years.

"A lot of what I do in my work is help people find meaning - everyone needs it, whether it's through their family or their work or some other cause," said Dr. Zinberg, who can operate a powered wheelchair. "Everyone has to feel that their life has meaning."

She says that some patients ask, "How can I talk to you about my problems when you have your own problems?"

She tells them: "Mine seem more obvious. But we all have our own challenges."

Dr. Lodish also counsels other people who have suffered life blows. He recalled that a doctor friend recently asked his advice about ways to help a friend who was deeply depressed after a serious automobile accident.

"Much of this boils down to whether or not one can hang on to who one is," he wrote in response. He said that he was still what he had always been: a father, a husband, a friend.

"In fundamental ways, I feel totally unchanged," he said. "Quintessentially, I have found that ambulation, movement, swallowing, eating, talking, breathing, and self care are not me. They are substantial physical losses; but they are not me."

EVENTS

Upcoming Events

March 12, Nashville, TN

Connection Conference featuring an expert speaker and support groups sessions. Also, meet the SPF Board of Directors at lunch, who will be having a Board Planning Meeting that day. Call Jim Sheorn 615-479-7369 for more information.

Date TBA Washington, DC

Contact Annette Lockwood 703-493-8779 for more information.

March TBA Saint Petersburg, FL.

Connection Conference. Call Doug Brand 727-526-7838 for more information.

March 17 Phoenix, AZ

Casual Lunch Connection to share stories and treatment modalities. Contact Bonnie Guzelf bguzlef@cox.net or call 480-838-1184 for more information.

April 1-3 Fifth Annual Spring Fling Berkeley Springs, WV.

Hosted by the Famous (or Infamous) Ronnie Grove Rooms have been held for the group at Best Western in Berkley Springs 304-258-9400. Besides Best Western, Berkeley Springs has Cacapon State Park Resort 1–304-258-1022 or 1-800-CALLWVA, Coolfont 1-800-888-8768 and The Inn and Spa at Berkeley Springs 1-800-822-6630. Hancock, Md., 6 miles away has a Motel Eight and a Value Inn. For reservations in either of the Hancock motels, go on-line and query “Hancock MD motels”.

Ronnie will have arrangements for a Friday evening get-together meal and will arrange for Saturday lunch and dinner. “No pay ahead charges,” Ronnie says, “ I am trying to work out something with the

Senior Center on Caregivers and Receivers but that's not written in stone just yet. It is mostly just social anyway."

Bangor, ME
First Thursday (evening) of each month at AlphaOne. In partnership with AlphaOne. Contact Wes Smith at 1-800-300-6016.

Ann Arbor, MI
Second Friday of the month, 6:30 pm - 8:30 pm, University of Michigan. In partnership with the NORD Michigan Chapter. Organized by Joan Mathay, R.N., nurse of John K. Fink, M.D., the SPF Medical Advisor.

Norristown, PA (near Philadelphia) 2nd Saturday of the month, 10:00 a.m. - 12:30 p.m., Mercy Suburban General Hospital. In partnership with the Ataxia Foundation local group. Contact Liz Nusseur.

Garden Grove, CA (near LA)
Monthly Support Group Meeting Third Saturday of each month. In partnership with the Ataxia Foundation local group. Contact Kay Bell.

North Carolina/South Carolina
Quarterly Support Group Meeting
Quarterly meeting alternates locations between Spartanburg, SC and Brevard/Asheville area in NC. In partnership with the Ataxia Foundation local group. Contact Cece Russell.