Synapse

Summer 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 . Thurza Campbell


PLS Symposium Attendees – Chaminade, CA - 6/5/04


PLS Symposium Conference Chairs & Facilitating PLSers – Thurza Campbell, Angela Dixon, Linda Gentner, Jennifer Thomson


Craig Gentner thanking Siddiques for Organizing & Leading the PLS Symposium


Liquid N Sample Storage Container at Northwestern University Medical School

2004 TEAMWALKS ARE UPCOMING

SP Foundation Third Annual TeamWalks For Our Cures
Complete details of all events are to be found at www.spfoundation.org/Teamwalk04/TWHome
Let's all get busy and see how much more we can raise than was raised in the last two years at TeamWalk. From $82,400.00 in '02 to $148,600.00 in '03 to $268,000.00 in '04 if we keep the same percentage increase. Are you up for the challenge? Have you increased your personal goal?

TeamWalk Weekend in Massachusetts
Four Points Sheraton Burlington. Overnight rooms are $89. Address: 30 Wheeler Road, Burlington, MA 01803. Phone: (781) 272-8800, 1-888-565-7654. Website: www.fourpoints.com/burlington
The closest airport is Boston Logan, about 20 miles east. Call Flight Line for limo service at 1-800-245-2525.

- Arrival Reception and Dinner, August 27, 5:30 p.m., Four Points Sheraton Hotel
- Research and Beyond Conference, August 28, 9:00 a.m., Four Points Sheraton Hotel
    - John K. Fink, M.D., University of Michigan and SPF Research Award recipient: "PLS - Finding the Causes and Cures" and "PLS and HSP - Similarities and Differences"
    - Douglas Marchuk, PhD., Duke University and SPF Research Award recipient: "HSP - Finding the Causes and Cures"
    - Drs. Paola Arlotta and Bradley Molyneaux, MA General Hospital and Harvard Medical School Center for Nervous System Repair: "Promises of Stem Cell Research and Regenerative Medicine"
    - Terry Wise, J.D., speaker and author: "Waking Up: Climbing Through the Darkness"
    - A Time For Us: Special break-out sessions for patients and loved ones
- Gala Dinner Banquet, August 28, 6:00 p.m., Dandelion Green Restaurant (near the hotel)
- TeamWalk Walkathon, August 29, 9:30 a.m., Lexington Visitor's Center

Use the Registration Form and mail it in or register online by August 19.

Satellite TeamWalks and Casual Connections

- **Toledo, Ohio**: Saturday, September 18; Side Cut Metropark, 11:00 a.m. – 3:00 p.m.
  Side Cut Metropark is located at 121025 River Road, Maumee (phone: 419-893-2789). Please mail your TeamWalk sponsorships in by September 10 and bring late sponsorships with you. The recommended hotel for travelers is the Holiday Inn at 2340 S. Reynolds Road (phone: 419-8651361). A Friday Arrival Dinner will also be organized for those interested in gathering together. Contact Moira: (419) 865-0517, francomkf@buckeye-express.com.
- **Tuckerman, Arkansas**: Saturday, September 18; Tuckerman City Park, 2:00 p.m. – 5:00 p.m.
  Tuckerman is a small town in northeast Arkansas, about 90 miles northwest of Memphis.

Tuckerman Park is at 200 West Main St. Please mail in your Sponsorships by September 10 and bring late sponsorships with you. The recommended hotel for travelers is Park Inn in Newport, about ten miles from Tuckerman (phone: 870-523-5851). Contact Sue: 870-349-5758, mawbell@cox-internet.com.

- **Pleasanton, California** (San Francisco Area): Saturday, October 2, 10:00 a.m. – 3:00 p.m. Meet at the Valley Community Church, 4455 Del Valle Parkway, Pleasanton for a Casual Connection gathering (phone: 925-846-6622). The TeamWalk will proceed from the church into downtown Pleasanton. The recommended hotel for travelers is the Hilton Pleasanton, located four miles from the church (phone: 925-463-8000). A discounted hotel rate of $72 is available for the "SPF TeamWalk". A Friday Arrival Dinner will also be organized. Contact Linda: 510-651-5676, LKgentner@aol.com.

PLS SYMPOSIUM

Chaminade PLS Diagnostic Criteria Conference

By Thurza Campbell

The PLS Diagnostic Criteria Conference was a success. It was held June 4-6 at Chaminade, in Santa Cruz, CA. Drs. Siddique, Armon and Fink had planted the seed of an idea for a diagnostic symposium in San Diego two years ago. The PLS community worked very hard to help raise funds for this important conference. The total we raised as of June 8, 2004 is $38,254.87. Other major donors were: Les Turner ALS Foundation, National Institute of Neurological Disorders and Stroke - NIH Office of Rare Disorders, NORD, Spastic Paraplegia Foundation and the Muscular Dystrophy Association.

48 researchers from the US, Italy, France, Saudi Arabia, Netherlands, Japan, Pakistan, United Kingdom, Canada and Switzerland came together for three days to discuss PLS and try to reach consensus on defining the disease.

Dr. Lewis Roland outlined the challenges for the Conference:

1. Define PLS at autopsy. How many inclusions make it ALS
2. Should definition in life exclude familial cases or causes?
3. Is PLS a syndrome or a disease?
4. Can we determine the natural history of PLS?
5. Are there new terms, such as Upper Motor Neuron-dominant ALS?
6. Need to define HSP, juvenile PLS and IASP.

Presentations were made in various specialties of neurology. These included:

Clinical – observation of patients

Neuropathology - the study of diseased brain and neural (nerve) tissues by microscopic and macroscopic examination.

Neurophysiology - the study of the function of brain and neural tissues and cells.

Neuro-imaging - the practice of examining brain and neural tissues by means of radiologic (x-ray) pictures (which includes CT scans), nuclear (radioisotope) brain scans (which includes PET scans), magnetic (MRI) scans, and Diffusion Tensor Imaging.

Genetics - the manner of inheritance of the genes that are associated with various forms of diseases.

There are many causes of progressive motor dysfunction. Causes may be hereditary or acquired or combined. Studies have been conducted and data collected both in the United States and abroad. Some of the observations presented include:

- PLS exists as an entity but is difficult to diagnose.
- It is relatively uncommon in relation to ALS and is not readily differentiated.
- It is a slowly progressive disorder with predominant UMN features.
- Without repeated EMGs it will not be possible to determine whether LMN involvement has evolved.
- Biomarkers for the disease include: Imaging, Electrophysiology, Biochemistry and Proteomics.

Nailah Siddique presented an outline for a **PLS Registry** which could be part of a Neurologic Disease Registry. Four elements will be incorporated;

1. Informed consent of all participants
2. Coded identification
3. Confidentiality
4. Appropriate storage – freezers for samples.

The assumption is that PLS has multiple causes. Therefore several components need to be included in a Neurologic Disease Registry:

- Blood samples from patient, family and spouses for DNA.
- Family history with ongoing family contact
- Environmental risk factor information
- Cerebro Spinal Fluid
- Urine samples
- Saliva samples
- Autopsy tissue bank
- Clinical information

All agreed that a PLS Registry is needed. This is something many in the PLS patient community have sought.

Following committee discussions of the various sub specialties, summaries were presented to the assembled group. Both clinical observation and laboratory analyses are required to diagnose PLS.

Ed. note: Publication of the Chaminade Criteria for Motor System Diseases is expected early in 2005. I have in the above article only tried to give our lay readership a general idea of the content of the Conference. A writer for Neurology Today attended the Conference. When her article is published, I will promptly reference it for the readership. Each PLS patient owes a debt of gratitude to these 48 researchers who took the time to participate in the Conference.

Attendees at the Chaminade PLS Diagnostic Criteria Conference

June 4-6, 2004

Abrams, Wendy – Les Turner ALS Foundation, IL
Appel, Stanley– Baylor College of Medicine, TX
Armon, Carmel- Baystate Medical Center, MA
Armstrong, Jennifer – NWU Medical Faculty Foundation, IL
Bertini, Enrico - Bambino Gesu' Children's Hospital, Rome
Boespflug-Tanguy, Odile – Inserm UMR 384, Cedex, France
Bowser, Robert – U. of Pittsburgh, PA
Bradley, Walter - U. of Miami, FL
Brooks, Benjamin – U. of Wisconsin-Madison Med. School, WI
Brugman, Frans – U. Medical Centre Utrecht, Netherlands
Dellefave, Lisa - NWU Feinberg School of Medicine, IL
Deng, Han-Xiang – NWU Feinberg School of Medicine, IL
Fink, John – U. of Michigan Medical Center, MI
Floeter, Mary Kay – Nat'l. Institute of Neuro. Disorders and Stroke, DC
Forshew, Dallas – U. of CA SanFrancisco, CA
Gascon, Generoso – King Faisal Specialist Hosp. and Research Center, Saudi Arabia
Gordon, Paul- Columbia-Presby. Medical Center, NY
Groeneveld, Geert – Umedical Center Utrecht, Netherlands
Haines, Jonathan – Vanderbilt U. Med. Center, TN
Harati, Yadollah – Baylor College of Medicine, TX
Hays, Arthur - College of Physicians and Surgeons of Columbia U., NY

Holden-Norris, Dee – California Pacific medical Center, CA
Ikeda, Joh-E – Tokai University, Isehara, Japan
Ikram, Amer – Lahore, Pakistan
Ince, Paul – U. of Sheffield, United Kingdom
Karsarskis, Edward – U. of Kentucky, KY
LeForestier, Nadine – Mazarin Hospital de la Salpetriere, Paris, France
Loemen-Hoerth, Cathrine – U. of CA SanFrancisco, CA
Lyles, Annette - NWU Feinberg School of Medicine, IL
Madison, Catherine – California Pacific Medical Center, CA
Mitsumoto, Hiroshi - College of Physicians and Surgeons of Columbia U., NY
Mora, Gabriel – Fondazione Salvatore Maugeri, IRCCS, Veruno, Italy
Mozaffar, Tasheen – U of CA Irvine, CA
Olney, Richard – U of CA San Francisco, CA
Pericak-Vance, Margaret – Duke U. Medical Center, NC
Roos, Raymond – U. of Chicago, IL
Rosenfeld, Jeffrey – Dr. Carolinas Neuromuscular/ALS-MDA Clinic, NC
Rowland, Lewis MD – Columbia-Presby. Medical Center, NY
Siddique, Nailah - NWU Feinberg School of Medicine, IL
Siddique, Teepu - NWU Feinberg School of Medicine, IL
Smith, Charles – U. of Kentucky Medical School, KY
Spencer, Peter – Oregon Health and Science U., OR
Strong, Michael MD – London Health Science Center, London, Ont., CA
Sufit, Robert MD - NWU Feinberg School of Medicine, IL
Swash, Michael – Royal London Hospital, London, United Kingdom
Takahashi, Hitoshi - U. of Niigata Brain Research Inst., Niigata, Japan
Tanden, Rup – UVM College of Medicine, VT
Ulug, Aziz – Joan and Sanford L Weill Med. College of Cornell U., NY
Weber, Markus – Kantonsspital St. Gallen, Switzerland

Bibliography of Background Articles: included in participant packets at Chaminade

“Amyotrophic lateral sclerosis and primary lateral sclerosis evidence-based diagnostic evaluation of the upper motor neuron.” Chan, et al. Neuroimaging Clinics of North America. Vol. 13 (2003) pp. 307-326.

“El Escorial revisited: Revised criteria for the diagnosis of amyotrophic lateral sclerosis” Benjamin Rix Brooks, et al for the World Federation of Neurology Research Group on Motor Neuron Diseases. ALS and other motor neuron disorders 2000 1, pp. 293-299.

“El Escorial World Federation of Neurology Criteria for the Diagnosis of Amyotrophic Lateral Sclerosis.” Journal of the Neurological Sciences 124 (Suppl.) (1994) pp. 96-107.

“The gene encoding alsin, a protein with three guanine-nucleotide exchange factor domains, is mutated in a form of recessive amyotrophic lateral sclerosis.” Yang, et al. Nature Genetics, Vol 29, October 2001, pp. 160-165.

“Primary Lateral Sclerosis A Clinical Diagnosis Reemerges” Younger, et al. Arch. Neurology Vol 45, Dec. 1988, pp. 1304-1307.

“Primary Lateral Sclerosis A heterogeneous disorder composed of different subtypes?” Zhai, et al. neurology Vol. 60. April, 2003.

“Primary Lateral Sclerosis. Clinical Features, Neuropathology and Diagnositic Criteria.”By Pringle, et al. Oxford University Press, 1992, pp. 495-520.

“Progressive Spastic Paraparesis: Hereditary Spastic Paraplegia and its Relation to Primary and Amyotrophic Lateral Sclerosis.” John K.

Fink. Seminars in Neurology. Vol. 21, Number 2, 2001.

MEDICAL UPDATES

Medical

Medical News of Note to Explore

New Neurons Can Get out of Spinal Cord

This article on EurekAlert gives a good layman's description of recent research on getting new motor neurons to migrate through the spinal cord to restore damaged central nervous systems.
http://www.eurekalert.org/pub_releases/2004-04/jhmi-snn042704.php

Genome News Network – research articles
http://www.GenomeNewsNetwork.org

New painless myography technique aids neuromuscular disease research

Northeastern University profs develop non-invasive test for collecting accurate muscle data

Two Northeastern University professors have recently developed an objective, but non-invasive and painless technique based on long known but previously overlooked properties of muscle tissue. The new technique, called "electrical impedance myography" (or EIM), was developed by professors Ronald Aaron and Carl Shiffman of Northeastern's Physics department, and it is now being studied at the Beth Israel Deaconess Medical Center in collaboration with Seward B. Rutkove, M.D., chief of the division of neuromuscular disease.
http://www.eurekalert.org/pub_releases/2004-05/nu-npm052704.php

The Future of Embryonic Stem Cell Research: addressing ethical conflict with responsible scientific research. by David M. Gilbert, Department of Biochemistry and Molecular Biology, SUNY Upstate Medical University, Syracuse, NY

Embryonic stem (ES) cells have almost unlimited regenerative capacity and can potentially generate any body tissue. Hence they hold great promise for the cure of degenerative human diseases. But their derivation and the potential for misuse have raised a number of ethical issues. These ethical issues threaten to paralyze pubic funding for ES cell research, leaving experimentation in the hands of the private sector and precluding the public's ability to monitor practices, research alternatives, and effectively address the very ethical issues that are cause for concern in the first place. With new technology being inevitable, and the potential for abuse high, government must stay involved if the public is to play a role in shaping the direction of research. In this essay, I will define levels of ethical conflict that can be delineated by the anticipated advances in technology. From the urgent need to derive new ES cell lines with existing technology, to the most far-reaching goal of deriving genetically identical tissues from an adult patients cells, technology-specific ethical dilemmas can be defined and addressed. This staged approach provides a solid ethical framework for moving forward with ES cell research. Moreover, by anticipating the moral conflicts to come, one can predict the types of scientific advances that could overcome these conflicts, and appropriately direct federal funding toward these goals to offset potentially less responsible research directives that will inevitably go forward via private or foreign funding.

To read the entire essay go to:
http://www.MedSciMonit.com/pub/vol_10/no_5/4448.pdf

Clinical Trials

Contributed by Dolores Carron

The following web-sites were listed in the June 17, 2004 issue of the Wall Street Journal. They also give some guidelines for evaluating studies: Studies published in peer-reviewed journals such as the New England Journal of Medicine, the American Medical Association or Lancet have editorial boards that review studies for publication. Specialty journals often contain the best studies on specific diseases and conditions, such as "Circulation" for heart conditions. Studies conducted by university teaching hospitals or funded by the National Institutes of Health are often the most reliable.

Results of studies often seem contradictory, but that may be because they used different eligibility criteria or different age, gender or ethnic groups. Results of one study have to be duplicated by other researchers at different locations before they are accepted as general medical practice.

Double-blinded randomized controlled trial studies are usually considered the most valid. That means neither the investigator nor the trial participant know who is receiving a drug and who is receiving a placebo.

In general, clinical trial results are considered statistically significant if there is a less than 5% probability that the difference observed would occur by chance alone.

Additionally, they advise that consumers consult with their doctor before relying on any one medical study or clinical trial. Some suggested sites to read about clinical trials are:

www.clinicaltrials.gov A service of the National Institutes of Health; largest register of federally and privately supported clinical research on human volunteers

www.cancer.gov National Cancer Institute's registry of cancer clinical trials

www.centerwatch.com Free listings of more than 41,000 active industry and government sponsored clinical trials; sponsored by company that recruits participants

www.trialscentral.org Trial listings Web site of the Center for Clinical Trials and Evidence Based Healthcare at Brown University Medical Center

www.medlineplus.gov National Library of Medicine consumer site with link to PubMed, its bibliographic database site with citations and abstracts from nearly 4,500 journals world wide

www.fda.gov/medwatch Offers safety information on drugs and other medical products regulated by the U.S. Food and Drug Administration

www.drugs.com Free advertiser-supported drug information site

Participant in Dr. Talbot's SP Funded PLS study

Contributed by Kiwi LindaI was in the UK and managed to make it to see Dr Talbot. I had to travel for 5 hours by car to get to Oxford but for me this was worthwhile. I hope by participating I helped with this research. Dr Talbot seemed confident that he might be able to provide a means of giving a more definite diagnosis of PLS from the special scan he is using and also to provide more information on the sites and nature of deterioration of the neurons.

I was really encouraged to learn of the research being done. It was really worth it to make the effort to get there. I hope to get more information about the results and I'll be able to keep the group informed.

Boost for Banks of Stem Cells

Contributed by Paul Bryant

From an article by Robert Pozen and Robert Langer, Boston Globe - 4/6/2004

While the Koreans recently cloned a human embryo and successfully extracted stem cells from that embryo, there will be years of scientific research and ethical debates before this Korean success translates into useful therapies.

Meanwhile, many hospitals in Massachusetts and other states have been neglecting an easily accessible source of stem cells with minimal ethical issues -- umbilical cords of newborn babies -- which have already proven their therapeutic value.

Here are the key facts about umbilical cord blood as a fertile source of stem cells:

Stem cells from umbilical cord blood have been used extensively for transplants in treating blood-related diseases such as leukemia, anemia, and Hodgkin's lymphoma.

The chances of a successful transplant are dramatically increased if these stem cells come from the patient, a sibling, or an otherwise well-matched donor.

Stem cells from umbilical cord blood are often easier to obtain than those from bone marrow because the latter require more invasive procedures and marrow matches may not be readily available.

For these reasons, some hospitals allow private companies to offer parents of newborns storage services for umbilical cord blood stem cells. The costs for such private storage range from $1,000 to $1,500 for collection and processing at birth, plus approximately $100 per year thereafter. But other medical professionals oppose private storage because the probabilities that these cells will actually be needed by the baby or someone in the baby's immediate family are so low, less than 1 in 1,000 (except for families with a strong genetic history of blood-related diseases).

These medical professionals recommend that umbilical cord blood cells be stored only in publicly financed banks, which would make these cells available to anyone who needed an available match. However, public banks reject 70 percent of proffered donations of umbilical cord blood stem cells because of limited funding or medical reasons like family history or sample contamination. Moreover, even if stem cells from a donor are accepted for storage by a public bank, there is no assurance that these still would still be available in the event that someone from the donor's family needed a close match for a transplant.

The best solution would be to allow private companies to offer storage services for a fee at all hospitals, subject to four conditions:

1. The company must provide parents with full disclosure about all the costs as well as the very low probability of usage (except in a family with specified genetic dispositions).
2. The company must store the stem cells in two separate portions -- one always kept available for the donating family, and the other offered to public banks.
3. The private company must submit identifying information on the second portion to a centralized computer system accessible by public banks for possible matches.
4. The donating parents will receive a tax deduction for the second portion, and the donors as well as nonfamily recipients must release all parties from legal liability if that portionis used by a public bank.

An objection to this solution could be that doctors doing transplants want as large a dosage as possible of matching stem cells. Hopefully, this objection will be overcome within the next decade by a new technology, now being tested, which would allow the amplification of a stored portion of stem cells if and when needed. In short, this policy would provide sound and consistent treatment of umbilical cord blood stem cells at all hospitals. The four conditions would harness the private incentives of the company storage system to the broader objectives of the public storage banks.

Robert Pozen is the John Olin Visiting Professor of Law at Harvard University.

Robert Langer is the Germeshausen Professor of Chemical and Biomedical Engineering at MIT.

Scientists Study Brain Cells Created From Bone Marrow

May 3, 2004

By MARK INGEBRETSEN

Those suffering from strokes, brain injuries as well as Parkinson's and other neurodegenerative diseases could benefit from a recent discovery that stem cells extracted from bone marrow can be transformed into brain cells. A research team from the University of Florida found that "a patient's own bone marrow might be used as a source of stem cells to regenerate lost nerve cells," according to Health Day News. The finding, which was published in the journal The Lancet, demonstrates that "bone marrow stem cells can migrate into the brain, [and] be influenced by their new environment, triggering their development into specialized brain cells-or, as the authors put it, `bone marrow can make brain,'" the Times Online said.

US Stem Cell Research Lagging

Without aid, work moving overseas

By Gareth Cook, Globe Staff | May 23, 2004

BRNO, Czech Republic -- Last spring, biologist Petr Dvorak's cellphone rang with the news that his lab, a simple cement building not far from the rolling farmland of Moravia, had just entered the forefront of global science. He rushed to work, down a cracked blacktop walkway and past a sagging barbed-wire fence. Then Dvorak, 48, peered through a microscope and saw what had triggered the call: He and his team had isolated a new line of human embryonic stem cells.

"We were so happy," said Dvorak, who is a member of the Czech Academy of Sciences. "I couldn't sleep for a week."

Although the first human embryonic stem cell line was created in the United States, a Globe survey has found that the majority of new embryonic cell lines -- colonies of potent cells with the ability to create any type of tissue in the human body -- are now being created overseas, a concrete sign that American science is losing its preeminence in a key field of 21st-century research.

Nearly three years ago, the Bush administration prohibited the use of federal money to work with any embryonic cell lines created after Aug. 9, 2001, because of moral concerns over the destruction of human embryos. At the time, the president said there would be more than 60 lines of these cells available. But today there are only 19 usable lines created before that date, and that number is never likely to rise above 23, according to the National Institutes of Health.

However, the number of cell lines available to the world's researchers, but off-limits to US government-funded researchers, is now much higher: at least 51, according to the survey. It could rise to more than 100 over the coming year. There are three new lines in Dvorak's lab, with four more in progress. And there are also new lines in Sweden, Israel, Finland, and South Korea. Last week, the world's first public bank of embryonic stem cells opened in the United Kingdom, a country where there are at least five new lines and more on the way.

"Science is like a stream of water, because it finds its way," said Susan Fisher, a professor at the University of California at San Francisco. "And now it has found its way outside the United States."

At a time when reports show the United States is losing its dominance in other areas of science, Fisher and many other researchers say they are increasingly worried that America is not building a competitive foundation in one of the most active areas of biological discovery. Many scientists believe that embryonic stem-cell research has the potential to yield profound insights into a range of afflictions, including Parkinson's disease and diabetes, which affect millions of Americans. By restricting American use of these cells, they say, the government is effectively keeping them out of the hands of many top scientists -- both slowing the pace of research that could lead to cures, and potentially putting the country behind in technologies that could be major business opportunities in the new century.

Included on the list of off-limits cell lines created since 2001 are some cells that are easier to use and would be safer for patients than the Bush-approved lines. Others are tailored for the study of particular diseases.

Each cell line is a colony of cells derived from a single embryo, which share the same DNA. One of the new cell lines has the common genetic mutation underlying cystic fibrosis. This cell line, developed overseas and not yet described in a scientific journal, could reveal the biological underpinnings of a debilitating disease that affects some 30,000 Americans. The US government will not pay for scientists to grow or study these cells because they were created recently.

For most diseases, embryonic stem cell research is likely many years from offering any help to patients. But it is becoming increasingly apparent that if researchers begin to make medical progress, the US government -- which funds the vast majority of basic science research in this country -- will be able to take little credit.

For many foreign scientists, the restrictions imposed on the world's leading biomedical power represent an opportunity. Dvorak once used old rum bottles as flasks in his underfunded lab. Now he is talking to a professor at Harvard Medical School, Dr. Ole Isacson, about collaborating on research.

"He is swimming," said Isacson, whose lab at McLean Hospital is famous for its research on Parkinson's disease. "But for us, it is like trying to swim on dry land."

When human embryonic stem cells were first isolated, the breakthrough happened in an American lab. In November 1998, a team of researchers lead by biologist James Thomson of the University of Wisconsin-Madison announced it had isolated human embryonic stem cells and could grow them in a dish. Embryonic stem cells, taken from a microscopic embryo in its first few days of development, are in a sense the most primordial and powerful human cells, and can develop into any part of the body.

The announcement created a sensation. It was clear these cells would be an important new tool for studying human biology, and they also raised the prospect that a wide range of diseases might be treated someday by replacing a patient's damaged cells. Yet the work is also ethically controversial, because growing stem cells requires destroying a human embryo. This led critics to charge the practice amounted to taking human lives and could not be justified no matter how great the potential benefits.

"A lot of stem cell biology is like gardening," said Stephen Minger, who isolated the cystic fibrosis cell line and is an American scientist who now works at King's College London. "Some people can grow orchids, and some can't grow tomatoes."

Governments around the world are stepping into the gap, and a number are emerging as powerhouses in the field. In the United Kingdom, as in the United States, there has been contentious public debate over embryonic cell research, but the government has designed a system of strict oversight. With the opening last week of the new UK Stem Cell Bank north of London, funded by the government at $4.6 million over three years, that country is taking the kind of international leadership role which in other fields has fallen to the United States. The bank will accept cell lines that meet a set of ethical standards, carefully study and grow them to ensure they are scientifically useful, and then make them available to researchers. "We see this as a truly international effort," said Glyn Stacey, the new bank's director.

In Australia, the government is funding research and helping to set up a national stem cell center. In the Czech Republic, Dvorak's lab at the Mendel University of Agriculture and Forestry is part of a Centre for Cell Therapy and Tissue Repair, supported by the government. South Korea has derived almost as many new lines of human embryonic stem cells as the United States, according to the Globe survey, and researchers there were the first to create stem cells from a cloned human embryo -- a scientific milestone that American researchers grumble should have happened in the United States.

This rush of work overseas is yielding other important advances, such as technology that could be key in turning the science of embryonic stem cells into usable therapies. All of the cell lines on the US government approved list are grown on a layer of mouse cells. These mouse cells, called a "feeder layer," sustain the human cells, but could also transmit mouse-borne viruses, making them potentially dangerous for use in humans.

Dvorak's laboratory has just begun working with human feeder cells instead, a technique that could yield cells safe to transplant back into humans. Already, laboratories in Singapore, Israel, Sweden, and Finland have isolated lines of stem cells that don't need mouse feeder cells. Only one American lab has done so: Susan Fisher's California lab, which is barred from receiving federal funding and is supported in part by the California-based biotech Geron Corp. None of these lines, including Fisher's, can be used by government-funded scientists in America. The result is that American scientists with private funding are making advances that they can share freely with scientists overseas, but which they cannot share with colleagues in their own departments.

As much as the Bush rules have limited embryonic stem cell research, they have prompted a substantial private effort to keep the research moving forward. Harvard announced last month that it is building a privately funded effort to do the work, and it has a fund-raising goal of $100 million. The University of California, San Francisco is already underway with a similar effort, started with a $5 million gift from Intel's Andy Grove, as are a number of other academic institutions. Earlier this month, the governor of New Jersey signed an agreement opening the nation's first state-funded stem cell institute.

"That is really something to keep an eye on," said John Gearhart, one of the field's founders and a professor at Johns Hopkins Medicine. Gearhart said that many of the younger scientists in his lab are interested in pursuing further training abroad.

Yet there could be changes coming. Last weekend, the NIH issued a letter hinting the White House may be open to changing its policy at some point. The letter, written by NIH director Dr. Elias A. Zerhouni, was a response to a letter signed by 206 members of the House of Representatives. In it, he acknowledges that "from a purely scientific perspective more cell lines may well speed some areas of human embryonic stem cell research."

US Representative Michael N. Castle, a Delaware Republican who helped organize the House letter, said that it seems to represent a softening of the White House stance.

In the meantime, many scientists abroad are nearly giddy with the possibilities the field now presents them. Dvorak and a colleague, Ales Hampl, are preparing to come to Boston for a major conference next month, organized by the International Society for Stem Cell Researchers. While he is in Boston, Dvorak is going to make a presentation of his work at Isacson's lab. Because of federal restrictions in the United States, Isacson said that he has been increasingly looking abroad for collaborators who are more free, and Dvorak is one possibility.

Gareth Cook can be reached at cook@globe.com

EVENTS

Spring Fling April 2-4 Berkeley Springs, WV

Produced, directed and summarized by Ronnie Grove

The Fling was Flung. I had a great turnout and judging by the comments I heard (yes, I managed to hear a few) everyone enjoyed it as much as I did. I was able to get a couple speakers. Shari, from Adult Day Care. Several caretakers told me they were impressed. She did, indeed, seem very interested and caring about our plight. She came for the day. The speaker for The Center for Independent living gave us some good information, too.

We had several donated raffle items and raised $156.00 for SPF from the raffle. Passed the hat to pay for the conference room. That netted $238.00 and when I settled up they only charged me $50.00 for the room plus tax. So I had a grand total of $341.00 to send the SP Foundation. Pretty impressive, I thought.

If only we would have had something to eat! Friday night we all went to bed hungry, I think. We had family style dinner at the church and all they gave us was meat loaf, turkey, stuffing, mashed potatoes, gravy, cranberry sauce, green beans & corn, rolls, coffee, iced tea, and cake. And seconds. Soup, salad and sandwich buffet on Saturday with cake, brownies and cookies. Dinner on Saturday was at the Park-N-Dine where we had to order our own. Their portions are so skimpy you only leave with enough for lunch the next day. I just know every one was starving by the time they left Berkeley Springs. We had 22 or 24 depending on when you counted. I can't begin to tell you what this WV Connection means to me. Ed & Carol Ames have made all four. Several have been there for three. And some have missed only because it couldn't be helped. As this fourth Fling got underway on Friday afternoon I waited in the lobby for my guests to arrive. It was just so heartwarming to see folks come, recognize someone they had met before, break into a big old grin, guys shaking hands and hugging, ladies hugging and kissing. It is just like some kind of homecoming. It makes me so proud of "my people". It is nothing short of a miracle when you stop to think that it was only a few ,very few, short years ago that none of these relationships existed.

Last year we welcomed Annette and Stan Nussey to the group. Annette is the PLSer and learned about the WV Connection from Synapse. They live in Massachusetts and do not have a computer. Annette told me she had phone calls from folks she had met last year at the Fling. One of those was Donna Isenhour. Annette was so happy about those calls and it made me feel really good to know she was being included. That's what we do in this group. I think it is so important that we take care of each other.

If you've never been to a connection, make the effort. You will be awfully glad you did. We sure did miss Bettie Jo and Don. In fact, we missed all of you who had been here before and couldn't get here this year. I think every one of you were asked about. Even the hostess at Park-N-Dine asked about Jeff and Elana, while last year's waitress recognized the group and came by to say hello. We had two HSPers and when it came to socializing it was hard to tell who was who. We mixed very well. It's a good way to get to understand each other's diseaseIt was just a great Connection and it will just keep getting better because of folks like you.

Mark your calendars now. It's only 51 weeks until the next WV Spring Fling Connection. We want you here.

SP Connection, Burlington, MA April 24

Contributed by Barbara Leary

Jim Hermance, Director of Brightside HomeCare, was the first speaker at the April SPF Connection held in Burlington. His informative presentation and handouts were about "What You Can Do To Prevent Falls". Although many of the suggestions were common sense, it is always good to be reminded about these health and safety issues. Regarding health and safety issues, he recommended doing a "brown bag" test with your medications. Show your doctor and pharmacist all the medications you are taking, and make sure that they are not causing vision, hearing or balance problems. In your home, perform a Home Assessment for safety to include lighting, flooring and furniture placement. Hazards include loose throw rugs, stairs without rails, clutter in your walking space and dark hallways or stairwells In case you do fall and are unable to get up, he strongly recommends having a Lifeline Phone and keeping a blanket and bottles of water around the house in baskets, in case help cannot get to you right away. His company will come to your home to do a free Home Safety Assessment: http://www.brightsidehomecare.org

The second speaker was Chris Dufresne whose highly motivating presentation concerned adaptive sports and other ways to increase flexibility when you have a disease such as PLS or HSP. He has PLS and was an active skiier and outdoorsman all his life, before his mobility became limited. Through a slide presentation and an active demonstration with a mono-ski by SPF President, Mark Weber, adaptive alpine skiing was shown at ski areas in New England, such as Attitash and Bretton Woods in NH, Mt. Snow in VT., and Wachusett Mountain in MA. He also included his kayaking, canoeing and whitewater rafting experiences in recent years, with photos to show just how much fun he was having!. He belongs to the North Shore Paddlers Network: http://www.nspn.org.

He concluded his presentation with more photos of his workouts at the Boston Pilates' Green Street Studios in Cambridge. There, with the assistance of his instructor, he exercises, strengthens and stretches his muscles using Pilates, Gyrotonic Expansion System and Gyrokinesis. Contact Martha Mason for more information: martha@bostonpilatescom or go online to The Pilates Method Alliance for information and instructor search: http://www.pilatesmethodalliance.org/index.html For information on the Gyrotonic system go to:http://www.gyrotonic.com

SP Connection, Tarrytown NY, May 1

Contributed by Bob Gustafson

I would categorize the event as a success. However, since I was the chairperson of the committee that put on the event, my judgment may be prejudiced. There were 37 registrants. There were many for whom this was their first conference, and for them I believe that they had a positive experience. Also, many people pitched in to help in many small ways, and a generalized "thank you" to all of them.

The program started with the roundtable discussion of the pros and cons of intrathecal baclofen therapy. The most salient points from this discussion were (1) that there is weakness following pump implantation and that a lot of rehabilitation work is necessary to build strength and functionality and (2) that getting the titration correct is a tricky process.

The roundtable was followed by Dr. Krakauer's presentation, which was sort of a college classroom presentation on neurology for people with spastic paraparesis (which was specifically what I had asked for). A lot of territory was covered from proprioceptive feedback to Sherrington's cats to issues of balance.

Lunch was served, and eaten, and followed by Dr. Smith's presentation on spasticity management, much of it being pharmaceutical. Most of what Dr. Smith said can be found on our website, but there were other interesting tidbits, for example the comparison of the concentration of baclofen in the spinal column when you use oral dosage and when you use intrathecal dosage. Other intesting items came up from questions from the participants. There was interesting dialogue between Krakauer and Smith regarding the definition of spasticity, how it is measured, and the validity of the claim that baclofen reduces spasticity.

Things lightened up with Ms. Diamond's presentation on the Alexander Technique. She explained what it was and wasn't, and she demonstrated the technique on volunteers.

Iowa Connection, May 22

I just returned from the 1st IA Connection!!! I want to thank Bethany, Kim, Jackie, Lana, Will, Geoffrey, Bruce, and Holly, and all our friends & family members who came & listened to all of us chatter away and compare notes about our disease. They are all a fantastic group of people that I now consider friends. I learned a lot, and laughed a lot!

We were far enough from the flooding and tornadoes to have no worries. For those that missed it, we plan on another gathering in the fall, probably October some time. It should be done raining, hailing, and tornadoing (is that a word?), and not snowing or sleeting yet. The weather in the midwest is really "fun". Thanks again everyone who came. I had a great time!!

Laurel

I want to thank Laurel for organizing the Iowa Connection. My husband, Tom, and I had a good time and met new friends.

It was important to me to meet someone with PLS, and that person was Laurel. Laurel is a great role model with her upbeat attitude, and calm & cheerful disposition.

I thought I was going just for my benefit, but I realized on the drive home that it was good for my husband, Tom, too. Now he too has a connection with this group, and I feel like he is listening more when I talk about some of the messages and people.

My goal is to attend a Teamwalk or other event to meet more of you. I value each and every one of you for the friendship,support, and advice.

Thanks for being out there!

Lana

SP Chicago Connection and PLS Conference Summary, June 25-26

60 PLSers, their caregivers, NWU staff and staff from the Les Turner ALS Foundation gathered June 25-26 to socialize, celebrate and hear some summary elements of the recent Chaminade PLS Diagnostic Conference. We began with an excellent Friday evening dinner where we received our weekend programs that were crafted by Angela Dixon. SP Foundation notecards were for sale, also crafted by Angela. (where would we be without her artistic talents?) We had a chance to become acquainted with many we had not met before, share stories and coping tips.

Saturday we met at NWU to hear Dr. Siddique, and others from the NWU staff discuss all they are doing for us. Dr. Siddique ended his talk presenting a slide delineating the mission following Chaminade:

- Our mandate is to consolidate what is known about PLS in categories of clinical manifestation, pathology, imaging, neurophysiology and genetic and other etiologies.
- This process will require separation of fact from speculation and definition of questions to be researched.
- We hope to come away with a consensus on a working diagnosis that would serve as a standard for research on etiology, pathophysiology and therapy of PLS.

Nailah Siddique outlined plans for a PLS Registry.(Please see all details about the registry in the Chaminade article.)

After lunch we had a tour of the research lab, sans mice, which are located in another building. The research staff was on hand to describe their various projects, and show us storage facilities and explain complex equipment. Blood draws and breathing tests were performed on all willing subjects.

LIVING WITH HSP OR PLS

Volunteer from Illinois Needed

Contributed by Mark Weber-President, Spastic Paraplegia Foundation

The Spastic Paraplegia Foundation is currently seeking a volunteer from Illinois to serve as its registered agent in Illinois. The registered agent's sole responsibility is to forward any mail to me in CT. It is expected that the resident agent will receive no mail that needs to be forwarded.

Please respond to me directly if you are interested in helping out the Foundation in this way. markw732@yahoo.com or 860-354-7071.

Resources for Caregiver Assistance

The federal government funds state Caregiver Support Programs, which help to offset some of the cost. (http://www.aoa.gov/prof/aoaprog/caregiver/careprof/state_by_state/state_contact.asp)

Support for Family Caregivers. Launched in 2001, the National Family Caregiver Support Program provides respite care and other supportive services to help hundreds of thousands of family members who are caring for their older loved ones who are ill or who have disabilities. In February 2002, HHS Secretary Tommy G. Thompson announced the release of $128 million in grants to states. See *www.aoa.gov/carenetwork/*.

The Family Caregivers Alliance, National Center on Caregiving, can help find local resources. Email: info@cargiver.org.

690 Market St., Ste 600, San Francisco, CA 94104. Phone 415-434-3388; 800-445-8106

In California Respite Care Grants are available through the California Cargivers Resource Centers. (http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=485)

Don't Break The Elastic

Maya Angelou was interviewed by Oprah on her 70+ birthday. Maya really is a marvel who has led quite an interesting and exciting life. Oprah asked her what she thought of growing older. And, there on television, she said it was "exciting." Regarding body changes, she said there were many, occurring everyday...like her breasts. They seem to be in a race to see which will reach her waist, first. The audience laughed so hard they cried. by Maya Angelou

When I was in my younger days,
I weighed a few pounds less,
I needn't hold my tummy in
to wear a belted dress.
But now that I am older,
I've set my body free;
There's the comfort of elastic
Where once my waist would be.
Inventor of those high-heeled shoes
My feet have not forgiven;
I have to wear a nine now,
But used to wear a seven.
And how about those pantyhose-
They're sized by weight, you see,
So how come when I put them on
The crotch is at my knee?
I need to wear these glasses
As the print's been getting smaller;
And it wasn't very long ago
I know that I was taller.
Though my hair has turned to grey
and my skin no longer fits,
On the inside, I'm the same old me,
It's the outside's changed a bit.
But, on a positive note...

I've learned that no matter what happens, or how bad it seems today, life does go on, and it will be better tomorrow. I've learned that you can tell a lot about a person by the way he/she handles these three things: a rainy day, lost luggage, and tangled Christmas tree lights. I've learned that regardless of your relationship with your parents, you'll miss them when they're gone from your life. I've learned that making a "living" is not the same thing as making a "life." I've learned that life sometimes gives you second chance. I've learned that you shouldn't go through life with catcher's mitt on both hands. You need to be able to throw something back. I've learned that whenever I decide something with an open heart, I usually make the right decision. I've learned that even when I have pains, I don't have to be one. I've learned that every day you should reach out and touch someone. People love a warm hug, or just a friendly pat on the back. I've learned that I still have a lot to learn. I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.

Three States to Offer More Freedom To Homebound Medicare Beneficiaries

Excerpted from: http://www.mdausa.org/news/040608homebound.html .

Missouri, Massachusetts and Colorado will begin enrolling up to 15,000 people this fall into a two-year "demonstration project" designed to test the effect of loosening restrictions on patients receiving Medicare home health care services.

"This demonstration will give those with chronically disabling conditions a chance to live full lives and contribute to their communities while still receiving services in their homes," Secretary of Health and Human Services Tommy G. Thompson said.

Under current Medicare regulations, people who qualify for home-health services must be "homebound" except for brief, infrequent absences, such as to go to the doctor or church. Attending a son's soccer game or catching a movie can be cause for termination of services.

The demonstration project removes this homebound restriction for qualified Medicare beneficiaries in the three test states, allowing them the freedom to leave home as they are able, except to do paid work.

Who Benefits? Qualified project participants are those who have a permanent, severe disability that is not expected to improve, and who meet the following criteria:

Need permanent help with three of five activities of daily living. Need permanent skilled nursing care and daily attendant visits to monitor, treat or provide help with activities of daily living; Require assistance to leave home; Are not working outside the home.

The project's goal is to determine the cost impact of loosening homebound restrictions on these individuals. After the two-year project is finished, Congress will consider lifting restrictions for qualified beneficiaries nationwide.

Some disability advocates are concerned that the demonstration will be harmed by resistance from home health agencies (HHAs) that provide in-home services. These agencies say they will lose money serving additional severely disabled beneficiaries.

An E-Mail from the Editor's Son

Dear Mom:

I have carefully read your email several times now, and have taken some notes so that I might more fully digest some of your concerns and fears. Sometimes it's just nice to know that you can express concerns and that someone will really listen and care. As we considered the mountain of stress inflicted on you with the onset and progression of PLS, we both thought, how would we handle the same set of hurdles that you face?… especially as the hurdles relate to two aspects of life - 1) social life and 2) a business relationship with a spouse. Both of these life components depend heavily on the instant communication of spoken dialogue. I know that I would not handle PLS with as much dignity or be thought of as strong. Your continued business endeavors and involvement in Synapse and SP fundraising have been incredible.

When I was fired from a sales job, it was the most gut wrenching experience of my then very limited career, in that I thought my identity was comprised of what I did for a living. In one afternoon, I remember thinking, the large corporate giant was able to strip my identity. What I took from the 'you're fired' experience is that I must continually redefine my work to mold around variables out of my control. And, that my identity was something more than what I did or how I was perceived.

I see the deterioration of your physical abilities as much like getting fired – out of your control, not fair – only worse, it is like being gradually laid off, a little more each day. Let's imagine that your body has been fired, or at least laid off to its current state. Here are some questions for you:

Have you set expectations, both physically, professionally, and socially for yourself in dealing with this disease that are beyond reach, or beyond your control? If so, how would you readjust the expectations?

Do your family members have realistic expectations for your handling of this disease? If not, how could you help adjust those expectations?

Do you have realistic expectations for caregivers and a business partner? If not, how would you change your expectations?

If you could strip out just your favorite part of your job and your daily life and do it, what would that be? Is there a way to keep doing it long-term?

How much business activity and social activity are necessary? What value do you get from either?

How can interacting using your voiced computer be done effectively in casual and business interaction?

I am not asking for answers, but hoping to offer some pathways for coping.

Love,
Bill Campbell

Law Suit Regarding Genetic Defect Allowed

The Minnesota Supreme Court recently ruled that a woman can sue her daughter's doctors for malpractice for failure to diagnose correctly, and warn about, the genetic defect that ran in her family. The woman claims had she known about the disease and risk, she would never have had more children. The daughter has Fragile X syndrome, which causes mental retardation. She was 3 when her pediatrician discovered she was developmentally delayed. He discussed the possiblity of a genetic cause but that was never pursued. The woman later had a son, with a more severe form of mental retardation. The family learned he had Fragile X syndrome and that the daughter, with her mild form of the disease, was a carrier of the genetic abnormality. The court ruled:

"We therefore hold that a physician's duty regarding genetic testing and diagnosis extends beyond the patient to biological parents who foreseeably may be harmed by a breach of that duty,"the court ruled. "In this case, the patient suffered from a serious disorder that had a high probability of being genetically transmitted and for which a reliable and accepted test was widely available"

Actual Lives: Sex, Death and Wheelchairs

Contributed by Bonnie Guzelf with excerpts from a news article about her theatrical endeavors and how she is coping with PLS

“Today is my 50th birthday. How did this happen? Because I swear to you—I *swear* to you—yesterday I was 28,” she tells her audience at a small rehearsal.

“I remember it distinctly. I was single, living in Daytona Beach, Fla. I had a great job with a good company, and I just bought my own house and a new fancy sports car. Not quite *Sex in the City*, but I was young and having fun.”

The story unfolds in a heartfelt performance. *Actual Lives: Sex, Death & Wheelchairs* is the combined story of a theatrical troupe whose members bill themselves as the Improbable Theatre Company. They are by a group of actors and actresses who just happen to have disabilities.

As to Guzelf’s experience, she says the disease of PLS changed the way she lived her life. She was forced to quit her job, and she and her husband Phil could no longer take the long vacations overseas that they enjoyed.

But the hardest change, she says, was losing the mobility she once had.

“I really resisted getting into a wheelchair,” she said.

Finding the actors’ group, said Guzelf, was a stroke of luck, helping her discover a new community of friends who knew what she was going through.

“Some of these people have been disabled for their entire lives, but they don’t let it get them down. They just go out and do it,” Guzelf said.

Acting in a wheelchair, she says, is different than her previous roles because of the limited range of movement; yet, what they lack in agility, she said, members of the troupe make up in determination and the ability to capture in facial expressions, tone and inflection. “I think this is something that everyone can relate to. I think everybody knows someone with a disability.

But on the other hand it’s about people, and it just so happens these people have disabilities,” said Guzelf about the play.

The group received a grant form the Phoenix Art Commission and the Arizona Commission on the Arts to hire Director Anthony Arunfola and Playwright Wendy Myers. By incorporating their own experiences into the play, the troupe hopes people with disabilities will become less invisible and more human in the eyes of the non-handicapped public.

Some excerpts from the play follow:

“I couldn’t even tell you what a 401K was,--- didn’t have a clue what my cholesterol level was,--- and had ***never*** *heard of HRT*. That’s Hormone Replacement Therapy…....for you ladies under 40.

“I’ve been married for almost 18 years now. My 401K has been steadily declining. Tech stocks are lower and I think I need to re-think my portfolio. My cholesterol level is 237... and I take a little purple pill to replace the Estrogen that is leaking from my body.

“We have no children, well I have no children. My husband has 2 kids from a previous marriage. That’s ok, because I’m really not a kid person...I think I was born without the Mommy Gene. We have Max. He is my 3 year old Cockapoo. Well he’s really more poo than cocker I guess.....Yes, I was definitely born *WITH* the Puppy Gene. He's the joy of my life and I love him dearly. Max is the center of the universe. Just ask him

"Who would have thought? Lucky for me for me I didn't always listen to my mother. Let me tell you, mother's don't always know best. Mom's favorite bits of advice were...."Be happy with your lot in life" and " This too shall pass".Traveling? Her advice was: "Why do you need to go to Europe now. It will still be there in 10 years Save your money. There will be plenty of time to go after you retire."

Yeah! Sorry Mom. Maybe it was a premonition or something because I was determined to travel as much as I could. I've been to more places than mom could have ever imagined … to England, Egypt, Italy, Greece, Turkey, Alaska and even on a Hot Air Balloon Ride over the Serengitti

- Oh Mom, you were so wrong... do it now...do it while you can.

Today is my 50th Birthday...what a difference a decade makes. Mom died in 1995, Dad the next year. I was suddenly the "Adult". Now we have worldwide terrorism, bombs going off in major capitals of the world, planes flying into buildings in NYC. (Pause)

I was diagnosed with Primary Lateral Sclerosis. A progressive neuro-muscular disease. No cure..... No Treatment. They say it's not life threatening. They say it's Life Style Threatening, Well that's the truth.

Today is my 50th Birthday My power wheel chair was delivered today.

My 401K is almost depleted. I drive an adapted van. ... my friends drive Miatas.

Today is my 50th Birthday.

But yesterday............... I was 28.

Zsolt's Book is Being Published!

Contributed by Lyndal Brown

Zsolt, one of our past members of PLS Friends, has been working in conjunction with Conundrum Press to publish selected examples of his wonderful Zsoltgossips (e-mails he has sent to his friends and e-mail buddies around the world since being diagnosed with a motor neuron disease). His book, Living, Loving, and Other Heresies, is currently at the printers and orders can be placed for copies at this time. A soft bound version of his book costs $15.95. A hard bound copy costs $23.95. To place an order, e-mail Cath Sherrer at Conundrum Press. conundrumr@mindspring.com.

I received the following statement from Zsolt in a recent e-mail: "as you know, the book is not about one disease, or even about disease specifically -- rather about life -- so it is a book anyone can enjoy."

Affirm Y-O-U

This is an exercise in self-affirmation and reinforcing a positive image of yourself. Writeyour name vertically down the left side of a sheet of paper. Next to each letter of your name write words from the list that describe you or that you would like to have describe you. The word does not have to apply to everything about you, but will describe certain areas of your life. For example, "capable" means that you are capable of doing certain things—not capable of doing everything nor does it have to describe your whole identity.

A: able, abundant, accurate, active, adaptable, appreciative, authentic
B: balanced, beautiful, beneficent, best, blessed, brave
C: capable, caring, character, compassionate, courageous
D: daring, debonair, decent, decisive, doer, distinctive
E: eager, earnest, effective, efficient, empathetic, energetic, expressive
F: fair, faithful, festive, fine, forgiving, forthright, free, fun,
G: gentle, genuine, giving, glad, good, grateful, grown-up, gutsy
H: handy, happy, healthy, honest, humanitarian, humble
I: illuminating, important, improved, individual, industrious
J: jovial, joyful, judicious, just, jubilant

K: kind, kindhearted, knowledgeable, keen
L: law-abiding, leader, level, liked, lively, loving
M: mannerly, mature, merry, motivated, mover, musical
N: natural, navigator, needed, noble, novel
O: obedient, open, optimal, ordered, orderly, original,
P: pacesetter, patient, peacemaker, peaceful, pleasant, practical
Q: quaint, qualified, quality, quick, quintessential
R: radiant, ready, real, reasonable, relaxed, reliable, romantic
S: self-disciplined, self-respecting, self-reliant, silly, solid, spirited, soft
T: tactful, tenacious, tender, thankful, thorough, tolerant
U: unbelievable, uplifting, useful
V: valuable, versatile, vigorous, VIP, vital
W: warm, well, wholesome, winner, wise, worthwhile
Y: young, youthful, yourself
Z: zany, zesty, zingy, zippy

*Taken from “The Physician Within” by Catherine Feste, Henry Holt & Company, Inc., New York, NY, 1995 (second edition).
Ed. note: “U” was missing, so I added that, needing it for my own name.

Corrections to Spring Synapse

1. In the article in the Spring Synapse "PLSers needed for study in England". The e-mail for Dr. Talbot is not correct. It must be: kevin.talbot@clneuro.ox.ac.uk Change the"'i" to "l" - he is sitting in the department of "clinical neurology" in the university in Oxford.

2. Correction about Extra Hands for ALS
People living with PLS can get help around the house through a national volunteer service program called Extra Hands for ALS. Through Extra Hands for ALS, high school and college students volunteer to help ALS/PLS families by doing non-medical chores and errands or just providing company for the homebound. Students also organize and participate in ALS public awareness events designed to teach their peers and communities about the disease. Created by the Jack Orchard ALS Foundation in St. Louis, MO, Extra Hands for ALS is now operating in six cities in the U.S. including St. Louis, Los Angeles, Orange County, San Francisco, Boston, and Boise. For more information, check out the Extra Hands for ALS website at www.extrahands.org, or call the headquarters in St. Louis at (314) 997-2311.

Thank you for your cooperation.
Sincerely,
Jack Orchard
Founder, Jack Orchard ALS Foundation and Extra Hands for ALS

TeamWalk REGISTRATION FORMS

Mail (with check for all payments) to: SPF, 209 Park Road, Chelmsford, MA 01824.

● Massachusetts TeamWalk Weekend Events: register by August 13

Research and Beyond Conference and Friday Arrival Reception Dinner

Aug. 27 Friday Arrival Dinner, $18. pp #_____ of people $______
Aug. 28 Saturday Conference, $30. pp #_____ of people $______
Combination Discount Price, $46. pp #_____ of people $______
$ TOTAL ENCLOSED $______
Attendee Name(s):____

____

TeamWalk For Our Cures Walkathon

Enter your name below if you plan to walk.
My Name:_____________________________ My T-shirt size: ____M ____L ____XL
____ I am registering a Team. (Call Kathi Geisler 989-256-2673 for Team details, including free tee shirts for team members if you get $250 in sponsorships.)

● Satellite TeamWalks in Ohio, Arkansas and California

I (we) are attending the TeamWalk and Casual Connection in
Ohio ___ (register by Sept. 3) Arkansas ___ (register by Sept. 3) California ___ (register by Sept. 3)
My Name:_____________________________ My T-shirt size: ____M ____L ____XL
____ I am registering a Team. (Call Kathi Geisler 989-256-2673 for Team details, including free tee shirts for team members if you get $250 in sponsorships.)

● Walker by Proxy from your home! Register by August 13

Join the team from afar as a Walker by Proxy! Collect sponsorships in your spirit and your assigned Walker will walk for you in Massachusetts. Send us your photo to post on our Board. (Call Kathi Geisler 989-256-2673 for Team details, including free tee shirts for team members if you get $250 in sponsorships

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Electric Scooter Raffle Ticket

Win a three-wheel Buzzy electric scooter, retail value $1,500
Drawing will be held October 2, 2004 at the California TeamWalk
Attendance is not required to win!
Scooter will be shipped anywhere in the continental U.S.
____ 1 ticket is $10 ____ 3 tickets are $25 ____ 6 tickets are $40

Name:____
Address:____
Phone:______________________________________
Email:____________________________________
Raffle Ticket proceeds will support the SPF General Research Fund
Make additional copies of this Ticket if needed for other Ticket purchasers