Synapse

Spring 2003

Serving the Primary Lateral Sclerosis Community since 1997

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Generous donations continue to be sent to the NUMS- PLS Symposium! This thermometer shows our progress as of March 31, 2003. Contributions totaling $1,965 were received this month, so we are now over 50% ($13,472). However, to reach our goal of $25,000 by June when Dr. Siddique must apply to NIH for the major funding request will take more effort by all of us. We will continue to update the total on a monthly basis. Below you will find a new sample letter which you can send to family and friends to request donations. Please keep in mind that many people are happy to find that there is a way they can help you; but you have to ask them for their help in making the Symposium a reality.

FUNDING

The Thermometer is Rising!

$25,000

$20,000

$13,472

$15,000

$10,000

$5,000

Raffle Time Again

Donna Isenhour has made these beautiful, sparkling, one-of-a-kind poinsetta café curtains with a valance. You have a chance to win these curtains. Chances are 6 for $10.00. Send a Check made out to N**UMS/PLS Symposium** in increments of $10.00 along with your name and address to: Donna Isenhour 2882 Palmer Dr. Conover, NC 28613 Donna will put the correct number of chances into the "pot" for you. The drawing will take place in the fall – In plenty of time for Christmas. increasingly apparent that the absence of clear diagnostic criteria for PLS is limiting our access to research funding. The symposium will include presentations and discussions by practitioners and researchers with the most interest and experience in PLS. Several sessions over a 2 day period would address such topics as epidemiology, criteria for diagnosis, collaboration in future research, and relationship to other diseases of the motor neuron. The symposium will be one giant step toward focusing research effectively to eventually find treatments and a cure for PLS. We need to raise $25,000 to fund the symposium. As of March 2003, our small group had already collected $13,472! We are heartened by this success, but more must be done to broaden the community willing to support research on PLS. PLS is extremely rare. It is estimated that there are fewer than 500 of us in the United States. If half of these PL Sers, or 250, contact ten others who give as little as $10 each, another $25,000 would be raised. This is why it is so important for us to reach beyond our core group for help. If you work or have worked for a corporation that matches donations to educational institutions, please apply for the funds to be sent to NUMS. It is a simple and painless way to raise more $S. At the bottom of this letter you will find all the information you need to learn more about PLS and to help fund the NUMS-PLS Symposium. If you make your contribution today, you will not only help assure that the symposium receives critically needed funds, but you will have secured a deduction for your 2003 taxes. Thank you for giving whatever you can to support our efforts.

Letter to Solicit Symposium Donations

Contributed by Debbie Poulos

Ed. Note: You should receive a copy of this letter in the mail this spring. If you would like multiple copies to send to family and friends, select the body of the letter, copy; create a new Word document and paste it in.

Sincerely,

Dear Many of us with *Primary Lateral Sclerosis (PLS) are working to expand our network to include not only PLSers and our families, but also our friends, associates, and others. That's why this letter has come to you. You are a relative, friend, business associate, or in some way connected to someone with PLS. We want to let you know how you can learn more about our illness, and what you can do to help advance PLS research. One of our goals is to continue to support the research of doctors such as Teepu Siddique, MD, and John K. Fink MD, at Northwestern and the University of Michigan, respectively, who are engaged in ongoing studies to advance knowledge of PLS. Our immediate goal is to raise funds for a PLS Symposium to be held in 2004. Our partner in this effort is the Northwestern University Medical School (NUMS) in Chicago. Dr. Siddique and Dr. Fink are working to get National Institutes of Health (NIH) to sponsor this meeting. The Symposium, "NUMS-PLS Symposium," will bring together leading neurologists, other interested medical researchers and practitioners, as well as, PLS patients. At the top of the meeting's agenda will be to establish clear diagnostic criteria for PLS. It has become

*PLS is believed to be a variant of ALS-Amyotrophic Lateral Sclerosis, better known as Lou Gehrig's disease. PLS, like ALS, is a progressive, degenerative disease of the central nervous system. Unlike ALS, which usually progresses rapidly, ultimately shutting down vital organs, PLS progresses slowly, usually affecting only the body's voluntary motor functions. You can learn more about PLS by visiting the following websites: www.als-pls.org and http://synapsePLS.home.attbi.com

NUMS-PLS Symposium Contribution Form Please record my contribution in the name of My Name:

Street
Address:

City:

State:

Zip
Code:

Check contribution amount:

$10 $25 $50 $100

$250 $500 $1000 Other Make check payable to: **NUMS-PLS Symposium** Send this form and your much-appreciated tax deductible contribution to: "NUMS-PLS Symposium" Office of Medical Development, Northwestern University The Feinberg School of Medicine Abbot Hall, Suite 1312 710 North Lake Shore Drive Chicago, Illinois 60611-3078 (If you would like to make a credit card donation, please call Northwestern at 1-312-503-8933.)

examining me/reviewing my medical records and said, "I have good news and bad news. The good news is the neurological disorder, PLS, which I have diagnosed you as having is not life threatening. The bad news is it is a life altering, degenerative progressive illness." I remembering walking to the window as the summer's rain beat against the pane, almost like a cleansing.feeling so relieved for now 'the nonsense' had a name, I had met the enemy! It was a blessing to finally share with family/friends/colleagues my diagnosis. In 1997 my profession was that of a Special Education Teacher of adolescents who were Severely Emotionally Disabled; I thrived on "living on the edge', not knowing one minute to the next what challenges would come my way. In the fall of 2000, I shared with my administrator that I would retire in June, as a result of my PLS. It was a struggle to complete the year, but I was determined. I turned my battle with "the ETHEL nonsense" into an opportunity to heighten awareness of my illness with colleagues/students/parents/other professionals/members of the community; how ironic that all my professional career I advocated for others, only to find myself advocating on a personal level for me! That spring I was nominated by a member of the community for "Disney Teacher of the Year." I then did the unthinkable, bought a beautiful home, and moved to Chincoteague Island, VA, to enjoy the call of the gull and ocean's roar: away from family/friends, living alone for the first time in my life, and readjusting to not "living on the edge." I have always considered myself one of the strongest women I know, but my first year living on the Island tested my mettle. The solitude and loneliness afforded me time to grieve 'them nonsense', walk in the wilderness, hit rock bottom in depression, then find a higher level of spirituality and inner peace, an acceptance of who I now am. Anne Morrow Lindberg's, 'Gift from the Sea', became my inspirational guide. I attended my first SPF gathering last April online Long Island; where I met Mark Weber, Kathi

PLSer Carolyn Sartain

Anderson named to SP Foundation Board

My name is Carolyn Sartain Anderson and I have PLS, or 'the nonsense', as I refer to it! On a dreary, rainy August day in 1997, my brother, Thomas, accompanied me to an appointment with Dr. Fred Plum (Cornell Med Columbia Presbyterian Hospital) in New York City. Ironically I was born in New York City; that day I was returning, from Virginia, to hopefully be diagnosed as to what was causing my symptoms of loss of balance, difficulty walking and slowness of speech. After a year of the emotionally draining, roller-coaster process of exclusion testing, my HMO continued to be baffled. That afternoon Dr. Plum returned after

Geisler, Dr. Fink and Bebe Leon; it was an emotional, as well as frustrating experience for me. Emotional to be with others afflicted with 'the nonsense', as well as HSP; frustrating because my mind was swirling with lots to share, but the noisy atmosphere, as well as being "stressed" in a new environment, was not conducive to projecting my voice. My brother became my verbal advocate. After the gathering, having time to process, I emailed both Mark and Kathi expressing an interest in finding a niche for me in SPF to contribute my talents. When I learned of an opening on the Board of Directors of SPF, my wandering in the wilderness, my prayers of finding my niche were answered. I pulled together my resume/statement of intent and emailed the Board. In my statement of intent I cited the Irish group, "The Waterboys" who sing a song entitled "Beginning to See a Bigger Picture"; the opening line reads, "I'm beginning to see a bigger picture, I'm beginning to color it in." My acceptance of my life altering "nonsense," has enabled me to now see the bigger picture and how I will be able to make a difference for our PLS/HSP communities by serving on the Board of Directors. Although I am strong willed and determined, I do have my "moments." After each "moment", I bounce back stronger and of more resolve. I am honored to share my journey with you and represent you on the Board of Directors. Please contact me at: beachmusic@esva.net. With love, Carolyn

Find those beloved recipes you'd like to share! Pull out mom's and grandma's, too. Food categories will include Main Dishes, Vegetables and Side Dishes, Soups and Salads, Appetizers and Beverages, Breads and Rolls, Desserts (of course!), Cookies and Candies, and This & That. Try to provide a recipe for more than one category! Submit your recipe online. Go to http://www.geocities.com/freyerse/recipeform.html. Please be sure to indicate how many books you'd like us to reserve for you, your organizations and co-workers. Any questions, please email Vivian Crouse, Chairperson: vivcrouse@aol.com or write to her for a form: 1213 Kimberly La. Glen Burnie, MD 21061

MEDICAL

UPDATES

SPF announces availability of research grants Contributed by Mark Weber The Spastic Paraplegia Foundation, Inc. (SPF) has announced the availability of its first research grants. These grants will be made available to scientists studying the neurodegenerative disorders covered by the SPF. One will be designated for Hereditary Spastic Paraparesis research and one will be designated for Primary Lateral Sclerosis research. Each grant will be in the amount of $40,000. We are honored that so many of you entrusted us with your contributions in our very first year - contributions that will put important funds into the hands of researchers working to discover our cures. We realize that every one of you expects us to invest your donation wisely, and we take that responsibility very seriously. Accordingly, the SPF has created a Scientific Advisory Board comprised of experts in the field of neurology who will review and rank all grant applications. This way, we can ensure that only the best proposals receive funding. We expect to

Cooking for a Cure Our cookbook has a name! One of our agenda items at Spring Fling was to vote on a name for the Cookbook. Cooking for a Cure won hands down, as an expression of what we are all trying to do. Now we need you to share your favorite recipes to create a cookbook we'll all be proud to have, enjoy, and share with all our friends and relatives. It's easy as pie:

announce grant awards this fall. I'd like to thank everyone of you who made this happen - our supporters, contributors, volunteers and board of directors. Without your help, we could not have launched the Spastic Paraplegia Foundation and we would not be issuing exciting grants like these! I am very grateful for your support and look forward to working together to make our cures become a reality. The SPF grant announcement may be viewed at: http://www.sp-foundation.org/pdf/grant ad.pdf. (A very special thanks to Doug Brand for his outstanding work in designing this dynamic ad).

Research Summary from Dr. John Fink There have been important advances in our knowledge of hereditary spastic paraplegia (HSP) and primary lateral sclerosis (PLS). In this past year, three new HSP genes have been discovered. Each gene discovery provides another "piece in the puzzle" that ultimately will expose the biochemical pathways that underlie nerve degeneration in HSP and PLS. This information is necessary to develop real treatments for these conditions. These treatments will be tested initially in laboratory animal (mice) models of these HSP and PLS. Laboratory mice bearing HSP and PLS gene mutations have been created and currently are being analyzed. Our research at the University of Michigan is committed to finding the causes and ultimately developing treatments for HSP and PLS. Direct family involvement is a critical aspect of our studies. Many individuals are asked to provide a blood sample. We are investigating many different aspects of HSP and PLS simultaneously (clinical features, MRI analysis, biochemical studies, genetic studies, for example). Our needs for specific blood samples changes over time. Sometimes we need blood samples from individuals with specific types of HSP or PLS (such as those in which symptoms began in childhood). At other times, we need blood samples from every member of large families. Sometimes we simply need one blood sample from an affected subject in each of 100 different families. Finally, there are times when we have to limit these studies because of cost: it costs (us) in excess of $100 per research blood sample. I am convinced that we can discover the causes and ultimately develop real treatments for HSP and PLS. My confidence in this is based on our current understanding of HSP and PLS; the rapid pace of HSP and PLS research; as well as because of discoveries in related fields of spinal cord injury and treatment strategies for other neurologic disorders. We have the technology to expose the molecular basis of these conditions and begin to devise treatment strategies. Whether we move swiftly (years) or at a snail's pace (decades) depends almost entirely on the level of research funding. Our research is supported by grants from the Department of Veterans Affairs, the National Institutes of Health, and the National Organization for Rare Disorders (NORD). Contributions from families with HSP and PLS make a very real impact on this research.

Individuals wishing to make tax-deductible contributions to HSP and PLS research at the University of Michigan should send contributions **to:** HSP/PLS Research.

c/o Ms. Lynette Girbach 5214 CCGCB Box 0940 1500 E. Medical Center Dr. Ann Arbor, Michigan 48109-0940. Working together, we will find the causes and develop real treatments for these conditions.

ALSA Research Site www.alsa.org/research/

The ALS Association has given me permission to pass on to the Synapse readers any of their valuable research information. To share with you the type of contents in the site, below is their glossary of terms related to the complex field of stem cell research. **Glossary Blastocyst** - a hollow sphere of cells formed four days after a sperm fertilizes an egg. **Bone marrow** - A soft, spongy tissue that fills the cavities inside most bones in the human body.

is the only national not-for-profit voluntary health organization devoted solely to ALS. To learn how ALSA covers all the bases in the fight against ALS, please visit www.alsa.org. Tina Walker is the ALSA Director, Internet Services.

Bone marrow is a source of stem cells that manufacture red blood cells, white blood cells and platelets. It is a conventional source fro stem cell transplantation. **Cellular therapy** - A field of medicine that uses cells to repair tissues that have been damaged by human disease or to generate new tissues with desired functional activities. Cord blood - Blood remaining in the umbilical cord immediately following the birth of the baby, It contains a rich concentration of stem cells. **Endogenous stem cells** - Stem cells that are already present in the body. **Inner cell mass** - A cluster of cells in the blastocyst from which embryonic stem cell lines can be isolated and grown in culture. **In vitro** - describes a state or condition that occurs and/or exists *outside* the body. This term often refers to testing conditions that occur in a laboratory environment. In vivo - describes a state or condition that occurs and/or exists *within* the body. This term is often used to describe testing conditions that occur within humans and/or animals. **Neuronal/neural stem cells** - cells capable of becoming tissues of the brain and central nervous system. **Pluripotent** - capable of giving rise to most tissues of an organism. Stem cells - cells that have the ability to divide for indefinite periods in culture and give rise to specialized cells. **Totipotent** - having unlimited capability. Totipotent cells have the capacity to specialize into extraembryonic membranes and tissues, the embryo, and all postembryonic tissues and organs. **Transplantation** - the process of giving tissues or cells to treat a disease. The tissue or cells may come from the same patient **(autologous)** or from another person (allogenic).

Center for Aging, Genetics and Neurodegeneration Massachusetts General Hospital has created the Center for Aging, Genetics and Neurodegeneration (CAGN) to foster an

the innovative approach to finding treatment

for Alzheimer's, ALS, Huntington's, Parkinson's and other neurodegenerative diseases. CAGN was established to speed up the pace of discovery by taking advantage of the synergies inherent in studying diseases together. They have found that as promising leads are developed on one disease, they can be tested in other neurodegenerative disorders. To learn more about CAGN click on Www.cagn.org or e-mail cagn@partners.org.
www

ALS Society of Canada News

To subscribe: www.als.ca/subscribe.asp To unsubscribe: www.als.ca/unsubscribe.asp

This announcementwas made at an ALS Society of Canada and McGill University Health Centre press conference at 10:30 am in Montreal on April 1, 2003. This is significant news, as it is research that may well lead to treatment and it has been funded by the ALS Society of Canada through the neuromuscular research partnership with MDAC.

DRUG COMBINATION INCREASES LIFE SPAN OF MICE WITH ALS Montreal, April 1 2003 - A new three-druge cocktail used to treat mice with ALS, or Lou Gehrig's disease, may increase life span and decrease disease progression according to a study conducted at the Research Institute of the McGill University Health Centre (MUHC). The study, published in today's issue of Annals of Neurology, is the first to look at this drug combination in a mouse model of ALS. "Last ES year, we demonstrated that minocycline, a

I am not reprinting any of ALSA's exciting research or drug trial reports due to their length and complexity. Just click on the link and you will locate all of the details. The ALS Association

"But in my dreams, I sing you a sweet lullabye. We laugh and pray until we sigh, " replies the grandmother *"Love me*" says the child. "My *heart is healthy, I do love you,* replies the grandmother. I have purchased one for each set of grandchildren even though some are teenagers, the message is wonderful. The feedback has been touching. The book is available for $12.95 US/$14.95 Canada from Les Turner ALS Foundation, Inc. the 8142 North Lawndale Ave. E
HERS Skokie, IL 60076
commonly prescribed antibiotic, on its own reduced disease progression, and delayed death in the ALS mice," says MUHC neuroscientist and senior author, Dr. Jean-Pierre Julien. "Findings from our current study show that a therapeutic approach based on a combination of minocycline with two other drugs is much more effective in delaying the onset of the disease and in increasing the longevity of the ALS mice." Dr. Julien, who is also a professor of Neurosciences at McGill University says that Dr. Kriz looked at the effect of combining three different drugs on the disease progression of ALS mice. The three drugs administered include minocyline- an antibiotic with anti-inflammatory properties, riluzole - the traditional ALS drug, and nimodipine - a drug that blocks calcium channels and normally used to treat brain hemorrhage and for prevention of migraine headache. Dr. Kriz compared the life span, muscle strength, nerve cell loss, and inflammatory response in ALS-mice who were fed a regular diet with those given food containing the three-drug cocktail. The mice fed the drug cocktail lived substantially longer, had a delayed onset of neuronal and muscle deterioration. "Our findings demonstrate the merit of a drug combination approach for treatment of a disease with complex degeneration pathways. The three drugs are currently available and we hope that our study will justify a trial on ALS patients," says Dr. Julien.

Octogenarian PLSer

ETETE Contributed by Lige Miller I started having some trouble at age about 68.

India thought it was because of a knee injury. Finally I went to a neurologist and he diagnosed it as PLS. I used a cane for a couple of years. Finally I had to go to a walker. At present I don't try to walk over twelve or so feet. I was speaking o.k. until maybe age 82 or 83. At present I can scarcely speak at all. I am 87. *Ed. Note: Lige came to Spring Fling this year and shared his history with us.*

LIVING WITH PLS

Book for our Grandchildren

. The Contributed by editor There is a wonderful book for a grandparent with PLS to send to grandchildren. The book is distributed through the Les Turner ALS Foundation. The name is In My Dreams I Do. The book is an illustrated book for young children.

An excerpt includes the following text: *"Sing with me!"* says the child. "M*y mouth does not move. I cannot speak up."*

Lyme Disease 101 – A Primer Contributed by Sallie Longeri, a Lyme disease survivor: Q. How do people get Lyme disease? A. By the bite of ticks infected with Lyme disease bacteria. (Deer tick)

Q. What is the basic transmission cycle? A. Immature ticks become infected by feeding on small rodents, such as the white-footed mouse, and other mammals that are infected with the bacterium Borrelia burgdorferi. In later stages, these ticks then transmit the Lyme disease bacterium to humans and other mammals during the feeding process. Lyme disease bacteria are maintained in the blood systems and tissues of small rodents.

Q. How is Lyme disease treated? A. According to treatment experts, antibiotic treatment for 3-4 weeks with doxycycline or amoxicillin is generally effective in early disease. Cefuroxime axetil or erythromycin can be used for persons allergic to penicillin or

Q. Could you get Lyme disease from another person? A. No, Lyme disease bacteria are NOT transmitted from person-to-person. For example, you cannot get infected from touching or kissing a person who has Lyme disease, or from a health care worker who has treated someone with the disease, or by sexual contact. Q. What are the signs and symptoms of Lyme disease? A. Within days to weeks following a tick bite, 80% of patients will have a red, slowly expanding "bull's-eye" rash (called erythema migrans), accompanied by general tiredness, fever, headache, stiff neck, muscle aches, swollen lymph nodes and joint pain. If untreated, weeks to months later some patients may develop arthritis, including intermittent episodes of swelling and pain in the large joints; neurologic abnormalities, such as aseptic meningitis, facial palsy, motor and sensory nerve inflammation (radiculoneuritis) and inflammation of the brain (encephalitis); and, rarely, cardiac problems, such as atrioventricular block, acute inflammation of the tissues surrounding the heart (myopericarditis) or enlarged heart

who cannot take tetracyclines. Later disease, particularly with objective neurologic manifestations, may require treatment with intravenous ceftriaxone or penicillin for 4 weeks or more, depending on disease severity. In later disease, treatment failures may occur and retreatment may be necessary. *Ed note: Sallie Longeri is editor of a garden club newsletter and a friend. She gave permission for me to include this piece in Synapse since the PLSers have indicated interest in the problem.*

(cardiomegaly). Q. What is the incubation period for Lyme disease? A. For the red "bull's-eye" rash (erythema migrans), usually 7 to 14 days following tick exposure. Some patients present with later manifestations without having had early signs of disease. Q. What is the mortality rate of Lyme disease? A. Lyme disease is rarely, if ever, fatal. Q. Can a person be reinfected with Lyme disease? A. Yes. Having had Lyme disease doesn't protect against reinfection. Some persons have had Lyme disease more than once after re-exposure to infective tick bites. The best means to prevent the transmission of tick-borne diseases and the development of tick paralysis is the prompt removal of ticks. Removed ticks should be immersed in alcohol to kill them. Disinfect the bite site and wash hands thoroughly with soap and **water**.

Exercise Contributed by Vaughn Hickman -It is well documented that for every minute that you exercise, you add one minute to your life. This enables you at 85 years old to spend an additional 5 months in a nursing home at $5000 per month. -My grandmother started walking five miles a day when she was 60. Now she's 97 years old and we don't know where she is. -The only reason I would take up exercising is so that I could hear heavy breathing again. -I joined a health club last year, spent about 400 bucks. Haven't lost a pound. Apparently you have to show up. -I have to exercise early in the morning before my brain figures out what I'm doing. -I like long walks, especially when they are taken by people who annoy me. -I have flabby thighs, but fortunately my stomach covers them. -The advantage of exercising every day is that you die healthier. -If you are going to try cross-country skiing, start with a small country. -I don't exercise because it makes the ice jump right out of my glass.

Appreciation Contributed by Mike Gray I have found that I appreciate many of the little things I used to take for granted. I have a chance to be with one of my children until he grows up, unless his mom or I kill him first. (He's just about to turn twelve and thinks he's a teen-ager. Can't wait for that!) I also have been able to appreciate other things recently, There have been 4 white swans on the Wabash river on my way to work. I know they are foule fowl, but they are beautiful to see. 4 of them! There is also at least one mature bald eagle flying around the same area of the Wabash. I am amazed at how easily that bird flies. It looks like no work at all. Today is March 7 and I have only heard the cardinals singing in the morning. Usually by now we have Robins, cardinals, song sparrows, finches and assorted others just passing through singing. It has been a strange Spring. I am ready for the snow to end, but we are expecting more on Sunday. Funny, though, I even appreciate the snow. I can drive in it without problem, so I am able to work. I even appreciate work and the ability to be able to continue. I appreciate our dog, who is the mad destroyer of furniture and drapes. She is loving and wants affection and attention all the time. I t appreciate our house, which needs some repairs. I appreciate a friend who is an M.D. and took met on as a patient when my other Primary Care Doctors retired. I enjoy the weather, even when it is not what I would like. It is what it is and I appreciate that. I could go on, but I'm beginning to sound maudlin and should stop.

exempted facilities, any place that provides access, goods, or services to the public is required to yield these equally to all citizens, regardless of their physical capabilities. This also extends to service animals. Global Access, the Network for Disabled Travelers http://www.geocities.com/Paris/1502/ includes travel articles, disability travel links, tips and resources, readers' suggestions, and a book list. Access-Able http://www.access-able.com/ is another great site for research. It features destination, service, and cruise line information, in addition to travel tips, a list of magazines, relay and voice phone numbers relevant to travelers, community forums, a monthly newsletter, and lists of tour and travel agencies that specialize in special-needs travel.

The Society for Accessible Travel and Hospitality http://www.sath.org/ is a long established nonprofit advocacy and information gathering organization for disabled Travelers. (212-447-7284.) The Disabled Driver's Mobility Guide Can be ordered at your local AAA club (specify title and stock number 3772) for $8.95 plus $3 shipping. Society for the Advancement of Travel for the Handicapped 888-240-1937 or 212-447-1928. By mail, contact the organization at 347 Fifth Ave., Suite #610 New York, NY, 10016. Provides information on air, rail, and bus travel, hotels and services worldwide for various medical conditions and impairments. Once you have decided on a destination, contact the visitor's bureau (or chamber of commerce) of that place. Besides providing general travel information, they may also be able to provide information about the accessibility of local public transportation and tourist attractions, suggest accommodations that have a reputation for being accessible, and point you toward organizations that serve the local disabled community. Often

Tips for Traveling with Disabilities Core information courtesy of The Denver Post So you've decided to hit the road this summer, but you, a family member, or a traveling companion is disabled. Perhaps the most important thing to know is your rights. Thanks to the Americans with Disabilities Act, discrimination anywhere in the United States against disabled people is no longer legal. Except for a limited number of

from

these organizations can give you an "insider's" view into your destination. Travelers should find out if the accommodations are truly accessible. It's best to be clear about your exact needs. Make sure you make arrangements well in advance for special needs you might have. Special considerations: Should your medications be refrigerated? Carry the prescription sheets for drugs, especially if you are traveling internationally. Carry an official document describing your disability. If you use special equipment, carry spare parts or a manual with you Consider a portable wheelchair or a telescoping cane. **Plan ahead; realize glitches are a normal part of travel; relax and have a great trip!**

juice. All of your drug may not be able to either be metabolized properly yet can't be eliminated from the body. The drugs can then reach dangerously high levels in the bloodstream. Therefore, it is probably safest to refrain from taking any medication with grapefruit juice.

2. If you're taking capsules, consider taking them with a hot beverage which will help them dissolve more quickly. is the

3. Tablets with enteric coatings, such as coated aspirin, are designed to stay undissolved in stomach acid and to dissolve in the intestine. Taking an antacid with them will reduce the stomach acid and cause the enteric coating to break down sooner than it should

4. Antacids may bind to vitamins especially thiamine, vitamin A, folate, and some minerals such as iron and phosphorus. 5. Mineral oil dissolves the fat soluble vitamins A, D, E, and K so that they can't be absorbed. 6. Some medications are to be taken with food to reduce direct irritation of the stomach. The food forms a barrier and keeps the medication from reaching the stomach lining and thereby prevents irritation and pain. 7. Some drugs should be taken on an empty stomach because they may adsorb (stick to the food, rather than going into the bloodstream 8.. Certain foods can enhance the absorption of some minerals. For example, orange juice (containing vitamin C) allows iron to be absorbed more completely. Food/drug **and drug/drug interactions are numerous. Always follow the instructions given on your prescription.**

DE

I Think I Can Unknown

If you think you are beaten you are; If you think you dare not, you don't; If you want to win but think you can't; It's almost a cinch you won't.

EESTI

1 Pa/1 .

If you think you'll lose you're lost; For out of the world we find Success begins with a fellow's will; It's all in a state of mind.

the

Life's battles don't always go To the stronger and faster man, But sooner or later the man who wins Is the man who thinks he can.

Food and Medications Contributed by Dolores Carron 1. Grapefruit juice contains bioflavonoids that are metabolized in the liver by a certain enzyme (cytochrome p-450 oxidase). Some drugs (such as some tranquilizers, blood pressure drugs, antihistamines, and immunosuppressants) require the same enzyme to be metabolized as grapefruit

Keepers

Contributed by Ronnie Grove Some things you keep. Like good teeth. Warm coats. Bald husbands. They're good for you, reliable and practical and so sublime that to throw them away would make the garbage man a thief. So you hang on, because something old is sometimes better than something new, and what you know is often better than a stranger.

each has 30 tips for various aspects of dealing with life's challenges. Self-Care Now – Self-help (30 ways to overcome obstacles that prevent you from taking care of yourself) Self-Care Now - Coping with chronic illness (30 tips to help you take care of yourself when chronic illness turns your life upside down) Self-Care Now – for family caregivers (30 tips to help you take care of yourself and minimize caregiver burnout) They cost $5.95 apiece They may be ordered on-line at http://www.selfcareconnection.com Or call 207-799-9363 Or e-mail: Booklets@SelfCareConnection.com

EVENTS

These are my thoughts, they make me sound old, old and tame, and dull at a time when everybody else is risky and racy and flashing all that's new and improved in their lives. New careers, new thighs, new lips, new cars. The world is dizzy with trade-ins. I could keep track, but I don't think I want to. I grew up in the fifties with practical parents - a mother, God bless her, who washed aluminum foil after she cooked in it, then reused it. A father who was happier getting old shoes fixed than buying new ones. They weren't poor, my parents, they were just satisfied. Their marriage was good, their dreams focused. Their best friends lived barely a wave away. I can see them now, Dad in trousers and tee shirt and Mom in a house dress, lawn mower in his hand, dishtowel in hers. It was a time for fixing things - a curtain rod, the kitchen radio, screen door, the oven door, the hem in a dress. Things you keep. It was a way of life, and sometimes it made me crazy. All that re-fixing, reheating, renewing. I wanted just once to be wasteful. Waste meant affluence. Throwing things away meant there'd always be more.

But then my father died, and on that clear autumn night, in the chill of the hospital room, I was struck with the pain of learning that sometimes there isn't any 'more.' Sometimes what you care about most gets all used up and goes away, never to return. So, while you have it, it's best to love it and care for it and fix it when it's broken and heal it when it's sick. That's true for marriage and old cars and children with bad report cards and dogs with bad hips and aging parents. You keep them because they're worth it, because you're worth it.

Spring Fling Report Spring has arrived in Berkeley Springs, WV. Forsythia, Plums and Magnolias are in bloom and the grass is green. 24 PL Sers and HSPers and their caregivers descended on Ronnie Grove and her wonderful community from CA, MD, MA, NC, VA, IL, DC, WV, FL, TN, PA, and OH. Pretty broad representation of states, don't you think? We began with lunch at Cacapon State Park followed by an informal afternoon for meeting new friends and seeing old friends. A hearty dinner was put on for us at the Methodist Church, served by Ronnie's Mother and several friends. Saturday's session was at the Best Western Motel where most of us stayed. We presented Angela Dixon gifts to honor all that she has done for the PLS community, voted a name for the Cookbook (Cooking for a Cure), plugged the Symposium, visited, and ate again. Our final gathering was another dinner together in Hancock, MD, right across the Potomac River. Many began the weekend as strangers; some had never been with others who have PLS; some caregivers had never had the chance to talk with other caregivers; all left the weekend with many new friends...new synapses!

CAREGIVING

Self-Care Booklets Contributed by the editor
I recommend a series of booklets for both caregivers, for anyone's daily coping with life and for those with chronic diseases such as ourselves. Written by Pauline Salvucci, a medical therapist,

Disability Issues For more Information and Registration Forms go to http://sp-foundation.org/pdf/phoenix.pdf

July 19, Long Island, NY. Connections Conference will feature Mark Gudesblatt, M.D., an expert on PLS and HSP and other programs. July 18 Arrival Dinner for those traveling in to get connected with others. Stay tuned!

Upcoming Events for PLS/HSP April 26: Albany, NY. Social gathering. Contact Rita DiClemente ritadfromhollis@webtv.net

April 26: Woburn, MA (near Boston). Lunch Connections Conference featuring a physical therapist: "Balancing Tips and Techniques". Medtronics pump presentation and sharing session. Register here: http://www.sp foundation.org/pdf/April26.pdf

September 13-14 Lexington MA TeamWalk 2003. Plans are underway for the 2003 Team Walk weekend this fall! Team Walk is our national community event to raise funds for research for PLS and HSP. The weekend experience is being organized by the Massachusetts Chapter. Lexington is in the greater Boston area. Remember your US history - Lexington is where "... the shot heard 'round the world" was fired to start the Revolutionary War; TeamWalk will take place at Battle Green! It will include Team Walk, a conference, and social gatherings. It's a great opportunity not only to support research and have a wonderful weekend of fun and learning, but a great opportunity to tie in a trip to the Boston area and northern New England during our beautiful fall foliage season. Stay tuned! Contact Thurza Campbell at 508-653-5246 or synapse PLS@attbi.com.

June 7: Long Beach, CA. Abilities Expo outing/Lunch. Read about the Abilities Expos here: http://www.abilitiesexpo.com/

Monthly Support Groups: Norristown, PA (north of Philadelphia) Ann Arbor, MI

June 7: Ft. Myers, FL. Luncheon Connections Conference Lee Memorial Hospital Auditorium 2776 Cleveland Ave. Ft. Meyers, FL 33901 11 a.m. – 3:30 p.m. Contact: Carol Liquori to register: h-239-561-9817 W-239-334-5182 caliquori@aol.com

June, CT Connections annual event, details TBD.

June 21, Phoenix, AZ. The Phoenix Connection The Conference will be held at the Grace Inn in Phoenix, AZ Feature Speaker: Fay Fishman, Attorney at Law will discuss Social Security and Long Term