



Synapse

Autumn 2003

Serving the Primary Lateral Sclerosis Community since 1997



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EVENTS

SP Foundation Conference and TeamWalk

September 12-14, 2003

Burlington and Lexington, MA

From across the country and Canada, 130 people joined hearts and hands for the 2003 "TeamWalk For Our Cures". Kathi Geisler chaired the committee that planned and ran the event. Her exceptional leadership and enthusiasm made the event a tremendous success. The weekend featured the national Research and Beyond Conference, a spectacular TeamWalk Walkathon, social gatherings and outings. The TeamWalk fundraising tally of \$141,700 was announced at the culmination of the TeamWalk walkathon. As of this printing the total has risen to \$151,000.

"Research and Beyond" Conference, Saturday, September 13.

Keynote speaker was Robert H. Brown, Jr., PhD, M.D., of Mass General Hospital, leading investigator of ALS and other neurodegenerative conditions. He reviewed current advancements in research and potential therapies relevant to HSP and PLS.

Afternoon break out sessions were well received. These included: John K. Fink, M.D., University of Michigan, SPF Medical Advisor, highlighting the progress in gene discovery; Kara Houde Ng, MS, Genetic Counselor from Athena Diagnostics on gene testing; Craig Gentner led a session for caregivers; assistive devices were demonstrated; Baclofen Pump demonstration; a Revolutionary War forum recounted local history.

Several SP Foundation Board Members spoke: Community Voices speaker Carolyn Sartain Anderson. (Her talk is in a separate article); Mark Weber, creator of the Foundation announced that there will be two \$40,000 research grants awarded this year; Linda Genter unveiled the newest Awareness Quilt panel, a PLS panel she coordinated and which was crafted by volunteer Margaret Twichell; Annette Lockwood closed the

Conference reading a poem she composed (Poem is in a separate article)

TeamWalk, Sunday, September 14.

The morning began under the tent on the Battle Green in Lexington. As 130 people were gathering, IBOT arrived for the day. IBOT is the wheelchair, approved in August by the FDA. Project Engineer Jim Turner from Deka Research, headed the software development team that created the sensational wheelchair, which can easily raise to eye level on two wheels as well as climb stairs. Other pre-TeamWalk morning activities included a Stretch and Get Set program by Rose Wolanski, P.T., a performance by the William Diamond Junior Fife and Drum Corps and a salute and send-off by the uniformed Lexington Minute Man Company. There were three one-mile loops for TeamWalk. These were completed with canes, crutches, walkers, and wheelchairs. As people returned to the TeamWalk tent, they enjoyed lunch, camaraderie and visited the Visitor's Center. The day's event concluded with David Lewis, SPF Treasurer, announcing the TeamWalk total of \$141,700. . . and then the rain began.

Adversity: the Abrasive that puts an edge on Courage

Talk given by Carolyn Sartain Anderson
September 13, 2003 at the Research and Beyond Conference, Burlington, MA.

Good Morning! I dedicate my message to my 90 year old Dad; my brother Thomas; my four daughters and family; my dear friends all across America; to Bob, Helen, and Rick who walked the diagnosis journey with me; and especially Ryan.

Looking around our gathering this morning, I see faces that have been touched by special persons in their lifetime. Prior to retiring in 2000 my career was one of a Special Educator of Severely Emotionally Impaired adolescents 16-21 years of age. Each day I thrived on 'living on the edge' and being challenged by adversity. I truly miss impacting/making a difference in my profession;

now I have found a niche as a Board member, impacting lives/making a difference once again. Back in 1959. I was in 8th grade, a very young, impressionable kid. Everyone knew the routine, the last week of August we awaited 'the dreaded letter' telling us our upcoming year's schedule, but most importantly who our homeroom teacher would be. You have to remember, homeroom was 'where it all happened', where you bonded with friends and hung out. Everyone knew the room 'dreaded most,' it was Miss Bennett's. Miss Bennett was a wonderful English teacher, but being in her homeroom was the 'curse.' For each morning Miss Bennett would have written on the old slate chalkboard with white chalk, in her perfect cursive penmanship 'the dreaded journal topic'.

The beginning of December when everyone was looking forward to the holidays, we encountered the mega-journal topic on the board; 'Adversity is the abrasive that puts an edge on courage.' I had no idea what adversity and abrasive were. My journal page was blank.

A week later, a topic, once again written in perfect cursive was, 'Follow your Dream.'

Miss Bennett, just before Holiday Break informed us that she had health problems and would not be returning for the remainder of the year, but would remember us each day and asked us 'to follow our dream. In May of my eighth grade Miss Bennett died of cancer. It was then that I realized that her latter journal topics were about her, and what she was facing.

I was diagnosed with PLS in New York City on a rainy afternoon in August 1997. I was numb, but optimistic; I then came face-to-face with 'adversity' and 'abrasive.'

For folks afflicted with PLS/HSP, indeed, our adversity, trials and tribulations; are the abrasive, scraping/cleansing that allow us daily to have 'the edge on courage.' My faith, family and circle of friend are with me daily and sustain me through 'my moments.'

As for her 'follow your dream' comment: Miss Bennett had no idea, that a mere four years later, Martin Luther King Jr., would eloquently deliver

his, 'I Have a Dream' on the steps of the Lincoln Memorial, which has changed the face of America. It is the same dream that those of us with 'life altering' illnesses wake up to each morning. Dreaming of a cure. The power of a dream can move challenges and mountains if you believe. I believe and I know you believe also. So each morning, let us remember our challenge to live out our dreams of yesterday and to welcome the dreams of today and tomorrow with faith and hope.

I love you all and may God Bless you.
Followed by CD of Celine Dion singing, 'The Power of the Dream.'

Notes from the Keynote Address at the Research and Beyond Conference

Given by Dr. Robert H. Brown

Notes compiled by editor

Dr. Brown began by explaining that there is overlap, commonality and convergence between various motor neuron diseases. Research pathways which are being pursued in ALS overlap and have relevance for PLS, HSP and other motor neuron diseases.

The challenge for the researcher in examining the biology of motor neuron disease is that all of them share the following aspects which are:

- a. progressive
- b. disabling
- c. untreatable
- d. age dependent (40 or 50 at onset).

There is a triumvirate of causes for onset of motor neuron diseases:

1. Aging sets stage - some inherited, others not. We need to understand the aging process. Motor neuron death is a normal part of aging but why in some instances does aging trigger motor neuron disease. In studying performance relative to aging, Dr. Brown studied three Boston marathon runners, Clarence Du Mar and two generations of John Kelly, who ran for many years. In all three runners, their times declined five to six times faster after age 60 than before age 60. In other

words, aging is the beginning of end of motor neurons.

2. Genetic approach is a powerful way to study motor neuron disease. Tracking familial patterns aids researchers. Genes: familial links are being used to track and try to understand genetic mutations which permit disease onset. Huge progress has been made in HSP in finding genes. 30 gene defects are involved in destruction of motor nerves.

3. Environmental triggers are being explored. These include insecticides, pesticides, smoking and a high glutinous diet.

What triggers the death of cell the body, or degeneration of motor neuron axon? If we can understand the spreading process of degeneration maybe we could contain and treat the disease.

There appear to be four components in degeneration of the axon and ultimate cell death.

Those components are:

- a. Too much electrical activity in the cell
- b. Protein clumping inside the nerve cells
- c. Reaction of the surrounding cells around the nerve cells
- d. Activation of cell death pathways

The energy factory of the cell also becomes sick (mitochondria) in motor neuron disease. Study of mitochondria is yet another pathway to study, along with motor protein abnormality.

Motor neuron diseases are orphan diseases. Pharmacological companies aren't interested in funding research as no good market share will develop for them.

Motor neurons are our sponsor. Every cell has a body. Axons are the communication cable and tubing which go to neuro muscular junction and take information back up from muscle. 99.9% of volume of a motor neuron cell is in the axon, not the cell body; built to never to divide or replace itself. Bad systems engineering for such a critical component of the body!!

Dr. Brown went on to explain upper and lower motor neurons. Both HSP and PLS deal with upper motor neurons that live in the brain and connect to lower motor neurons. In PLS the involved upper motor neurons are bulbar and

spinal; in HSP the involved upper motor neurons are spinal.

Targets can be defined when we can analyze and understand cell sickness. Then we can come closer to treatment for you. Several treatment options have shown some benefit. These drugs include Riluzole, Creatine, CoQ10, and Celebrex.

Studies are being conducted in labs now using a variety of hosts:

1. Flies, worms, yeast experiments are tracking aging. Some knowledge learned in these experiments may transfer to humans.
2. Mice and rats which are bred to contain SOD1 genes are used in study of the disease. Sick proteins in the SOD1 genes can impair cell function and those sick proteins become a target for therapy. When we make the motor neuron sick, surrounding cells also get sick. It takes a village to kill a cell; conversely, it takes a healthy village sustain a cell.
3. Fruit fly models are being engineered for study..

The cost and time line of drug discovery was explained. If humans are used in the trials, the trials take 2-3 years and cost up to \$5 million dollars per drug. If mice are the subjects in the trials, they take 6 months, and cost \$50 thousand per drug. If the trial is conducted in a petri dish, the trial takes 1 day at a cost of \$10 per drug. The research community has had a paradigm change to begin screening with petri dish models. Obviously success in a petri dish does not directly transfer as success for humans, but it may streamline the process.

What are some of the exciting avenues being pursued now?

1. A consortium of 22 centers in New England has been established to collaborate on drug trials.
2. We are planning national study group for study of ALS. HSP should be in this group.
3. Gene therapy has just been announced. Brain and spinal cord barrier is an "iron curtain". It is hard to get proteins to cross blood brain barrier.

The hope is that corrective genes can be delivered by a virus. Experiments took a virus and infected muscles of a mouse; that virus got into the motor nerves, and prolonged the mouse's life.

Researchers want to do that in humans soon.

Protein growth factors can therefore work if they can get them where they need to be.

4. Using tetanus as a model as another way to inject proteins into a motor neuron cell, he explained that tetanus has a toxin which can go into the motor neuron and spinal cord; since the toxin can find the motor neuron, that can be helpful. Protein as a cargo; the delivery vehicle is tetanus. The researcher must trick the non-lethal protein to get into spinal cord this way.

5. Stem cells have potential. Researchers surround or pack a sick motor neuron cell with healthy ones. In mice, life is extended if 20% surrounding cells healthy; these stem cells slow cell death or even stop it.

6. If we could shut off an offending gene which has a toxic protein, nothing else would matter. Can we stop the offending protein from being produced? This approach is a long shot at this point, but possible. To shut off production of the offending proteins is the most important thing to do. There is even hope that damage could be reversed if we can shut down offending gene.

Poem

Written by and Read by Annette Lockwood at the close of the Research and Beyond Conference, September 13, 2003, Burlington, MA.

A day without the friendly stares,
Or the more often unfriendly glares.
A day of dancing to the wee hours,
And climbing stairs in the tallest towers.
A day to fall head over heels in love,
Instead of face down on the rug.
A day of walking without worries,
And not being bushed aside by those in a hurry.
A day of walking like most,
Being able to walk both up and down the coast.
A day without doctors, tests or pills,
Or denied insurance claims and bills.
This day will come,

And what a beautiful day it will be.
But for now we must wait,
For research will determine our fate.

TeamWalk Reflection

Contributed by Bebe Leon

My thanx to all those who made the MA conference possible. It was an experience that I shall never forget. The Friday night dinner was filled with friends that I had never met. Saturday was inspirational as Carolyn spoke about "Adversity being the cutting edge of courage"... Dr. Robert H. Brown, a well respected researcher from Mass. Gen., spoke on "Research and Beyond." He gave an outstanding presentation giving us academic facts, yet, I felt it was framed by his sensitivity to his audience (not being professionals) and their need of feeling that progress is being made. Night was great with dinner at the Colonial Inn. Sunday was something that Lexington will never forget. We were an interesting group of those walking, walking with canes, walking with walkers, and rolling in wheelchairs....or peddling in a wheelchair as Joel Seidman did. Mark, and probably others, were driving around in case anyone wanted to stop. Each time he pulled up to meeven if I was exhausted in that humid day....I was not going to give in. All the townspeople in Burlington, Lexington, Concord were very helpful and friendly.

TeamWalk Reflection

Contributed by Linda Gentner

Everything was so organized, it went off without a hitch. The working committee did a magnificent job and should be proud which I'm sure they are. I, too, was very impressed with Dr. Robert H. Brown. I especially found it fascinating that they can do research with mice, rats and fruitflies, at a fraction of the cost of human trials, and in a petri dish! After his presentation a Q&A followed. Immediately following lunch I was scheduled to unveil the PLS Quilt. I got through it (despite shaking legs) and the quilt is really very lovely

and hopefully you have seen pictures of it. There were several different breakout sessions on Saturday afternoon--assistive devices, augmentative devices, Dr. Fink on HSP heredity, Spouses and Significant others (that my husband, Craig, facilitated..yea Craig...he said about 25 people attended and thought it was very worthwhile) and also a Revolutionary War Forum since we were at the place of where "the shot heard round the world". Sunday was extraordinary..including the weather. I took my Jazzy so I rolled the entire 3 miles. The Minute Men and the young Fife and Drum Corps started us off. It took all I had not to cry when the "kids" play the Star Spangled Banner. I agree with Bebe, Lexington will not soon forget us.

Colorado Connections Report

The first ever Colorado Connections was held on 26-July-2003 at the Canyon Cafe in Denver Colorado. We had originally hoped to get 15-20 people, we were very pleasantly surprised to have 29! It seems like everyone enjoyed it and it was decided to have another in Jan. of next year. Dr. Rollins of MDA was the guest speaker. She is doing research in motor neuron diseases and gave a talk on "HSP and PLS: comparison and treatment of spasticity". Dr. Rollins needs more participants for her studies; many indicated interest. It was a very good day for all of us. For many this was the first time they had met others with either PLS or HSP.

2nd Annual Austin TX Report

Contributed by Marlene Doolen

After dinner Steven List was guest speaker whose subject was about not taking people for granted that we love and to let them know we do appreciate them. Three groups were presented Certificates of Appreciation for their contributions:
1.The Austin Windsurf Club has a "Learn to Windsurf" Day each year with the proceeds benefiting a charity. The last three years they have sponsored the SP Foundation.

2. TICOM, Geomatics, Inc. has year-end employee contributions and company-matching funds for different charities and the Spastic Paraplegia Foundation is one of them.

3. TICOM, Inc. the company I work for has generously allowed the use of their equipment and supplies to print materials for a variety of events. The expense of printing the materials for the TeamWalk 2003 have been provided by TICOM, Inc. It was a wonderful evening of sharing and learning new things.

If you want to go to a patient connections in your area, why not set it up yourself in your area of the country? I have been surprised that with our rare disorders there are a lot of us in close range. There are a variety of possibilities such as meeting for coffee, dinner, lunch, etc. Doesn't have to be anything fancy.

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Upcoming Conferences and Events

San Francisco

“Gaining Access to Research Resources”

November 7 –9, 2003

A regional training workshop for leaders of national patient support groups focusing on rare disease issues sponsored by the Office of Rare Diseases (ORD) of the National Institutes of Health (NIH) and the U.S. Department of Health and Human Services (HHS)

Argonaut Hotel
495 Jefferson Street
San Francisco, CA

For additional information, contact Jean Campbell, Vice President of Development or Susan Olivo, Administrative Assistant, NORD, 203-744-0100 ext 211 or by email at jcampbell@rare diseases.org.

Annapolis MD Conference and Golf Tournament

November 8

Both events are detailed at . <http://sp-foundation.org/events-golf.htm>

First Annual Richard G. Milbourne Memorial Golf Classic

Renditions Golf Club. The Golf Tournament registration includes an Awards Dinner for golfers and Conference Attendees.

The Mid-Atlantic Connection Conference will be 11:00 - 4:00 Renditions Golf Club while golfers are golfing. The focus will be meeting others and sharing stories as well as a featured speaker to do a program on Spasticity Treatment. The price is \$20.

Silent Auction. We need quality auction items for the Silent Auction during the Awards Dinner! Suggestions are: collectibles, art, vacation rentals, professional services (that can be done from anywhere), travel points, jewelry, sport items (like autographed pictures or equipment) Please contact Annette at annette.lockwood@verizon.net if you have something to donate for the Silent Auction.

Atlanta Connections

November 9, 5:00 p.m.
Sheraton Atlanta Hotel
Reservations by October 31 to Kathi Geisler kathigeisler1@aol.com
There is no registration fee; attendees will pay for their own dinners.

San Mateo, CA

Annual Abilities Expo
November 14-16

Harlington, TX

November 29, 11:30 am
Olive Garden (Pinot Grigio Room)
1802 W. Lincoln St., Harlingen, Texas, 956-428-7381
Send your email reservation by November 10 to: MDoolen512@aol.com
"Cookin' for a Cure" cookbooks will be available at \$12 per book.
Hope to see you there!!

Myrtle Beach, SC

November 29, 10 a.m – 3 p.m.

I have been able to tentatively schedule a support group meeting in an accessible location. I would also arrange dinner (dutch treat) the night before, and Brunch the day of our meeting...

Please respond to Bonnie McIsaac
googlesbc@aol.com for more details

Westchester Co NY

November ? or early December

Planning meeting for a conference in May, 2004 on Treatment of Upper Motor Neuron Disorders. Please respond Kathi Geisler (kathigeisler1@aol.com) if you'd like to be involved.

Visit <http://sp-foundation.org/calendar.htm> for information on ongoing Connections.

MEDICAL UPDATES

Northwestern Blood Study

Nailah Siddique has informed the editor that the total number of patients who have sent blood to the lab is 104. There are 16 patients that appear in the patient-parent sets and 70 who are in sib pairs. NINE of these are the same people, so they should only be counted once. Then there are 27 people who don't have any relatives to go along with them.

There is a newer technique for risk gene identification that uses patient, parents and a sibling, so they are keeping track of those as well. They have samples, which may indicate possibly five familial cases. Looking for a locus means that they know from looking at the pedigree that PLS is inherited, but are still trying to find the chromosomal address of the gene that causes the disease. Once they know that, then they can say the family is "linked" with a certain place. For instance, before they had the ALSIN gene, those families were first "linked" with a place on chromosome 2. Later on, they were able to find the ALSIN gene in that location.

Nailah indicates that the PLS community should

not be discouraged about the numbers. As a point of reference, they've been collecting the same samples in sporadic ALS, and since Jan of 1996 (that's more than 7 years, and there's more ALS out there than PLS) they have 226 patient-parent sets. They've been looking for sibling pairs since mid-'98 and have 351 of those. So it just takes time. So we just have to keep plugging. She personally thinks this is phenomenal progress for a disease that seems to be as uncommon as PLS and is so difficult to diagnose accurately. We need all PLSers to participate in the study. The drawing of blood for the PLS study is no different from other blood test you have undergone. There is no cost to you. NWU will send you the collection package, and pay return shipping, too. <http://www.als-pls.org/recruitment.htm> gives you the form for applying to participate. For those without Internet access, please call Nailah @ (312) 503-2712.

Clinical Trial of QR-334 for Sialorrhea (excessive drooling)

Contributed by www.alsa.org

The Quigley Corporation is currently enrolling participants for a clinical trial of QR-334, an investigational dietary supplement, which is being studied for the treatment of sialorrhea. Sialorrhea is a condition experienced by some people with amyotrophic lateral sclerosis (ALS), where an excess of saliva accumulates in the mouth. This condition comes from an inability to adequately swallow the normal amount of saliva the body produces, and it can result in drooling.

This is a multi-center trial that will enroll approximately 100 participants within the United States. While this study includes people living with ALS, it is open to people with other diseases. For more information regarding entry or exclusion criteria for the trial as well as participating sites, please call (201) 672-0055, and potential participants will be referred to a study site coordinator in their area.

Sites in the following cities have already received approval:

Englewood, New Jersey
Colts Neck, New Jersey

New Brunswick, New Jersey
Washington, D.C.
Charlotte, North Carolina
Miami, Florida
Tampa, Florida
Houston, Texas
Phoenix, Arizona
Las Vegas, Nevada
San Francisco, California
La Jolla, California

All participants within this open-label, safety trial will receive QR-334. The compound is taken orally. There are a total of three clinic visits required. An individual's participation may take up to six weeks to complete, including any necessary follow-up visits.

Research Websites

--Insulin growth factor 1 (IGF-1) shows therapeutic potential in ALS and other neurologic conditions

<http://www.sciencemag.org/feature/data/als/>

-- 9th mutation in the ALS2 gene causes another disorder. Eight mutations in the ALS2 (ALSin) gene cause forms of either PLS, HSP or ALS. Now a 9th mutation is found to cause infantile-onset ascending spastic paraplegia with bulbar involvement.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12919135&dopt=Abstract

-- ALS2 may help in elucidating the key pathways involved in motor neuron degeneration

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12919135&dopt=Abstract

ds=12919135&dopt=Abstract

NORD PLS Research Grant

Recipient:

Kevin Talbot, MB

University of Oxford

Oxford, England

Study Description:

Dr. Talbot of Oxford University will study patients with the rare neurodegenerative disorder Primary Lateral Sclerosis (PLS) using new magnetic resonance imaging technologies

developed in Oxford. This will allow an assessment of the progress of the disease and it is hoped, will allow trials of treatments in PLS patients. PLS is a form of motor neuron disease, related to ALS (Amyotrophic Lateral Sclerosis or Lou Gehrig's Disease) but with a number of atypical features, including slower progression and absence of muscle wasting. Its cause is unknown and there is currently no treatment.

NIH Roadmap for Research

Soon after becoming the Director of the National Institutes of Health (NIH), in May 2002, Elias A. Zerhouni, M.D. convened a series of meetings to chart a "roadmap" for medical research in the 21st century <http://www.nihroadmap.nih.gov> explains how work will proceed.

On The Trail of Proteins Gone Awry

excerpted from the Robert Packard Center News Network

Two new ALS studies help shore up a favored idea on how the disease harms motor neurons. Packard researcher Jeffrey Elliott and his team aren't alone in suspecting that unusual behavior of a mutant protein called SOD1 may trigger a downward cascade that ends in the death of motor neurons -- the hallmark of ALS. But their new work, both described in the Journal of Biological Chemistry and on the way to publication, makes an unusually concrete step on the route to proving it. People with a rare, inherited form of ALS have mutant forms of the gene that codes for the SOD1 protein in cells. And mouse models, engineered to carry that same mutant gene, lose their motor neurons in ways similar to people with the disease. "We know that mutant SOD1 protein typically forms clumps or aggregates in the spinal cords of mouse models and people with familial ALS," says Elliott. "We also know that protein aggregates are common in other neurodegenerative diseases, such as Huntington's or Parkinson's disease. "But one key thing we haven't known -- and what might provide a therapeutic target for ALS at some point -- is what causes the mutant protein to clump. That's what our work aims to find out."

Dr. Elliott is with the Department of Neurology, University of Texas Southwestern Medical Center in Dallas.

The Robert Packard Center for ALS Research at Johns Hopkins University is a collaboration of scientists worldwide working aggressively and rapidly to develop new treatments and find a cure for amyotrophic lateral sclerosis (ALS).

www.alscenter.org

Metabolic Profiles and Signatures in ALS

Bogdanov M1, Rozen S2, Kristall B3, Matson WR4, Vigneau-Callahan K4, Flarakos J5, Vouros P5, Cudkowicz ME6, Brown RH7, Beal MF1, Kaddurah-Daouk R8

Amyotrophic lateral sclerosis (ALS) is a progressive, uniformly lethal neurodegenerative disease of motor neurons in the spinal cord, brain stem and motor cortex. ALS occurs both in a sporadic and familial forms. The clinical similarity between genetic and sporadic cases of ALS would indicate that although the etiology may be multifactorial, different disease-triggering factors converge on a final common pathway of motor neuron death. We have established metabolic profiles and small molecule databases from ALS patients' plasma. A comparison of these profiles with those from unaffected controls results in unique signatures for the disease. Our analysis suggests that the profiles contain both known and unknown compounds that are significantly associated with ALS or control samples. The chemical identification of these small molecules will highlight disease-related biochemical and signaling events, potential therapeutic lead molecules and diagnostic markers for the disease. A comparative analysis with other neurodegenerative disorders is underway to determine common pathways in neuronal cell death and those that are unique for ALS.

With Gene Therapy in Mice a Success, Researchers See Hope for ALS Patients

By Carey Goldberg, Boston Globe Staff, 8/8/2003 (excerpted)

Scientists yesterday said they had found the most effective treatment yet for lab mice with Lou Gehrig's disease, and researchers at Massachusetts General Hospital said they hoped to start trying the technique in humans in about a year. The treatment relies on gene therapy, which has been known to cause serious, even fatal, complications in humans. Nevertheless, the results in mice are so striking, and the disease is so terrible that human trials are justified, researchers and patient advocates said. They also noted that the virus to be used in the gene therapy has a good safety record. "There's not one effective treatment for this uniformly fatal disease -- it's just crazy," said Valerie Estess, research director of Project ALS, a nonprofit group that largely financed the research. The new therapy, published in this week's edition of the journal *Science*, slowed the degeneration in mice that had been genetically altered to have ALS, and extended their maximum life span to 265 days from 140 days. Researchers at the Salk Institute and Johns Hopkins University injected the so-called adeno-associated virus into the legs and torsos of the mice. The virus had been engineered to carry a gene for "insulin-like growth factor-1," which can fight the neuron-killing effects of ALS. The virus migrated right into the central nervous system, a notoriously difficult target. The technique "provides a novel way of delivering potent therapy directly to the heart of the disease -- the dying or at-risk motor neurons in the spinal cord," said one researcher, Dr. Jeffrey Rothstein, director of the Packard Center for ALS Research at Johns Hopkins. Drugs and another gene therapy have shown some effect in mice with ALS, Rothstein said, but they have generally been administered when the mice were babies; this latest therapy worked even when it was given to adult mice with ages parallel to the adult ages at which humans come down with ALS. Still, he cautioned, even in mice, "It's not a cure." Plans are already underway for initial safety tests of the new gene therapy in human patients at Johns Hopkins and Massachusetts General Hospital. The rough timetable is to get them going in a year

or so, said Dr. Robert Brown, director of the Day Neuromuscular Research Laboratory at MGH. "As the day approaches, we'll be looking for candidates," Brown said.

Gene therapy remains controversial, acknowledged Fred H. Gage, another author of the paper published in Science. But whether the treatment will work in humans "can only be determined by doing human experiments," he said. To run trials on humans, the researchers must get approval from the Food and Drug Administration © [Copyright](#) 2003 Globe Newspaper Company.

Robert Packard Center for ALS Research at Johns Hopkins

Published: 10/02/03

Abstract: In amyotrophic lateral sclerosis (ALS), neighborhood may be everything, if a new study in mouse models of the disease holds true for patients. ALS, or Lou Gehrig's disease, brings about a gradual death of the motor neurons that activate muscles. Paralysis follows. But according to work described today in the journal Science, the cells that neighbor motor neurons—that aren't themselves nerve cells—can play a major role in advancing or limiting the disease.

"What we've been given is a new principle for extending survival or, perhaps, overcoming ALS, based on how many healthy cells surround an ailing motor nerve cell," says Don Cleveland, Ph.D., a scientist with The Packard Center for ALS Research at Johns Hopkins and, with Larry Goldstein, Ph.D., co-leader of the research team. "All this has great implications for stem cell therapy," he adds. "We now believe delivery of normal, non-neuronal cells to spinal cords could be completely protective, even without replacement of a single motor neuron."

In a series of experiments, the team measured the effect of having different proportions of healthy cells to at-risk cells in mice, clocking their survival time. Normally, the scientists work with standard animal models of ALS. Those mice or rats carry a mutant human gene—called SOD1—that triggers a rare, inherited form of the disease in people. In these models, every cell carries a

mutant SOD1 gene. The animals typically slip into death by the time they're six to eight months of age.

But in this study, the researchers used chimeric animals—"calico" mice engineered to be a mix of normal cells, also called wild type, and cells containing the mutant SOD1 gene. They tagged the cells with molecular flags to make it clear which were which. The percent of wild-type cells in the animals' spinal cords ranged from five to 90 percent.

Having wild type cells mixed in had the effect of extending mouse survival from one to eight months, depending on the number of cells and type of SOD1 mutation. In a second group of chimeric mice, brought about by a different technique and with a different type of tracer, the animals survived disease-free until sacrificed for study at an age at least twice the age at which typical SOD1 animal models die.

Even though further study showed that as high as three-fourths of the motor neurons in the animals' spinal cords carried the mutant gene, all the motor neurons remained amazingly healthy, apparently from having healthy non-neuronal cells in the "neighborhood." This was especially true of the second batch of mice, which had no microscopic evidence of disease.

"It's really striking," says Cleveland, "to see what a small number of normal cells effectively eliminated damage to motor neurons from the ALS-causing genetic error."

The opposite effect also appeared: mice with normal motor neurons but with surrounding cells carrying an SOD1 mutation showed early signs of disease. Normal neurons, then, can apparently acquire something toxic from at-risk non-neuronal neighboring cells.

"So we're seeing a real-life metaphor here," says Cleveland. "Living in a bad environment can damage good cells. And more important, restoring a better environment to 'bad' neurons by surrounding them with healthy neighbors can significantly lessen toxic effects. In some cases, having normal cells completely stops motor neuron death."

Motor Neurons: A Primer

Contributed by Mark Weber

You may have wondered why PLS selectively attacks motor neurons? Why not other brain cells? In fact, why not other cells in the body? One theory has to do with the fact that motor (and sensory) neurons are very different from any other cells in the body. Motor and sensory neurons have tails (axons). These axons can be up to 3 feet long. Other cell types don't have long axons, if they even have axons at all.

The cell bodies of upper motor neurons reside in your brain. They are in the motor cortex portion of the brain that ranges down both sides of your head from an area at the middle of the top of your head. The axons from these cells extend down through the spinal cord. An axon of a neuron that controls an arm muscle extends to about the shoulders, where it connects to a lower motor neuron's cell body. That lower motor neuron also has an axon. That axon then extends out of the spinal cord and attaches to the arm muscle cells that it controls.

Some axons are longer than others. The upper motor neuron's axons that control the legs extend from the brain down near the bottom of the spine. They are the longest upper motor neurons. Cell bodies manufacture almost all of the various substances needed by axons to both stay alive and to function--to send signals. Cellular transport mechanisms exist to both move these substances down the axons to where they are needed, and then to move all of the breakdown products back to the cell body where they are recycled or destroyed. In addition, chemical signals travel up and down the axon. This constant movement of cargoes going both down, and then back up the axons is called "axonal transport".

Scaling the size of a neuron up to human proportions helps to show how incredible axonal transport is. According to Dr. Lawrence Goldsmith of the Howard Hughes Medical Institute at the University of California at San Diego, if a cell body were scaled up in size to that of a round room 30 - 50 feet in diameter, then the axon would be almost 200 miles long. Most

supplies for the axon, and most chemical communications are manufactured in the room and then transported down the 200 mile long pipe that is about 10 - 20 feet in diameter at the beginning, and then tapers down substantially. Axonal transport is critical to the normal functioning of a neuron according to Dr. Goldsmith. It may also be its' "Achilles heel". For instance, recent research has shown that mutations in the genes that produce the chemical motors responsible for axonal transport can cause neuro-degenerative diseases. Further, the long length and sometimes narrow diameters of the longest axons may help to cause blockages in the axons if there are problems in axonal transport. Such blockages are thought to cause a number of neuro-degenerative diseases.

Helpful Websites to Better Inform You about PLS

Contributed by Mark Weber

I've relied on a number of web sites to help me learn. Medical dictionaries:

<http://cancerweb.ncl.ac.uk/omd/>

<http://www.medterms.com/script/main/alphaidx.asp>

Find an abstract at PubMed

<http://www4.ncbi.nlm.nih.gov/PubMed/>).

If you need to learn more about a medical term, click the "links" on the far right across from the title of the abstract that you are looking at. That gives you a pull-down menu. Click "books". That gives you a list of books, including links to the relevant sections of each book that will provide information about the word you're interested in.

LIVING WITH PLS

IRS and Medical Expenses

IRS Publication 502 Medical and Dental Expenses.

<http://www.irs.gov/pub/irs-pdf/p502.pdf>

If your medical expenses are more than 7.5

percent of your gross income you can deduct that part. There is a long list of things you can deduct: insurance premiums, mileage to see the doctor, cost to convert your van or car to carry your wheel chair, eye glasses, dental. Home improvement deduction involves a home appraisal.

Example Gross income \$30,000.00. First calculate that 7.5% of \$30,000.00 is \$2,250.00. If your expenses were \$5,000.00, you could deduct \$2,750.00. These expenses are above what your insurance paid.

Of course there is always a down side too. If your insurance paid you more than your expenses, the excess might be taxable. Also, if you sell your medical equipment you might have a capital gain. Read the bulletin carefully and check with your tax accountant

ALS Advocacy Department

Visit The ALS Association's Advocacy Department webpage at:

http://www.alsa.org/serving/adv_update.cfm. in order to get up-to-date information about our advocacy program and for more information on how to get involved.. If you have any questions please contact Ted Burnes toll-free at 877-444-2572 or via e-mail at ted@alsa-national.org.

Anti-Constipation Fruit Paste

Contributed by Bobbi Woodard; recipe from a pharmacist

1 pound prunes
1 pound raisins
1 pound figs
1 cup lemon juice
1 cup brown sugar
4 ounce package Senna Tea
Steep tea 5 minutes in 3 1/2 cups of boiling water. Strain. To 2 cups of tea, add fruit and boil for 5 minutes stirring frequently. Add sugar and lemon juice. Cool. Use food processor or blender to turn mixture into a smooth paste. Put in a plastic container and place

in freezer.

Take 1 or 2 tablespoonfuls daily

New State Directories to Assist You with Accessibility

<http://www.nadc.ucla.edu/states.htm>

The National Arts and Disability Center [NADC] would like to inform you about our new State Resource Directories on ADA Compliance and Technical Assistance. Each state has its own directory that contains listings of organizations and agencies that provide technical assistance regarding the ADA and the Arts. Included in these listings are disability agencies and organizations for creating an access advisory committee for conducting outreach to the disability community. Please review your state directory at

<http://www.nadc.ucla.edu/states.htm>

The NADC is a resource, training and information center dedicated to promoting the full inclusion of artists and audiences with disabilities into the arts community. You can visit our web site at <http://nadc.ucla.edu>

For Questions regarding information contained in this message contact:

Beth Stoffmacher

Technical Assistance Coordinator

National Arts and Disability Center

Phone: (310) 825-5054

Email: bstoffmacher@mednet.ucla.edu

Websites for Augmentive Speech Devices

Assistive Technology Inc.

1-800-793-0227

www.assistivetech.com

DynaVox Systems

1-888-697-7332

www.dynavoxsys.com

Enkidu Research

1-800-297-9570

www.enkidu.net

Gus Communications Inc.

1-866-487-1006
www.gusinc.com

LC Technologies Inc.
1-800-393-4293
www.eyegaze.com

Madentec Solutions
1-877-623-3682
www.madentec.com

Mayer-Johnson Inc.
1-800-588-4548
www.mayer-johnson.com

Natural Point
1-888-865-5535
www.naturalpoint.com

Prente Romich Company
1-800-262-1984
www.prentrom.com

Words+ Inc.
1-800-869-2521
www.words-plus.com

Zygo Industries
1-800-234-6006
www.zygo-usa.com

The next time you're "down", think about this!

Contributed by Vaughn Hickman

Michael is always in a good mood and always has something positive to say.

When someone would ask him how he was doing, he would reply, "If I were any better, I would be twins!" He was a natural motivator. One day I went up to Michael and asked him, "I don't get it! You can't be a positive person all of the time. How do you do it?"

Michael replied, "Each morning I wake up and

say to myself, you have two choices today. You can choose to be in a good mood or .. you can choose to be in a bad mood. Each time something bad happens, I can choose to be a victim or...I can choose to learn from it

"Yeah, right, it's not that easy," I protested. "Yes, it is," Michael said. "Life is all about choices. When you cut away all the junk, every situation is a choice. You choose how you react to situations. You choose how people affect your mood. The bottom line: It's your choice how you live your life."

Several years later, I heard that Michael was involved in a serious accident, falling some 60 feet from a communications tower. After 18 hours of surgery and weeks of intensive care, Michael was released from the hospital with rods placed in his back. I saw Michael about six months after the accident. I did asked him what had gone through his mind as the accident took place.

"The first thing that went through my mind was the well-being of my soon to be born daughter," Michael replied. "Then, as I lay on the ground, I remembered that I had two choices: I could choose to live or ...I could choose to die. I chose to live." Michael continued, "...the paramedics were great. They kept telling me I was going to be fine. But when they wheeled me into the ER and I saw the expressions on the faces of the doctors and nurses, I got really scared. In their eyes, I read "he's a dead man". I knew I needed to take action. There was a big burly nurse shouting questions at me," said Michael. She asked if I was allergic to anything. "Yes", I replied as loudly as I could. The doctors and nurses stopped working as they waited for the rest of my reply. I took a deep breath and yelled, "Gravity." Over their laughter, I told them, "I am choosing to live. Operate on me as if I am alive, not dead." Michael lived, thanks to the skill of his doctors, but also because of his amazing attitude. Attitude, after all, is everything. After all today is the tomorrow you worried about yesterday.

I'm Glad You're In My Dash.....

I read of a man who stood to speak
At the funeral of a friend
He referred to the dates on her tombstone
From the beginning...to the end.

He noted that first came her date of birth
And spoke the following date with tears,
But he said what mattered most of all
Was the dash between those years.
(1934 - 1998)

For that dash represents all the time
That she spent alive on earth...
And now only those who loved her
Know what that little line is worth.

For it matters not, how much we own;
The cars...the house...the cash,
What matters is how we live and love
And how we spend our dash.

So think about this long and hard...
Are there things you'd like to change?
For you never know how much time is left,
That can still be rearranged.

If we could just slow down enough
To consider what's true and real,
And always try to understand
The way other people feel.

And be less quick to anger,
And show appreciation more
And love the people in our lives
Like we've never loved before.

If we treat each other with respect,
And more often wear a smile..
Remembering that this special dash
Might only last a little while.

So, when your eulogy's being read
With your life's actions to rehash...
Would you be proud of the things they say

bout how you spent your dash?

Foundation Offers Free Computers to People With Disabilities

Spurred by the notion that access to technology "has the potential to change lives significantly," the Beaumont Foundation of America will be giving out computer equipment to low-income people with disabilities over the next five years.. BFA will provide \$350 million worth of Toshiba brand equipment with Internet capability. The foundation also provides grants to schools and community organizations.

BFA will give away almost 2,000 technology packages this year to people living in the District of Columbia and these 21 states (Group A):
Alabama, Alaska, California, Colorado, Hawaii, Idaho, Illinois, Kansas, Mississippi, Montana, Nebraska, New Mexico, New York, North Dakota, Oregon, South Dakota, Texas, Virginia, Washington, West Virginia and Wyoming.

Applications from people in Group A will be accepted until March 31, 2003.

In 2004, people living in the remaining 29 states (Group B) will be eligible to apply.

Demand for grants is expected to be high. Factors the foundation will consider when evaluating applications include: low income, demonstration of a strong need for technology equipment and indication of a place to house or use the equipment. Those whose backgrounds and needs can be most readily verified might also have an advantage.

People served by MDA who are interested in applying for a grant can call the foundation at (866) 505-2667, or register online. Applications and more information about the program can be found at www.bmtfoundation.com

I Am Okay

Contributed by Rita DiClemente

Every Day I am asked "How are you?" What I really like to say is "Yes - I am OK." I have my sight...although not perfect, I can still see the glorious sunsets, the antics of a puppy, the smile

of a child. I have my hearing...even though impaired can hear the music that takes the wrinkles out of my day...I can hear others tell me~they love me!

I have my sense of smell. . .although marred with allergies I could tell if the house is on fire ~ or the baby need changing ~ oh and isn't it heavenly to smell that first cup of coffee in the morning? I still have my sense of taste . . .I can tell when something has gone bad or sour. . .even though I wonder about my own cooking sometimes. I still have my sense of touch. . .even though some people say I am really touched .The joy of touching another, loving another, petting your cat, makes you feel you are not alone. I am o.k. You see I can walk even though I may stumble. . .I can talk sometimes without stopping or slurring~I can laugh even when nothing is funny and I can cry anytime I want to. In fact I think I am I am BETTER than JUST OKAY!! How about you my friends?

Facial and Tongue Exercises

Contributed by G. Henry with thanks to his therapist

1. Push lips slightly forward with corners of upper and lower lips touching; release lips and make "w" sound. Repeat 10 times; 2 sessions per day.
2. Lift lower lip over upper lip. Hold 3 seconds; repeat 10 times 2 sessions per day.
3. Lift lower lip behind upper lip. Suck. Hold 3 seconds; repeat 10 times 2 sessions per day.
4. Press lips tightly together. Suck. Repeat 10 times 2 sessions per day.
5. Make a big smile. Hold 3 seconds; repeat 10 times 2 sessions per day.
6. Keep lips tightly together and push forward (pucker). Then pull corners of mouth back toward ears (smile). Keep mouth closed. Repeat 10 times 2 sessions per day.
7. Open mouth as wide as possible. Hold 3 seconds. Repeat 10 times 2 sessions per day.
8. Lift one cheek toward eye; then other side; alternate one time per second. Repeat 10 times 2 sessions per day.

9. Suck air into mouth and puff out both cheeks. Hold lips tightly together so air does not escape. Hold 3 seconds; repeat 10 times 2 sessions per day.

10 Place tongue tip on center of upper lip. Press. Hold 3 seconds. Repeat 10 times 2 sessions per day.

11. Place tongue tip on center of lower lip. Press. Hold 3 seconds. Repeat 10 times 2 sessions per day.

12. Place tongue tip in center of upper lip and slide tongue completely around upper and lower lips, back to center of upper lip; then reverse direction. Repeat 10 times 2 sessions per day.

13. Push tongue tip into right/left cheek. Lips may be closed or separated. Hold 3 seconds. Repeat 10 times 2 sessions per day.

14. Place tongue tip on outside of right/left side of upper and lower gum. Press. Hold 3 seconds. Repeat 10 times 2 sessions per day.

15. Push tongue forward as far as possible. Keep tip pointed. Feel the stretch in the back of the tongue. Hold 3 seconds. Repeat 10 times 2 sessions per day.

16. Place tongue tip outside right/left corner of lips. Press. Hold 3 seconds. Repeat 10 times 2 sessions per day.

17. Push tongue to the right/left corner of the mouth. Keep tongue stretched while lifting tongue tip. Hold 3 seconds. Repeat 10 times 2 sessions per day.

Swallowing Tips

Contributed by Carolyn Sartain Anderson

After my diagnosis I was fortunate to have my HMO approve a Speech Therapist. Joanne was a godsend to me for six months of intensive therapy, breathing and oral exercises, and learning to use compensatory skills for eating/drinking. She recommended to my neurologist that I undergo a Swallowing Test; it's conducted in a hospital lab and absolutely painless. They have you swallow different consistencies of Food and x-ray with each type. They are looking for any blockage and to see how the muscles are

functioning in the swallowing process. These tips have helped me; I hope they will help you also:

*cut up everything into small pieces and chew thoroughly

*alternate between moist and dryer foods

*eat slowly and sip a liquid in regular intervals

*I also tilt my head down to the left on my chest when swallowing becomes labored

* **MOST IMPORTANTLY:** Advocate for yourself. Inform family, friends, even

waiter/waitresses at restaurants that it may take longer to eat your meal.

* when I'm eating out with friends I order things that I know I can eat at a faster pace...I will order fish, or a

pasta dish; not prime rib, steak, or salad(they are time consuming and I fear choking). I eat those when I am at home in a relaxed environment

*. We are all intelligent folks and we know what we can and cannot eat, if we are having that problem, and we don't have to apologize for our use of compensatory skills.

*sucking lemon slices helps clear the pooling of saliva, as well as sucking ice chips/ice chips with lemon (fresh) juice squirted on top.

Vital Stim Therapy

VitalStim™ is a dual-channel electrotherapy system designed specifically for the treatment of dysphagia from any etiology except mechanical causes that would need surgical intervention. VitalStim™ delivers an FDA cleared clinical waveform with fixed parameters via adult or youth-sized electrodes. VitalStim™ electrodes are placed at on of several sites of the throat for muscle re-education and for the creation of functional muscle use patterns in the throat muscles necessary for pharyngeal contraction to restore swallowing. Proper electrode placement is determined from the review of a patients modified barium swallow report and therapist evaluation.

<http://www.qhpincb2b.com/Electrotherapy/vitalstim.asp>

Throat Exercises

Contributed by G. Henry with thanks to his therapist

High pitched "E": Say "E" as high as you can and hold it out. Feel the muscles in your neck tighten.

Hard swallow: Push your whole tongue flat on the roof of your mouth; smile; swallow with as much effort as you can; feel your larynx rise up with the swallow; (pretend you are swallowing a golf ball, tense muscles in the throat and then force the swallow.)

Mendelsohn Maneuver: Feel the rise of your larynx during the normal swallow. For a Mendelsohn swallow, stop the larynx at its highest point and keep it there as you silently count to 3. let your larynx fall to its resting position to finish the swallow.

Masako Swallow: Hold tip of tongue between your teeth or lips and swallow.

Modified Mendelsohn: Put your tongue behind your upper teeth; push out your chin and swallow.

Head lift 1: Lay flat, lift your head up enough to see your toes. Hold as long as you can, up to 60 seconds.

Head lift 2: Lay flat, lift your head up and down just enough to see your toes.

These exercises are good for strengthening the muscles in your throat. These muscles enable us to swallow safely.

Do each exercise 10 times at least 2 times a day.

Today

Today I will delete from my diary two days: yesterday and tomorrow

Yesterday was to learn and tomorrow will be the consequence of what I can do today.

Today I will face life with the conviction that this day will not ever return.

Today is the last opportunity I have to live intensely, as no one can assure me that I will see tomorrow's sunrise.

Today I will be brave enough not to let any opportunity pass me by, my only alternative is to succeed.

Today I will invest my most valuable resource: my time, in the most transcendental work: my life; I will spend each minute passionately to

make of today a different and unique day in my life.

Today I will defy every obstacle that appears on my way trusting I will succeed.

Today I will resist pessimism and will conquer the world with a smile, with the positive attitude of expecting always the best.

Today I will make of every ordinary task a sublime expression,

Today I will have my feet on the ground understanding reality and the stars' gaze to invent my future.

Today I will take the time to be happy and will leave my footprints and my presence in the hearts of others.

Today, I invite you to begin a new season where we can dream that everything we undertake is possible and we fulfill it, with joy and dignity.

CAREGIVING

A Friend has PLS – What Can I Do for Her?

Contributed by Ellie

I have been reading your emails and have been moved to tears. My dearest friend in all the world was diagnosed with PLS a little over 10 years ago. The progression of the disease has been slow until recently but it now seems to be speeding up. This is terrifying to me and I do not know how to deal with it in a way that will be most supportive, helpful and beneficial to her. What do friends do? We do not live close to each other and only see each other once every other month or so, when we meet halfway for a weekend together. We rely on phone calls and the computer to stay current with each other's lives. Needless to say, our time together has changed as she slowly loses physical abilities. My heart breaks as I contemplate what will happen if she can no longer drive, no longer talk on the phone, no longer type on the computer. I would change places with her if I could, yet I feel sorry for "me" too. I am losing my best friend, a woman I love dearly. I do not know what to say to her. I wonder sometimes if she will want to live if she becomes totally

incapacitated or if she has even thought about it, but I fear her answer. I wonder how scared she is and how much she feels she must be strong for her family and friends. I wonder if I should ask questions or keep quiet. Should I tell her of my fears or keep them to myself? Should I just go to "her" city to see her instead of taking our weekend jaunts together? If I do, will that make her feel even more "helpless"? Her personality is changing and I feel it could be due to depression and I do not know how to deal with this. Do I ignore it? Do I pretend it is no different?

I know that every one of you has more to worry about than how your friends deal with this, but if you should have a few minutes, I would love to hear your insights. What do you want or need from your friends? What can your friends do for you? How do you want them to relate to you?

Ed. Note: The above was in PLS Friends October 18. Many caregivers, both family and friends must have these same questions. Below I have added responses from PLSers. The concerns of a friend/caregiver and insights of PLSers expressed here seem profound for all – whether caregiver or patient.

Response from Dolores Carron

First let me say that your friend is very lucky to have you in her life. Your caring and sensitivity is admirable. As for how you should show your support, I think that honesty is the key. Please verbalize your concerns and feelings and encourage her to do the same. Don't assume that she is terrified, depressed or whatever--ask her, so you know exactly what she is thinking. Her thoughts and concerns may change from day to day or week to week, so ask periodically. Your reassurance that you'll willingly make the necessary accommodations to maintain the relationship will be comforting to her. She may be grieving the loss of her "healthy" self and the possibility of losing you, too. Ignoring the subject is not productive to your relationship. Don't pretend that things are not different, because they are, but what will remain unchanged is the quality

of your feelings for each other. You don't always have to know what to say; sometimes what we need is to have someone listen to us. You are not losing your friend, only the way you spend your time together is changing and those changes my result in a deepening of other aspects of your friendship. Don't worry about what tomorrow may bring. Take one day at a time and follow your heart.

Response from Pat Croom

Your friend is very blessed to have you in her life. If she ever needed a friend she needs you now. Some of my friends just drifted out of my life, but the ones that remained are so supportive. Talk about your feelings to your friend. Be honest with her and please remain close to her. Don't let PLS scare you away!! I would suggest that you tell her about PLS Friends!! She will need to talk with others that understand what she is feeling. She will get an abundance of love, support & information here! This group has made such a difference in my life. I felt so alone before! Take one day at a time. By the way, it's OK for your friend to see you cry! Don't hold back any feelings!

Response from GEO

Fear? This causes all kinds of problems - Fear of saying the wrong thing; Fear that you might lose your best friend; Fear of the unknown. This is something we all have to deal with. We all choose different ways to deal with this. I would say above all be honest. Find ways to help your friend get along .My wife chooses to focus on the positive. When I have a bad day she stays her distance. If you are scared tell your friend you are scared for her. You need to be honest with each other. We all have to go sometime. Be there to give your friend a hug when she needs it. Help her find ways to make it easier to cope. My wife sometimes takes out the garbage and I find her lifting heavy things, which before she would not have done. When you go to see your friend take her out to eat or shopping, rent a movie, cook her

a dinner, have a few laughs, take some pictures to look at.

FUNDING

New SPF Board Member

Contributed by Mark Weber, President, Spastic Paraplegia Foundation

I take great delight in announcing that Linda Gentner recently became the newest member of the Spastic Paraplegia Foundation's Board of Directors. Linda has been extremely active for several years, both behind and in front of the scenes, to support the PLS community and PLS research. Thanks in part to her efforts, generous PLS research grants have been awarded and the NORD PLS Physician's Guide was created and distributed to neurologists across the country. She has also assisted with several PLS Connections events. Over the past year, she has broadened her focus as a volunteer for the Spastic Paraplegia Foundation, which is dedicated exclusively to both the PLS and HSP communities. Her efforts have included serving as the PLS Communications Liaison, coordinating the development of an Awareness Quilt Panel, taking a leadership role in the Cookin for a Cure cookbook and serving as a TeamWalk Coordinator for the PLS community. Linda has a background in non-profit organizations—a background that will help the SPF grow and help us all. As everyone who knows her will tell you, her enthusiasm is contagious. I'm thrilled that she's on the Board and I look forward to working with her in this capacity.

Shop Smart Nets \$1927.62 to Date

It's so easy to Shop Smart. . . through either www.SynapsePLS.org or www.als-pls.org Just go to the site, click the box which says Shop Smart, then click the vendor you need. The most important thing to remember is that by shopping

through a PLS site, you are not paying one cent more than you would if you went directly to the vendor.

Some of you may never have tried on-line shopping. Some of you might have a concern about putting your credit card number into your computer and transmitting an order this way. These vendors have secure sites. You have greater privacy through a secure on-line site than with your cordless phone!

Some vendors, such as Amazon.com have links to many other vendors with a huge array of types of products. Even if you don't want to buy something today, browse through the possibilities . . . you'll find no clerks so busy talking to their friends about their social life that they cannot wait on you!

. . . those of you with bulbar involvement will find that no one has a problem understanding you!

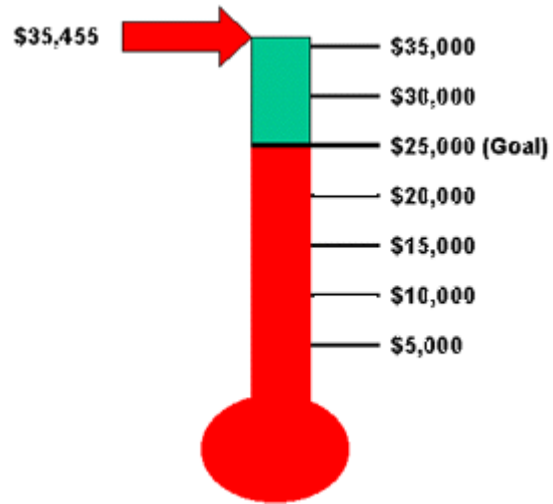
. . . you'll find reliable facts about the inventory available

. . . you'll be able to find items you are looking for

. . . you'll find it so easy to have packages delivered to your door instead of struggling to haul packages home

If more of us get in the habit of thinking Shop Smart whenever we need just about anything – books, gifts, vitamins, equipment, etc. just think of how much money we can raise . . . for us! You just have to remember to think Shop Smart first!

Symposium Grand Total \$35,455 as of September 30, 2003



Photos of TeamWalk Weekend

			
<p>Kathi Geilser opens conference</p>	<p>Keynote speaker Dr. Robert Brown of MGH</p>	<p>Conference audience finds speech very enlightening</p>	<p>Drs. Brown and Fink confer with Kathi and Mark</p>
			
<p>Mark Weber delivers SP Foundation president's address</p>	<p>Unveiled PLS quilt and some of the creators</p>	<p>Angela Dixon points out squares in the new PLS quilt</p>	<p>Carolyn Anderson, Thurza Campbell and Angela work with speech assistive devices in breakout session</p>
			
<p>Conference attendees at Concord's North Bridge Revolutionary War site</p>	<p>Junior Fife & Drum Corps of Lexington entertains Teamwalkers</p>	<p>Minute Men salute TeamWalk marchers at start of walk</p>	<p>IBOT wheelchair moving on two wheels</p>
			
<p>Kathi with TeamWalk leader Bob Swain</p>	<p>Joel Seidman, high TeamWalk fundraiser, catches up to IBOT</p>	<p>Maureen Hall arranges lunch buffet</p>	<p>Dave and Kathi announce the grand total collected - \$141,715!</p>