Synapse

Spring 2004

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

Editor's note: This newsletter and other material useful to dealing with PLS or HSP is available on-line at www.synapsepls.org If any of you have computer access available, please transmit your e-mail address to me at SynapsePLS@comcast.net With use of a computer, you would have a much greater use of the resources. If you do not have your own computer, please inquire at your local library about Internet access for the public. Thurza Campbell

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MEDICAL UPDATES

SPF announces $240,000 in Research Grants

Contributed by Mark Weber President, Spastic Paraplegia Foundation

The Spastic Paraplegia Foundation is extremely pleased to announce that it will fund $240,000 in research grants this year. There will be a total of 3 grants.

There will be two each $90,000, 2-year grants ($45,000/year). One will be for research on HSP and one for PLS. In addition, there will be a $60,000, 2-year grant ($30,000/year) focusing on innovative procedures to diagnose HSP and PLS. Areas of interest include, but are not limited to, spinal fluid or serum biomarkers and diffusion tensor MR imaging or other imaging modalities. (For more info about our Research Grant Program, please see http://www.sp-foundation.org/2004-grant-program.htm.)

Our fundraising really accelerated last year. I'd like to thank everyone who made this happen--all of our supporters and contributors, organizers, our directors, and everyone who worked to make last year's fundraising campaign such a tremendous success. Thank you all so very much. Without your help we could not issue grants like these. I am very grateful for your support. We will do our best to continue to earn your support, every day. I realize that every one of our contributors expects us to spend their donation wisely. We take that responsibility very seriously. Accordingly, the SPF Scientific Advisory Board will review all grant applications to ensure that only the best proposals receive funding. We expect to

announce grant awards no later than September 1st.
Thank you all once again for your support and tremendous efforts in making this happen.

Organization and Journal Websites

Ed. note: The recent survey for readers of Synapse indicated that learning about medical updates is the most important part of the newsletter. Research findings are being reported regularly by institutions and non-profit organizations. These encouraging findings are published in medical journals and reported in newspapers too. Often the abstracts are too technical for those of us who are "non-medical". I will try to obtain permission to summarize some published accounts. Below you will find a compilation of websites which you can regularly check for the latest information on advances. We are living in a truly exciting time, with many promising developments.

Organizations:

ALS Association. Volunteers are the driving force behind the ALS Association. Local chapters depend on the efforts of many volunteers to support patient services programs and fund raising activities. Since its opening in December 1997, ALSA's Capital Office in Washington, D.C. is the hub of The ALS Association's advocacy and public policy activities in the nation's capital. Our goal is to communicate to every legislator and government agency representative to ensure that government funding of meritorious research is pursued without hindrance, to help establish a sound policy for the eradication of ALS and to improve the quality of life for people with ALS.
http://www.alsa.org

Coalition for the Advancement of Medical Research is comprised of nationally-recognized patient organizations, universities, scientific societies, foundations, and individuals with life-threatening illnesses and disorders, advocating for the advancement of breakthrough research and technologies in regenerative medicine - including stem cell research and somatic cell nuclear transfer - in order to cure disease and alleviate suffering.
http://www.camradvocacy.org/fastaction/default.asp

The Muscular Dystrophy Association is a voluntary health agency — a dedicated partnership between scientists and concerned citizens aimed at conquering neuromuscular diseases that affect more than a million Americans. MDA combats neuromuscular diseases through programs of worldwide research, comprehensive medical and community services, and far-reaching professional and public health education. http://www.mdausa.org

National Institute of Neurological Disorders and Strokes. The mission of NINDS is to reduce the burden of neurological disease - a burden borne by every age group, by every segment of society, by people all over the world.
http://www.ninds.nih.gov/index.htm

The Robert Packard Center for ALS Research is the only one of its kind dedicated solely to the disease. Working to discover effective treatment and ultimately a cure for ALS. Although the Center operates within the Johns Hopkins Hospital at the Medical School's East Baltimore campus, its scope is international.
http://www.alscenter.org/ and
http://www.hopkinsmedicine.org/alscenter/index.cfm

Journals:

Cell. For over 25 years, Cell has remained at the forefront of exciting scientific developments, continually redefining the important areas of science with cutting-edge papers. Many of the most important life science discoveries are published in the pages of *Cell*.
http://www.cell.com/

Nature. Nature Publishing Group (NPG) is the scientific publishing arm of Macmillan Publishers Ltd, combining the excellence of: *Nature*, Nature Research Journals, Nature Reviews, NPG Academic Journals and NPG Reference publications, to provide the world's premier information resource for the basic

biological and physical sciences.
www.nature.com

Neurology is the official journal of the American Academy of Neurology. As the leading clinical neurology journal worldwide, Neurology is directed to physicians concerned with diseases and conditions of the nervous system. The journal's purpose is to advance the field by presenting new basic and clinical research with emphasis on knowledge that will influence the way neurology is practiced. The journal is at the forefront in disseminating cutting-edge, peer-reviewed information to the neurology community worldwide.
http://www.neurology.org/

Neurology Today is official publication of the American Academy of Neurology. Neurology Today is a monthly newspaper covering important clinical, research, policy, practice, and other news relevant to neurologists. Readers can expect in-depth and timely reports on professional meetings, ongoing trials and therapies, strategies for improving quality of care and systems management, and articles by opinion leaders on the critical issues confronting neurologists today.
http://www.neurotodayonline.com

Neuron. For over a decade, *Neuron* has featured some of the most exciting developments in cellular and molecular neurobiology. Recognizing the importance of interdisciplinary strategies, *Neuron* also has worked to expand its scope and serve as the intellectual focus for the entire neuroscience community, integrating biophysical, cellular, developmental, and molecular approaches with a systems approach to sensory, motor, and higher-order cognitive functions. *Neuron* continues as the leading original research journal of neuroscience. You must register and pay to download articles.
http://www.neuron.org/

PLoS Biology is a peer-reviewed open-access journal published monthly by the Public Library of Science.
http://www.plosbiology.org/plosonline/?request=index-html

PubMed, a service of the National Library of Medicine, includes over 14 million citations for biomedical articles back to the 1950's. These citations are from MEDLINE and additional life science journals. PubMed includes links to many sites providing full text articles and other related resources. www.pubmed.com

Research Snippets

Smoking Implicated as Likely Risk Factor in Sporadic ALS

Smoking is a risk factor that is "more likely than not" linked to the development of sporadic ALS, according to a leading neurologist who reported this finding as a result of an analysis of epidemiological literature. This conclusion, reported in the February 2004 issue of Neurology Today, was made by Dr. Carmel Armon, chief of the Division of Neurology of Baystate Medical Center in Springfield, Mass.
http://www.neurotodayonline.com

Virus May be Responsible in Onset of Some Forms of ALS

In the January 2000 issue of the journal Neurology, researchers presented evidence that the genetic material of a particular virus is found in 88 percent of tissue samples taken from people who died of ALS but in only 3 percent of tissue samples from people who died of other causes. Specifically, the viral material was found in the anterior horns of the spinal cord, a region containing motor neurons that's affected in ALS.
http://www.neurology.org/

Scientists Find Fourth Gene for Inherited ALS

From the Packard Center for ALS Research:
An international research team has pinpointed the gene for ALS4, now the fourth gene to be discovered for a familial variety of ALS. The rare form of the disease appears earlier than the more common sporadic form of ALS, affecting boys in their teens and women in their thirties. Also, because it doesn't injure breathing or swallowing muscles, patients with the ALS4 gene typically live a normal life span, though they may be wheelchair-bound as the disease progresses. http://www.alscenter.org/

Stem Cells Mined From Human Embryo Clone

AP Wire services 2/04

Researchers in South Korea for the first time have cloned a human embryo and then culled stem cells from it, marking an important step toward one day growing patients' own replacement tissue to treat diseases.

Growth Factor May Link Two Paralyzing Disorders

In the March 4, 2004 issue of the journal Neuron, MDA-supported investigators Albert La Spada of the University of Washington in Seattle and Lisa Ellerby of the Buck Institute in Novato, Calif., report on a mechanism by which the flawed androgen receptor may cause spinal-bulbar muscular atrophy (SBMA) and ALS. They found that the abnormal androgen receptor, itself a protein, sticks to and interferes with a binding protein, and that this binding protein is needed for the manufacture of Vascular Endothelial Growth Factor (VEGF). The result, a deficiency of VEGF, is likely responsible for the loss of motor neurons.

Further Evidence of Dementia in SPG4-linked Autosomal Dominant Hereditary Spastic Paraplegia. McMonagle P, Byrne P, Hutchinson M. Department of Neurology, St. Vincent's University Hospital and University College Dublin, Republic of Ireland Objective: To investigate the progression of cognitive impairment and its behavioral aspects in patients with SPG4-linked autosomal dominant hereditary spastic paraplegia (SPG4-ADHSP). www.pubmed.com

Primary Lateral Sclerosis: A heterogeneous disorder composed of different subtypes?

Zhai P, Pagan F, Statland J, Butman JA, Floeter MK.

Electromyography Section, National Institute of Neurological Disorders and Stroke, Clinical Center, National Institutes of Health, Bethesda, MD 20892-1404, USA.

OBJECTIVE: To determine identifiable subgroups of patients with primary lateral sclerosis (PLS) with distinct clinical features as a first step in identifying patients likely to have the same disorder. METHODS: Twenty-five patients meeting previously proposed diagnostic criteria for PLS were seen for examination, measurement of gait and finger tapping speed, and physiologic tests to assess motor pathways. Motor cortex excitability and central motor conduction time were assessed with transcranial magnetic stimulation. Brainstem motor pathways were assessed by the acoustic startle reflex. MRS was performed in a subgroup of patients to assess metabolites in the motor cortex. RESULTS: Fifty-six percent of the patients with PLS had a similar pattern of symptom progression, which the authors termed ascending. In these patients spasticity began in the legs and progressed slowly and steadily. Spasticity in the arms developed 3.6 years after the legs, on average, and speech impairment followed 1.5 years later. Motor evoked potentials were absent. MRS showed a mean reduction of N-acetylaspartate/creatinine in the motor cortex. The remaining patients with PLS had heterogeneous patterns of symptom progression and physiology. CONCLUSIONS: Patients with PLS with an ascending progression of symptoms form a distinct clinical subgroup that may be amenable to investigations of etiology and treatment.

NIH Study Recruiting Participants

Title: Movement Related Cortical Potentials in Primary Lateral Sclerosis

Number: 04-N-0017

Summary: This study will examine whether the motor cortex (the part of the brain that controls movement) works properly in patients with primary lateral sclerosis (PLS), a disorder in which voluntary movements are very slow. Healthy volunteers between 40 and 75 years of age and patients with ascending PLS (a subset of PLS) may be eligible for this study. Patients with ascending PLS have a slowing of finger-tapping movements that corresponds to a particular abnormality of certain neuronal (nerve cell) activity.

Participants perform a finger-tapping reaction time exercise while brain wave activity (electroencephalography, or EEG) and muscle activity (electroymogram, or EMG) are measured. The subject is seated in front of a computer screen. A signal appears on the screen and the subject taps a key as quickly as possible in response to the signal.

For the EEG, brain activity is recorded by placing electrodes (small metal discs) on the scalp with an electrode cap or glue-like substance. A conductive gel is used to fill the space between the electrodes and the scalp to make sure there is good contact between them. The brain waves are recorded while the subject taps his or her fingers very slowly. For the surface EMG, electrodes filled with a conductive gel are taped to the skin.

Participants also undergo magnetic resonance imaging (MRI). This test uses a strong magnetic field and radio waves to obtain images of the brain. During the procedure, the subject lies still on a table that can slide in and out of the scanner - a narrow metal cylinder. Scanning time varies from 20 minutes to 3 hours, with most scans lasting between 45 and 90 minutes. Subjects can communicate with the MRI staff at all times during the scan and can ask to be moved out of the machine at any time.

Contacts:

Patient Recruitment and Public Liaison Office
Building 61 10 Cloister Court
Bethesda, Maryland 20892-4754
Toll Free: 1-800-411-1222
TTY: 301-594-9774 (local),1-866-411-1010 (toll free)
Fax: 301-480-9793
Electronic Mail: prpl@mail.cc.nih.gov

NIH PLS Study Experience

Contributed by Vaughn Hickman

Neal and I went to DC on Jan 11-13. Dr. Floeter is a super nice lady who takes all the time necessary to answer all your questions she can. In fact, her entire staff go out of their way to make you welcome and comfortable. They have a new EEG procedure that is, in my opinion, the most stressful test they give. That may be an unfair statement because they were late getting started, my blood sugar dropped and I got sleepy. But I got a colored scan of my brain, which I am reducing to wallet size!

Procedure: Once you are accepted (my neuro wrote Dr. Floeter a letter on my behalf.), you will be contacted by Billy, Coordinator of Travel and Other Questions who will explain everything you need to know. You make your own Hotel reservations and work with a travel agency on airline reservations.

We were allowed $90/day for the hotel and $20 each/day for dining. The Travel Agency is reimbursed directly for the airfare to Dulles, Reagan or BWI (Baltimore). You will be sent a schedule for the FREE shuttle from each airport to either NIH or your hotel. There is also a FREE shuttle from all area hotels to NIH and back on a regular schedule. There is a Voucher Office that issues checks and a Cashier who will cash them. They give you
the food allowance the first morning and reimburse you for your hotel on the last day. We stayed at the Park Inn & Suites (nothing to write home about, but clean - not handicap accessible - at least our room was not) and (surprise) they charge what NIH reimburses. There was a Deli at the hotel and a Chili's two doors away. A LARGE Mall just across the street (@150 yards) that has several restaurants. You can get the hotel van to carry you back and forth.

We thought it was a great experience. You will be contacted about every six months for follow-ups, but the beauty is - WHEN a new protocol is developed or WHEN a new treatment is developed, NIH already has your profile and THEY WILL CONTACT YOU. That way you don't have to keep wondering if they have discovered something.

PLSers needed for study in England

Contributed by Mark Weber

Anyone with PLS living in England, or planning to travel there, is strongly urged to participate in a study being conducted by Dr. Kevin Talbot of Oxford University in London. Participants will undergo an MRI exam.The MRI equipment being used has special software not found on any other MRI unit. This allows Dr. Talbot to develop images never seen before of the corticospinal tract. It is this area that is affected in PLS.

Dr. Talbot is using a diffusion imaging (MRI) technique called Probalistic Diffusion Tractography to measure the integrity of the corticospinal tract. He is aiming to develop this tool as a biomarker of PLS and ALS (which would create a measure that would allow clinical trials of PLS patients). It may also help to define the relationship between PLS and ALS.

To participate in Dr. Talbot's study, you'll need to go to England. If you're interested, please contact Dr. Talbot at kevin.talbot@cineuro.ox.ac.uk .

This study is funded by the PLS Research Fund at NORD and comes from monies exclusively raised almost a year before the creation of the SPF.

Upper Motor Neurons and Lower Motor Neurons

Contributed by Mark Weber

Picture the connection from a light switch to a light bulb via two extension cords.

Flipping the light switch sends electricity down the first extension cord. That extension cord connects to the second extension cord. The electricity then goes to the other end of that second extension cord and lights the light bulb. The light switch is the brain. The first extension cord is an upper motor neuron (UMN). The second extension cord is a lower motor neuron (LMN). The light bulb is a muscle fiber. The only way to light the light bulb (a muscle fiber) is for the electricity from the light switch (the brain) to travel through both extension cords (UMN and LMN). Whether the muscle fiber is in the arm, hand or big toe, the signal must travel through both extension cords--an UMN and then a LMN.

To activate a muscle in the hand, a nerve impulse goes from the brain, down a short UMN that extends down the spine only to about shoulder level where it ends. (UMN's come in varying lengths, just like extension cords.) At that point, the signal goes from the end of the UMN to the beginning of a LMN. The signal continues down the LMN that extends out from the spine, down the arm to the hand, where it connects to a hand muscle fiber.

To activate a muscle in the lower leg, a nerve impulse goes from the brain, down a much longer UMN that extends down near the end of the spine where it ends. At that point, the signal goes from the end of the UMN to the beginning of a LMN. The signal continues down the LMN that extends out from the spine, down the leg to the lower leg, where it connects to a lower leg muscle fiber.

There are four ways in which the light bulb will fail to work. First, the light switch could be defective. (Something wrong in the head. Our neurologists have ruled out that possibility with MRI's.) Second, the light bulb can be defective. (Our muscles are OK--the doctors have ruled out that possibility.) Third, the second extension cord (LMN's) could be defective. (An EMG exam tests for that. It is not our problem.) Fourth, the first extension cord (UMN) could be defective. THAT is our problem. We weren't born that way, but something is slowly destroying our UMN's.

Cell Biologist on the Importance of Research

Contributed by Linda D. Martin, Ph.D., Assistant Professor of Cell Biology, Department of Molecular Biomedical Sciences, North Carolina State University.

Ed. Note: Following the announcement of the firing of two research scientists from the President’s Bioethics Council, I contacted a university researcher whom I respect for her professional opinion. I felt all of us need to *understand the research process, its challenges, pitfalls and possibilities.*

"I have read the PLoS article you sent. *(You can access the entire article at: http://www.plosbiology.org/plosonline/?request=index-html In the search box type in "Reason as our Guide" or "Blackburn")* I think it is a very important article and your newsletter readership should get it into the hands of all your Senators and Congresspeople. The article is suggesting that there is not enough funding for stem cell research in the public sector. Because of this, good scientists can't even make proper decisions about the issues, scientific or ethical, because there has been no consistent way to do the research. We can't draw conclusions about what embryonic or adult stem cells can do, or what either can be used for, because there has not been enough research done in a consistent way, carefully repeated and confirmed by other laboratories. The article is also suggesting that the Council reports are not good, critical, balanced documents. Therefore, the people voting on research funding might make the wrong decisions because they don't have a balanced view of the facts.

Certainly there is sufficient preliminary data regarding embryonic stem cells and their use in animal models to suggest the hopeful possibility that these will lead to therapies to help people like yourselves. But the bottom line is that research in this area needs to be funded and funded well. Adult stem cell research should also be pursued, but as the article pointed out, data from early reports in this area are not solid enough to suggest adult stem cells be examined at the exclusion of embryonic stem cells.

Getting the PLoS article to your appropriate Congressional representatives is a way to emphasize that the Bush administration is not looking at this area of research in an appropriately scientific, balanced manner...and you want something done about that!"

Frequently Asked Questions About Somatic Cell Nuclear Transfer (SCNT or Therapeutic Cloning)

From the Coalition for the Advancement of Medical Research (CAMR)

Whether you call it "therapeutic cloning" or "somatic cell nuclear transfer" or "nuclear transplantation," it is still cloning - isn't it?

Scientists do many kinds of cloning every day, most of which is commonly accepted. Cloning has allowed scientists to develop powerful new drugs and to produce insulin and useful bacteria in the lab. It also allows researchers to track the origins of biological weapons, catch criminals, and free innocent people.

There's a world of difference between reproductive cloning - something that should be banned right away - and therapeutic cloning. Therapeutic cloning offers great promise for curing deadly and terrible diseases. Therapeutic cloning could save lives; it doesn't *create* people.

What exactly is therapeutic cloning?

Better described as somatic cell nuclear transfer (SCNT), therapeutic cloning is the transplanting of a patient's DNA into an unfertilized egg in order to grow stem cells that could cure devastating diseases. The promise of SCNT is that the patient's body would accept these cells after transplantation. Therapeutic cloning produces stem cells, not babies. NO sperm is used in this procedure. The cells are not transplanted into a womb. SCNT aims to treat or cure patients by creating tailor-made, genetically identical cells that their bodies won't reject. In other words, SCNT could allow patients to be cured using their own DNA.

What exactly is reproductive cloning?

Reproductive cloning is the use of cloning technology to create a child.

CAMR opposes reproductive cloning. Patient advocacy groups and leading scientists, including the National Academy of Sciences, and a huge majority of the American people agree that human reproductive cloning should not be allowed.

How can therapeutic cloning, or SCNT, help cure disease?

Many of the most debilitating diseases and conditions are caused by damage to cells and tissue. When combined with stem cell research, SCNT could be used to develop new and innovative treatments - such as replacement cells and tissue - that allow organs to function again and restore hope to millions of families.

SCNT is also integral to improving scientists' understanding of how stem cells and other cells develop. This new knowledge could speed the search for new treatments - and possibly cures - for some of the most complex diseases that plague our society.

In particular, SCNT could allow researchers to move stem cell research to a new level, developing stem cell therapies that are specifically tailored to an individual's medical condition. Moreover, SCNT could help scientists develop stem cells that will not be attacked and destroyed by the body's immune system. This holds particular promise for patients who suffer from diabetes, heart disease, and spinal cord injuries.

A Primer on Stem Cells

Ed.note: This article is the property of ALS Association, 2003

By Lucie Bruijn, PhD, ALSA's Science Director and Vice President

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. 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)** .

ALSA Funded Research

Investigator-initiated Research:

Lee Martin, PhD

Johns Hopkins University, Baltimore, Maryland- *Autologous Stem Cell Therapy for ALS*

Lou Gehrig Challenge:

Clive Svendsen, PhD

University of Wisconsin, Madison, Wisconsin- *Stem Cell Therapy for ALS*

Su-Chun Zhang, MD, PhD

University of Wisconsin, Madison, Wisconsin-

Generation of Human Motor Neurons from Stem Cells

EVENTS

Event Reports:

Jan 17, 2004 CA-SP Connection

Contributed by Linda Gentner (PLS)

The luncheon was held at the hospital (where I have volunteered for 15 years) in one of the meeting rooms. It was particularly nice since there was plenty of room for people in scooters and chairs (and a 2 year-old who needed space). There were 19 of us (6 PLS and 4 HSP and their families). For some this was the first time that they had had the opportunity to meet others with our diseases. One couple came from southern CA and another couple from Oregon so you can see just how important it is to be able to visit with people who truly understand. Everyone went away feeling good and are looking forward to another Connection. If you can arrange a Connection in you area, please do.

January 24 CO-SP Connection

Contributed by Dale Rutschow

Ok, maybe it's just my opinion since I put it together but it seemed like everyone had a great time. We had 22 people there. We had a talk from a PT on mobility devices and stretching, ate, then I talked until booed off the stage. For some reason they want to see the Ibot demo!!! Yes, we had that intelligent wheel chair there and also the other Iglide that they make. These are fantastic w/c's, just amazing how well they work, of course for $29,000 for the Ibot and 7000 for the other, they better be something! Everyone voted for another one in the Summer and duct tape for me. I think my wife brought that up.

March 6 NC-SP Connection

Contributed by Linda Gentner

Our day started with 15 PLS and HSP folks making their way to the Crabtree Holiday Inn in Raleigh, NC. There were 28 of us counting family and friends. Linda Gentner introduced the Committee (Don Wilson, Pat Croom, Cece Russell, Sarah Duncan) and then Cece Russell led a Sharing Session. One of Cece's questions was "who has traveled the farthest to this connection?" Wow, were we shocked! One family member came from Columbia (and I don't mean anywhere in the US). That sparked conversation. Richard Milbourne shared comments about the National TeamWalk and also a bit about himself since he has had HSP for more than 30 years. He invited others to ask questions of him; there were no topics off limits. Don Wilson then read what Bettie Jo had written describing her PLS "journey". It was a good Sharing Session for all who attended.

After lunch, Douglas Marchuk, Ph.D., Duke University, recipient of SPF Research Grant for HSP, presented "A Look at HSP and the Search for its Cures". He talked about his mice models as well as a lot of technical information. Q&A followed.

The PLSers met in a different room for "Reconnecting" and sharing of items that make their daily lives easier. Don Wilson had his van loaded. He brought an exercise machine that Bettie Jo can use while in her power chair, very long handled gardening equipment that she can use also from her chair. One of Bettie Jo's passions is gardening so nothing stops her. Don even brought an add-on bidet for all of us to see (he hadn't installed it yet). ;-) Also he had a motion sensor handsoap dispenser. Ronnie had her stick with Fun-Tak and demonstrated how she uses it almost daily to pick anything off the floor or out of her reach.

We had nice raffle items too...from a hand-carved cane, motion-sensor soap dispenser, hand-crafted wood items, hand-crafted curtains (grapes and apple motif) and even a Fiber Optic Easter Bunny that flashed Happy Easter.

We gathered back together for our finale'. Miss Cornelia Kipp Lee, disabled by polio, demonstrated briefly using her wheelchair. Ms. Lee says "Every **Body** Can Dance". She held a hands-on, fun workshop that offered accessible ways to spark creativity through dance and expressive movement. Maybe some of us didn't take her as seriously as she would have liked, because there was much giggling and fun times happening. We did experience hand-contact dances and I think everyone came away with a better appreciation of what we can do.

I tried to meet people that I didn't know and one interesting couple are professional musicians...he is a DJ and his wife sings. Of course, I couldn't help but think about the possibility of a future Fundraiser Connection!! Wouldn't that be fun; I left feeling good.

March 12 FL-SP Connection

Contributed by Flora Brand

We went over Friday night got into the Hampton and there were PLS friends in the lobby already. The SP-Foundation Broad members were already there. Finally got to meet Mark Weber, yes there really is a Mark Weber. Kathi Geisler was there with her husband Ed. I've met them both before and they are a great couple. Linda Gentner and her husband Craig; finally got to talk to her face to face and not just on line. Also Marlene Doolen; what a trooper she is and husband. Annette Lockwood, sweetheart of a lady and many more. We all went to dinner at Bennigan’s. They had an area outside that accommodated us all. I can only image what people thought about us, canes, scooters, walkers, crutches walking through the restaurant. I had to laugh to myself. The Board had their meeting and we had ours - PLS & HSP'ers. Meet old friends and made new ones. I even met GEO!! he's spunky and he has a lovely wife. We all told about ourselves and spoke about different problems and how to get over them and many more things. The caregivers had their session too. I just hope all of you get to go to at least one of these connections. You come back feeling so great from it

Contributed by Edith Kravitz

I've also just returned from Orlando and it was wonderful. I had real concerns about going. I thought I'd see people in terrible states of deterioration that would only depress me, and I didn't want to face that. But Flora, Linda and Kathi encouraged me to go, and am I glad I did! This is a group of positive, enthusiastic people who are dealing with disabilities on a day to day basis, but always have a smile and encouragement for others. We shared concerns, jokes, laughter, ideas, tips and everything else that came to mind.

I'm planning to go to Chicago in June, and hope to meet some of you there.

April 3-4 Spring Fling Berkeley Springs, West Virginia

Report of this all time favorite event will be printed in the Summer issue, since the event is happening as we go to press.

Upcoming Events:

April 24, Burlington, MA – SP Connection Luncheon

11 am-3:30 pm Sheraton Four Points; $18. ea.

To register, go to http://sp-foundation.org/assets/pdf/MA-spring04.pdf or contact Kathi Geisler 978-256-2673.

The featured speaker will be Chris Dufresne, speaking on the topic**: “Sports and Recreational Opportunities for People with Disabilities in the New England Area”**

When Chris Dufresne was diagnosed with PLS in 1994, his doctors told him that physical exercise would be a good thing for his condition. He took them at their word and decided that he would continue to participate in sports and physical activity to the maximum extent possible. Having been a dedicated downhill skier for 20 years, he joined the New England Handicapped Sports Association at Mt. Sunapee, NH for some intensive instruction in adaptive skiing. He went on to serve as an instructor and board member. Chris recently joined the staff at the White Mountain Adaptive Snowsports School at Loon Mountain, NH where he teaches adaptive skiing and is also a member of the New England Disabled Ski Team.

Looking for summer activities, Chris has taken

up sea kayaking and joined the North Shore Paddlers Network. He has participated in numerous safety training sessions and is now working on his roll. He has organized and led groups of up to 50 disabled people on canoeing/kayaking and camping trips on the Saco River in Maine.
We will also have an informational program. The President of a local home care company will do a program called "Falls - Facts, Risk Assessment and Prevention". Falling is the catalyst for 40% of all nursing home admissions and causes $70B in medical costs each year. This program will give some great tips and techniques to reduce falling and also make our homes safer.

May 1, Tarrytown NY-SP Conference "Understanding and Treating Spasticity"
8:30a.m.-4p.m.
Featuring:
"Spasticity: What is it and How do we Treat it? John Krakauer, M.D., Assistant Professor of Neurology and Lab Co-Director, Columbia University College of Physicians and Surgeons. Research interests include brain mechanisms for control of limb movements and motor learning.
"Physical Therapy for Spasticity", Charles Smith, M.D., Neurologist at the Multiple Sclerosis Care Center of Westchester and Professor of Physical Therapy, New York University
"Alexander Technique to Improve Human Use and Functioning" Karla Booth Diamond, teacher, member ACAT and AmSTAT.
Medtronic Pump Round Table moderated by Rob Redden, M.D.
Registration Fee includes the meeting room and programs, coffee arrival period with bagels/muffins, lunch, and handouts.
$35 per person for SPF members
$40 per person for non-members
There will be a Dinner Casual Connection at the hotel restaurant at 5:00 p.m., after the Conference.
Registration Form is now available here: http://www.sp-foundation.org/assets/pdf/NY-may04.pdf
Contact: Bebe Leon, 631-864-9344
Social1997@aol.com Bob Gustafson, nosfatsugbob@netscape.net

May 22, 2004, IA- SP Connection Clear Lake, Iowa
11:00 AM - ? to gather, eat, and gab!
Bennigan's Irish-American Grill & Pub
connected to the Best Western Holiday Lodge
Highway 18 & I-35, 50428
Ph. 641-357-5253 (to book a room, if needed)
Contact: Laurel Yost laurel@wctatel.net. Or call 641-568-3050

The PLS Symposium: A Diagnostic Criteria Conference *(ed. note:The Symposium is about us, not for us. This is the gathering we have been waiting for – the gathering of the foremost researchers from around the world to establish diagnostic criteria for PLS)*
June 4-6, 2004 Santa Cruz, CA
Friday June 4, 2004
Background and history of PLS from Charcot onwards: Why this and why now? *Lewis Rowland*
Saturday June 5, 2004
Session 1: PLS and its Diagnosis *Michael Swash (Chair)*
Introduction and welcome: *Teepu Siddique*
Participants: *Michael Strong, Carmel Armon, Geert Groeneveld, Arthur Hays,Paul Ince, Hiroshi Mitsumoto, Petra or Charlie Smith, Mary Kay Floeter, Michael Swash, Richard Olney, Markus Weber*
Session 2: PLS and alsinopathies and related disorders *Teepu Siddique (Chair)*
Participants: *Teepu Siddique, Faycal Hentati, Enrico Bertini, Afif Hentati, Jo-E Ikeda, Odile Boespflug-Tanguy, Han-Xiang Deng, John Fink, Lisa Dellefave*
Session 3: Panel Discussions *Lewis Rowland (Chair)*

PLS Criteria set apart from ALS: *Michael Swash, Stanley Appel, Walter Bradley, Hiroshi Mitsumoto*

PLS Criteria set apart from Spastic Paraparesis: *John Fink,Terry Heiman-Patterson, Franca Cambi*

PLS as a syndrome – differential diagnoses of PLS and differential diagnoses: Raymond Roos, Peter Spencer

Sunday June 6, 2004

Session 4: Current and Future Research Directions in PLS *Robert H. Brown Jr. (Chair)*

Participants: *Margaret Pericak-Vance, Jonathan Haines, Nailah Siddique, Markus Weber, Mary Kay Floeter*

Session 5: Proposed Concurrent Forums *Benjamin Brooks (Chair), Stanley Appel (Co-Chair)*

Session 6: Final Diagnostic Criteria Meeting *Benjamin Brooks (Chair), Stanley Appel (Co-Chair)*

Clinical criteria subcommittee *Michael Strong*

Neurophysiology criteria subcommittee *Mary Kay Floeter*

Imaging criteria subcommittee *Hiroshi Mitsumoto*

Neuropathology criteria subcommittee *Arthur Hays*

Genetics subcommittee *Margaret Pericak-Vance, Jonathan Haines*

Wrap-up ***Teepu Siddique***

June 25-26 Chicago "Highlights of the PLS Symposium" Conference

Friday Arrival Celebration Connection Dinner. Join us at the Radisson Hotel & Suites at 6:00 p.m. We raised over $10.000.00 for the seed money for the Symposium. Now we need you to come help celebrate! The Radisson is adjacent to the Feinberg Pavilion at 160 East Huron St., Chicago, IL 60611. Pre-registration for the Dinner is required using the form below. $29 per person.

Saturday Conference: Featured speaker: Teepu Siddique, M.D. Professor of Neurology, Professor of Cell and Molecular Biology, Duane and Susan Burnham Abbott Laboratories Research Professor Director, Neuromuscular Disorders Program Feinberg School of Medicine, Northwestern University. Dr. Siddique will summarize in lay terms the findings of the June 4-6 Symposium which will have taken place in Santa Cruz, CA.

9:00 a.m. – 1:00 p.m. Conference and Lunch

1:15 p.m. – 2:00 p.m. Laboratory Tour

The Conference is at Feinberg Pavilion of Northwestern Memorial Hospital, 675 North, St. Clair Street, 3rd floor Conference rooms C and D. The lunch and lab tour will be at 300 East Superior Street, Tarry Bldg, (Lunch in Atrium; Lab Tour on the 13th floor). Map: www.nmh.org/visitor_info/map_campus.html

Registration: $15 per person includes the Conference, lunch and lab tour

For Travelers: Rooms at the Radisson Hotel & Suites are available at a discounted rate of $109; however, **room reservations must be made by April 23 to take advantage of this price**. Please call (800) 333-3333 and ask for pricing for the Spastic Paraplegia Foundation Conference. The Feinberg Pavilion is about 100 yards from the hotel. Hotel website: http://www.radisson.com/chicagoil Phone: (312) 787-2900.

* *

Registration – Deadline: June 11, 2004

$15 Conference Fee includes conference, lunch and lab tour # people: _____

$29 Friday Arrival Celebration Connection Dinner # people: _____

Also enclosed is a donation to the Research Fund: $________ **Total $_______ enclosed**

Please make checks payable to Spastic Paraplegia Foundation and mail with this Form to:

Linda Gentner, 1605 Goularte Place, Fremont, CA 94539. Contact: 510-651-5676, lkgentner@aol.com

Name of all individuals attending (please print):

____

____

Your phone # & email:________________________________

I need a vegetarian meal option: _______

August 27-29 National SP Foundation Conference and TeamWalk 2004

The weekend will begin Friday evening with dinner. The Conference speakers for Saturday are being lined up this month. Look for detail soon. TeamWalk will again be in Lexington, MA on the Battle Green.

It's not too soon to plan your trip and make your hotel reservation.

Conference headquarters is:
Sheraton Four Points Hotel, Burlington, MA
(781) 272-8800
http://www.starwood.com/fourpoints/search/hotel_detail.html?propertyID=1264&back=-1

September 11, Austin, TX-SP Patient Connection

This is an advance notice of the third annual Austin Patient Connection to be held in Austin, Texas on Saturday, September 11, 6:30 PM, Brick Oven, Aboretum area. Persons living with HSP and PLS, their family and friends are invited. More information will be announced in July for registration.

Marlene Doolen is arranging the event.

LIVING WITH PLS

Extra Hands for ALS

The ALS association has a help group known as Extra Hands for ALS. High School and College students volunteer to assist you with non-medical needs in your home.People with PLS may also qualify for this help. You can check to see if they serve your area by going to WWW.extrahands.org or send e-mail to brooke@extrahands.org.

No State Excise Tax on Autos Owned by Handicapped

Contributed by Thurza & Jim Campbell

In Massachusetts (aka Taxachusetts), anyone with a handicapped license plate pays no excise tax. You have to ask, and follow proper procedure. Check out your own state to see if you have a similar regulation which provides this nice benefit.

Call or fax the Medical Affairs Branch of the Registry of Motor Vehicles to obtain handicapped plates for your car. Phone: (617) 351-9222. Fax: (617) 351-9223. If you have never gotten a handicapped placard or plate, you will have to start with an application submitted by your primary care physician to the RMV which states your need. The procedure is for RMV to replace your current handicapped placard with a 24 month temporary renewable one. (You always need a placard to use when riding in someone else's car.) Once the handicapped plate has been delivered to your nearest RMV office they contact you. You then fill out the forms and pay for the new plates at the Registry. The final step is to take a copy of your new registration to the your Town's Assessor's office, where they will fill out paper work for the Tax Collector and Treasurer to reimburse any excise tax you have paid on that car this year. The Assessor will not send further excise tax bills as long as you maintain that handicapped plate.

Medicare part A & B

Contributed by Joanne Gaffney

If you have Medicare A or B and they are the first insurance billed, they will pay 80% of covered items if all of Medicare's "criteria" is met for that item. For example, if you need a walker, the diagnosis must imply impaired ambulation. After they pay their 80% the 20% left over will be billed to the second insurance for their payment. Some "secondary" insurances like Blue Cross Blue Shield will pay anywhere from 80-100% of that remainder balance if you have a Durable Medical Equipment rider. Let's say a walker costs $100. Medicare will pay $80 and the extra $20 will be billed to the secondary insurance instead of the customer. If the secondary only pays a portion of that $20 then the balance will be billed to the customer. It's important to let the company that's providing your equipment and doing the billing know all of you insurances. Too often people don't do this and end up paying for something the secondary insurance will help on. I strongly advise everyone to make sure all of their insurances have been billed before they pay any money. Medicare will send what's called an Explanation Of Medical Benefits to you every time they pay on a claim. They will tell you what was billed to them and what they paid and also if they billed your secondary insurance. If Medicare doesn't say they billed your secondary insurance make sure the company providing the equipment does bill your secondary carrier. If for some reason the equipment company doesn't bill the secondary carrier, you will have to pay the balance and submit the bill to your secondary insurance who will reimburse you.

Memorable Quote to Live by

Contributed by Eugene A. Secor

"...hope, as opposed to cynicism and despair, is the sole precondition for new and better experiences. Realism demands pessimism but hope demands that we take a dim view of the present because we hold a bright view of the future; and hope arouses as nothing else can arouse...a passion for the possible." Rt. Rev. William Sloan Coffin

My HSP Story

Contributed by Donna Sampson

I was 7 years old when I was diagnosed with HSP my father had it, his mother and 3 of her siblings as well as her father & possibly her grandmother. I am in my mid 50s now. I've had a long time to get used to the idea of having something wrong with me. I have gone through the progression of not using anything to walk with in my early years to using a cane at 30 and going to 2 sticks shortly after that. I walked or should I say dragged myself around on those sticks for about 15 years. When I started having such horrible back problems I went to the chair all the time. I know we all fight using a wheelchair, like the chair makes us more disabled than we are stumbling around with a walker, crutches or whatever. I just want to let you know the chair has set me free, I am able to do more from my chair than I ever was able to using crutches. I wouldn't go into a mall or big stores or places where there was a lot of walking involved because I might get somewhere and not be able to get back out not to mention the fatigue from dragging myself around. With the chair I love to go to the mall and I go all over, I also work full time 40 plus hours a week whenever there is overtime available, do my own grocery shopping, my own laundry all of my own personal upkeep and hygiene.

I have had a pump since 1998; in fact I'm on my second pump and I am ever so thankful for the pump. I was on oral baclofen from 1980 until I got the pump in 1998 and the dosage had increased over the years. I did go off of baclofen for a short time and tried zanoflex before I got the pump and that was a nightmare. I was up to almost 100 mg of baclofen a day and working a full time job when I got the pump in 1998. One of the things the Dr said to me when we first talked about the pump, was that the pump wouldn't make me or help me walk again. The whole procedure, trial and surgery all went well. I live in southern CA and both of my pumps were put in at Loma Linda University Medical Center.

I realize that not everyone has had the same great experience with the pump as I have had, but I consider it a Godsend. I am on a much lower dosage of baclofen now and it really does help the spasticity. Getting the proper dosage can be a bit of a challenge and I went to Loma Linda about once a week for the 1st 6 to 7 weeks I had the pump to get the dosage just right. The dosage can be adjusted with different dosages for different times of the day, I am in a wheelchair but do stand up to transfer and get in & out of my car so I need to have some spasticity and can't be on too high a dose or I'm too limp and can't move. I think it is important & helpful if you don't live too far from your doctor so the dosage can be adjusted weekly or daily if necessary.

I still work full time and with the pump and I don't have to take 4, 6, or more pills a day and wonder if they are going to work or when they are going to work and if I will be sedated from the medication orally. It was awful to have to go back on the medication orally when I was waiting to have my pump replaced. It took about 3 weeks before I could get my pump replaced and I had to go back on oral baclofen.

I would say that having HSP and being diagnosed at a young age 7, has affected me in many ways. I don't think I would be the person I am today if I didn't have HSP. One of the ways it has affected me is that I don't take anything for granted and I know that no one can. None of us get any guarantees in this life, your life may start out one way but you never know how it will end up. The golden beautiful people have no guarantees, they may be stricken with a disease or be involved in an accident and loose body function or any number of things can happen to people, either by their own omission or an accident. I have always felt I had a slight advantage because I knew I had HSP at an early age. Because I knew in advance that I would face certain physical limitations I could make adjustments in my life and somewhat plan for the eventuality of a wheelchair, if anyone is ever truly able to do that.

I am the kind of person who looks for and tries to find the good in all people and in every situation and I believe I have done that with HSP. I'm not saying that I think it is wonderful to have this disease, believe me, but I know there are a lot of people in a lot worse shape than I am. I am especially reminded of this when I go to Loma Linda University Medical Center to have my baclofen pump refiled, I see the young children and babies with all kinds of horrible diseases, they will never have the opportunities to do the things I have done or live the life I have . On these visits I thank God that I have HSP and not some other disease.

The world needs people like us out there doing and smiling.

PLS coverage under Muscular Dystrophy Association

Contributed by Linda Neilson

An excerpt of Linda's letter to MDA:

"I note from your web site information and support for ALS. My question is whether PLS is also included under this umbrella for your purposes or whether this is considered a separate condition."

Excerpts of the MDA response follow:

Dear Linda:

Technically, PLS is not one of our covered disorders, however, some discretion is allowed on the part of the individual MDA clinic directors, who are typically neurologists.

As you may know, "muscular dystrophy" is an umbrella term for a group of inherited diseases characterized by progressive weakness and degeneration of the skeletal(voluntary) muscles that control movement.

To assist those affected by muscular dystrophy, MDA sponsors a nationwide network of 230 outpatient clinics staffed by teams of top healthcare professionals skilled in the diagnosis and medical management of neuromuscular diseases. The best person to address case-specific concerns - including providing a definitive diagnosis - is a MDA clinic physician. The only requirement for an individual to receive an evaluation with a MDA clinic is the written recommendation of a physician, in whose judgment, an individual may have one of the disorders encompassed by this Association. To learn more about MDA's clinic program or to obtain additional information regarding registering with the Association for services, may we suggest that you contact the local MDA office Health Care Service Coordinator. Please keep in mind that your visit to the clinic may not be covered through the MDA program of services. You may obtain your local office information by referring to the following zip code locator website below:

ZIP CODE LOCATOR:
http://www.mdausa.org/locate/index.html
Once you are registered with the MDA, you can obtain assistance with home medical equipment and communication devices, if needed.MDA strives to be a source of help and hope to families affected by neuromuscular diseases by supporting cutting-edge research and providing comprehensive programs/services for those affected by any of the over 40 neuromuscular disorders in the Association's purview.
Kindest regards....
Sincerely,
Sallie K. Bitner, MS, RRT
Program Information Coordinator
Muscular Dystrophy Association

Thanks to God for Computers

Contributed by Janet from Oz

Dear Lord,
Every single evening as I'm lying here in bed,
This tiny little prayer keeps running through my head.
God bless all my family wherever they may be,
Keep them warm and safe from harm for they're so close to me.
And God, there is one more thing I wish that you could do,
Hope you don't mind me asking; please bless my computer too.
Now I know that it's unusual to bless a motherboard,
But listen just a second while I explain it to you, Lord.
You see that little metal box holds more than odds and ends,
Inside those small compartments rest so many of my friends.
I know so much about them by the kindness that they give,
And this little scrap of metal takes me in to where they live.
By faith is how I know them much the same as you,
We share in what life brings us and from that our friendships grew.
Please take an extra minute from your duties up above,
To bless those in my address book that's filled with so much love.
Wherever else this prayer may reach to each and every friend,
Bless each e-mail inbox and each person who hits send.
AMEN

Phone Relay Service

Contributed by Ronnie Grove

You really owe it to yourself to check out this information if speech is a problem for you. I have been using AT&T Relay services for years because I have a profound hearing loss. I was aware that the Communication Assistant (CA) was trained for speech loss as well as hearing loss customers. I use a TTY and called the operator to put through my calls. WOW! I can't believe what all is available-FREE. You don't even need any special equipment and ANYONE can make phone calls to doctors, lawyers, mom, boyfriends, catalog ordering. When you type to a CA they read the written message to the caller and thus will clean up your typos. Read all about it at www.att.com/relay

The Spiral Stairs of Acceptance

Contributed by Dolores Carron

Reference has been made in the past that experiencing the progression of a chronic illness is really grieving the death of our former selves. I agree with that concept. It is the death of the healthy, able-bodied person we were before. One account that I found especially meaningful was that the steps of the grieving process are more like a spiral staircase than a traditional ascending one. So, while we adjust to the losses and changes, we are

achieving acceptance, except that as we come around the circle, we have to process some of the same emotions and feelings again, albeit a little differently each time. We come back to the same place, but on a higher plane each time. It would then be very understandable, that the previous challenges of denial, bargaining, etc. will resurface from time to time. Rather than giving up on things that you seem unable to do, not that there won't be some, try to think about different means to achieve the same goal.

Beauty Tips

By Audrey Hepburn; read at her funeral.
For attractive lips, speak words of kindness.
For lovely eyes, seek out the good in people.
For a slim figure, share your food with the hungry.
For beautiful hair, let a child run his/her fingers through it once a day.
For poise, walk with the knowledge that you never walk alone.
People, even more than things, have to be restored, renewed, revived, reclaimed, and redeemed; never throw out anyone.
Remember, if you ever need a helping hand, you will find one at the end of each of your arms. . .

CAREGIVING

A Friend

Contributed by Sandy
If I could catch a rainbow
I would do it just for you
and share with you its beauty
On the days you're feeling blue.
If I could build a mountain
You could call your very own
A place to find serenity
A place to be alone
If I could take your troubles
I would toss them in the sea
But all these things I'm finding
are impossible for me.
I cannot build a mountain
Or catch a rainbow fair
But let me be what I know best-
A friend who's always there.

Something Good

Contributed by Dale Rutschow

The last few weeks have not been kind to me but I want to share this. We write when our caregiver does something thoughtless but very seldom hear good things, well here is one. Recently I have progressed very rapidly, to the point that I am thinking it might be time for a wheelchair. No medicines have helped and so the pump is my last chance and is waiting for the insurance company. Last week I had to give up driving to my wife. I heard my wife on the phone say to her sister-in-law last week when they were talking about how I was doing, that I can't do hardly anything and now she was also "Dale's taxi". She didn't say it mean or anything just stating a fact and was actually being a little humorous. My logical mind understood but not the rest of me...

This had been eating on me recently also. I can barely do anything and as I have to give up more things it means more that my already overworked wife has to do. I was feeling guilt, anger and paranoid; I was totally losing control of my life and another person is actually making my decisions. I started thinking, if she said "no" to something I wanted, what could I do??? I wanted to talk to her about the comment but also was thinking (thank heavens) that wait, she needs to be able to express herself also. This is a big burden on her. If I make it so she feels she can't express her frustration it will kill her also. So I held my frustration in. Next week we see the counselor and I figured that would be the place to talk about it.

Last night we had just gotten into bed and I told her that for the first time I am going to need her to cut my toe nails, I just could not. She said, "sure, after you shower tomorrow". It took a lot for me to ask, to give up another thing and put it on her. I told her "Jen, I'm sorry I have to put everything on you."She was looking at the ceiling and said: "Oh Dale, every time I see you laying there doing nothing I want to cry. I know that is not my hyper, bouncing, lets do everything Dale and it breaks my heart to see you progressing like this. I know how much it has to hurt to ask me to do stuff for you, but I will gladly do them"

It was if a giant weight lifted from my heart. I was so worried I would make her so overworked with my "demands" that she will become angry; not leave but angry and start despising me. Instead I found out it was breaking her heart... God, what a revelation!

I love that woman so much. Remember, when the caregiver says something "thoughtless" what they are going through also. It's so easy to hear the remark as "aimed at you"...

Buddy System

Contributed by Shell Fisch

The thought of anyone giving up scares all of us. We live in a war zone. We fight a war with our own bodies. We fight back its aggressive attacks that bring pain, fatigue and barriers to be overcome. Our morale is drastically affected by the winning or the losing of our latest battle. When a person is looking through tear stained eyes it is difficult to see the brighter side of life. It takes family, friends and support to dry away those tears and let in the light of brighter possibilities.

Several people feel it would be a good idea to have a buddy system in place. Where friends on the lists could partner up with several individuals so that if one could not be reached another person could. The idea being an information exchange so that if any of us ever became overwhelmed there would be a person there to help move us through it. We are all connected to one another and need to be there for one another. We need to know that others just like us are all right so that we can look at our lives and feel that we too are all right.

If you would like to participate in a buddy system send a private email to those you would like to be your contact person. Just provide a phone number and address in the email to a person from the list you feel comfortable with. Think it over and send a private email to a buddy.

Good Times Scrapbook

Contributed by Dale Rutschow

My daughter came home to visit. She gave me a photo album that she had made called "The Good Times". Each page has a theme, like Mommy, family etc. decorated with pictures she cut with a special scissors and sayings. One of the sayings in the album I really liked, is: "The only courage that matters is the courage that takes you to the next moment"... They all are good memories and I really like it. She even left a few blank pages and she said she would fill them in with the good times to come! She then said that she named it that because when I have those bad days I should look through the album and hopefully it will help!

Massage and Stretching

Contributed by Don Wilson

Bettie Jo has a weekly massage. The therapist works to smooth muscles and ranges limbs to work on maintaining as much flexibility as we can. Generally, Medicare and private insurance will not pay for massage therapy. However, some insurance companies are now offering "discounts" to policy holders as long as they use therapists that are under contract with the company to accept a fixed rate. If a physician prescribes massage therapy, the entire cost is tax deductible if you itemize your tax return.

There is massage, then there is massage. There is a difference. There are many different forms of massage, and a trained therapist will be able to use the techniques needed to produce the most positive results. This may not be a spouse, who gives "back rubs". I like to think that I am fairly good, but not certified, in upper body massage with special attention to face, head and back. However, Bettie Jo does not like the type of massage that I do.

There is a trick that may help. Put a couple of tennis balls in a thick sport sock and then roll them over the areas being massaged. That will put pressure in a relative small "foot print" without a lot of direct contact.

Bettie Jo and I do try to stretch tight ligaments before she goes to bed each night. We begin with her leg bent at the knee and I them push from the ball of her foot toward the knee. After holding that position for a few seconds, I then push her shin toward her chest, which stretches both the knee and the hip. She straightens her leg and I turn the foot to the outside (spasticity is forcing her feet to turn towards each other) and lift the straightened leg upward a few inches. This stretches the tendons in the back of the leg and at the hip. After this is done to both legs, I then cross her legs at the knee with my forearm between the two legs, then push down on the upper leg. Then the legs are changed and the other leg is compressed. This stretches the tendons that are attached to the hip. It does not take long, nor does it require a lot of skill.

Believe and Succeed

Contributed by Ann Schroeder

We caregivers know that tomorrow finds you fighting to stand up, struggling to speak, and showing the courage to get through the day. Continue your battle. We stand beside you to help in any way we can. Courage does not always roar. Sometimes, it is the quiet voice at the end of the day saying, "I will try again tomorrow."

Editor’s closing:

June’s two upcoming events are monumental for the PLS community. The Symposium to clinically define PLS is taking place in Santa Cruz the 4th through the 6th.. We’ll receive “the scoop” on it in Chicago the 26th. Many of you have worked hard fundraising to make the Symposium happen. I hope you’ll make every effort to come to Chicago for the reporting and celebration.

If you would like to reach me by mail with comments, questions, or a donation to help fund this newsletter, I may be reached @

Thurza Campbell
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