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The Eleanor & Lou Gehrig MDA/ALS Research Center at Columbia University

This issue of the Eleanor and Lou Gehrig MDA/ALS Newsletter is dedicated to the courage and strength demonstrated by: Joseph Broschart, Juana Guzman-Martel, Robert Gold, Rosemary Izzo, William Kempner, Helen Mayer, Carlos Matos, William Meehan, Guadalupe Mejia, Suzette Moore-Benn, Nicholas Meyers, Maria Martinez, Glenn Ousterhout, Constantito Presta, Edith Schroeder, Gary Spradling, Lorin Zeltner

From the desk of Hiroshi Mitsumoto, MD

Now, it is the time for the Spring Issue of our Newsletter. One highlight during this winter season was obviously our trip to Japan. A number of us went to Yokohama to attend the 17th International Motor Neuron Disease Symposium in December. I was proud that this important event was finally held in Japan because more Japanese ALS investigators have joined in the search for the cause and cure of this disease. In this issue of the newsletter, you will find our staff members' impressions of the trip and the meeting.

I was asked to give the Clinical Highlights summary at the last plenary session of the meeting, so I listened carefully to all clinical presentations. This symposium has two simultaneous sessions going on, and attendees can choose which they wish to attend: one has a clinical focus, and the other, a basic science focus. One key point in basic science research stands out: The early results of human genome-wide scan project, which was supported by MDA through Augie's Quest, were presented. Investigators found that roughly 50 genes are potentially different in patients with ALS, and a few crucial genes are now the focus of studies which show exciting developments. A similar genome-wide study has been also performed at Johns Hopkins and the NIH. These efforts may yield an exciting breakthrough in the near future. Also highlighted was the issue of cell traffic and transport, which controls all proteins and cell chemicals, and seems to meet with some difficulty in this disease. Other topics included research that shows the

cells that are affected in ALS are not just motor neuron cells, but also surrounding and supporting cells, such as glial cells, and even blood white cells.

In the clinical arena, there were many important papers presented, but I was especially struck by the way the Japanese people deal with tracheostomy and long-term mechanical ventilation (LTMV). A number of Japanese colleagues gave excellent talks on this issue. The Japanese Government long time ago passed a law covering all the expenses of care involved with intractable diseases such as ALS. Now, all Japanese communities, neurologists who provide care, voluntary disease organizations, patients and family caregivers are acting as a team to make a major transition from long-term stays at teaching hospitals to either a long-term stay at the National Hospital network or home care setting. Each community in Japan is trying to develop unique programs for improving functional independency and even job opportunities for those who are treated with LTMV. It seems patient care is clearly shifting to home or National Hospital settings with a positive attitude towards ventilatory care in ALS. Once LTMV is placed, no alternative course can be allowed in Japan at this point, although debate has begun. In contrast to Western procedures, respect for self-determination is still limited. This exchange of ideas about Western and Japanese practices helps us learn more about the best way to deal



(continued on page 3)



Wheelchair Transfer: Tips for You and Your Caregiver

by Jamie L. Miles

(Source: Pierson EM, Fairchild SL. Principles and Techniques of Patient Care. 3rd ed: W. B. Saunders Co.; 2002: pp.127-166.)

Transferring to and from a wheelchair can be a challenging for a person with ALS. As the body changes, altering the transfer method may be necessary. If your current method is no longer working, ask your physical therapist for transfer training. Below are some tips to help with the process. Remember, safety takes precedence. If you are unsure of your ability to carry out any of these recommendations, please do not attempt them.

For all transfers:

- Your wheelchair should be positioned at a 45° angle to and midway between the head and foot of the transfer surface.
- For manual wheelchairs, lock the brakes and have the caster wheels positioned facing forward. If the caster wheels are facing backwards, the wheelchair loses stability.
- For power wheelchairs, turn the power off once the wheelchair is in the proper position for the transfer.
- Remove or swing away the footrests and the armrest closest to the transfer surface.
- Position your buttocks forward in the wheelchair and place your feet on the ground.
- Your caregiver should avoid pulling on any weakened extremities, because the muscles do not adequately support the joint.
- Do not grab clothing to assist in the transfer, as this may compromise your safety and comfort.
- Do not hug your caregiver's neck while transferring, as this will place undue strain on his neck.
- Once a transfer is complete, your caregiver should not leave you unsupported until you are stable on the transfer surface.
- To return to the wheelchair, the procedures described are reversed. Make sure the wheelchair is positioned and locked, and that you move forward on the transfer surface.

Stand-Pivot Transfer:

Position your wheelchair and body as described above. Your caregiver should partially squat and place his legs around your legs. If possible, hug your caregiver's middle or upper back, while he hugs you securely or positions his hands beneath your buttocks. Count to three while rocking back and forth to gain momentum. On "three," stand up with his assistance, and allow him to stabilize your knees by pushing in and forward. Before you pivot, you should be in a position high enough to clear your wheelchair and the transfer surface.

Sliding Board Transfer:



Two-person transfer

Position your wheelchair and body as described above. Shift your weight to one side, placing the sliding board under your thigh, in front of the drive wheel, so that it extends from the wheelchair seat to the transfer surface.

Your caregiver should partially squat and position his legs around your legs, and position one hand beneath your buttock and the other on your upper trunk. Place the hand closest to the transfer surface on the sliding board, 4-6 inches away from the thigh, with the fingers flat. Do not wrap your fingers around the edge of the sliding board, as you risk crushing them when your weight is shifted onto the board. Place the other hand next to the other thigh. With your caregiver's assistance, perform a push-up and quickly move your hips towards the transfer surface. Repeat the push-up as you move along the board until you are on the transfer surface. Then shift your weight to one side, and remove the sliding board from under your thigh.

Two-Person Lift Transfer:

Position your wheelchair as described above. The taller and stronger caregiver should stand behind the wheelchair, putting his arms underneath your armpits and grasping your opposite forearms. The other caregiver should remove your feet from the footrests and swing the footrests away, then place his arms underneath your thighs, grabbing hold of his forearms. On the count of three, both should lift you simultaneously. They should place you gently onto the transfer surface. An alternative method is to have caregivers standing on either side of you. Both caregivers should squat and place one arm under your thighs and one under your shoulder and around your back. They should then grasp each others forearms for stability. Both caregivers should count to three, and on "three," lift you simultaneously. They should place you gently onto the transfer surface.



ALS Advocacy in Action

Jaydeep M. Bhatt, M.D.

As neurologists at the Eleanor and Lou Gehrig MDA/ALS Center we are intimately aware of the challenges our patients with motor neuron disease face when searching through current research for a cure. There are ongoing clinical trials at different centers across the nation and promising drugs in the pipeline. Since this information can be overwhelming, many patient advocates recognize the immediate need to consolidate existing databases of ALS patients. Centralizing data would streamline research efforts and make it easier for patients and scientists with mutual needs to find each other. It is vitally important that our elected officials in Congress understand this need and enact legislation to achieve it.

I recently attended a forum organized by the American Academy of Neurology (AAN) to gather neurologists who advocate for their patients on a variety of issues, and who work to create public policies that make a difference. My issue was raising the profile of ALS in Congress, and specifically, to encourage Congress to pass the ALS Registry Act, which is currently an outstanding bill in both the House of Representatives and the Senate. This bill would allow the Centers for Disease Control (CDC) to fund a national system to collect environmental and genetic information that would help us understand the causes of ALS and serve a variety of research needs. I met several neurologists in the AAN who agree that ALS research is a crucial issue that must be addressed. Thanks to the tireless advocacy of patients, their families, and concerned caregivers acting through organizations such as ALS Association and the MDA, several congressmen and senators have sponsored the bill.

However, our work continues. Unfortunately, the ALS Registry Act was not included in the administration's 2007 budget. This means its advocates across the country will need to work with their elected officials to make the ALS Registry a priority on the congressional agenda. If past efforts of ALS advocates are any measure, this challenge will be met and handled tirelessly and successfully.

For those interested in learning more, please e-mail me at alscenter@columbia.edu Attn: Dr. Jaydeep Bhatt.

From the Director's Desk (from page 1)

with this difficult issue of long-term mechanical ventilation.

In addition to this Symposium, I went to Fukuoka to give a talk at Sangyo College of Medicine, and also attended another meeting in Awaji Island to develop a consensus about ways to improve electrodiagnostic (EMG) criteria for an early and accurate diagnosis of ALS. Awaji Island is located in a beautiful inner sea, accessible by the world's longest suspension bridge that goes between Kobe and the Island, where 12 years ago, an earthquake took place. There were only eight international members at the meeting, which lasted from 7:30 am till 10:00 pm for two days, leaving us no time to enjoy outside. It was rather a hectic meeting. If you allow me to say something personal, I also attended a reunion of my medical school class, 38 years after graduation, and met old friends. It was a great joy to see many friends, some working in different field and some already enjoying the meaning of their lives. So I must say this trip was very productive indeed.

In the next Newsletter, we will discuss the research activities at our Center. For the last few months, I have been working feverishly on an NIH grant submission. We are all working very hard to provide care for our patients and advance our research.

Save the Date:

Monday, June 4th 2007

The Eleanor & Lou Genrig MDA/ALS
Reasearch Center and Standard Tile
Host the Third Annual

Golf for Life Outing
in memory of Carol Spina

Join us for lunch, golf, dinner
and a silent auction, at

Rockaway River Country Club
Denville, NJ

For more information
contact Bill Spina: 1-800-648-TILE



Perspectives on Japan: Sushi Shock

by Sheena Chew, Research Assistant



Some very expensive shrimp!

At the International Symposium on ALS/MND we learned about research on topics from epidemiology to new technologies for communication, and it was fantastic to hear

perspectives from prominent scientists and clinicians from around the world. But outside of the symposium we learned a great lesson too...

The last day we were in Tokyo, the three most adventurous eaters in our group and I decided we could not leave Japan without having tried sushi. The entire trip we had not ingested any raw fish. It was time to step over to the dark side. The four of us traveled to Roppongi Hills – the Tokyo equivalent of Fifth Avenue on steroids – and found an adorable little sushi restaurant tucked away on a second floor behind some buildings. It was late, around 9 pm; we were terribly hungry so we stepped inside even though there was no menu or pricing outside the restaurant. We were delighted to be the only patrons in the restaurant and sat down at the bar as our sushi chef prepared, one by one, the freshest sushi I have ever tasted. As he placed the pieces of raw fish wrapped on rice on our plates, he would murmur what they were. “Tuna... shrimp... mackerel... sea urchin... eel...” We would gather our courage, sip our green tea, and then take a bite. Delicious! Who would have thought that sea urchin would be so delectable?

As our meal came to a close we sat happily, chatting about our trip and about our excitement to return home. The restaurant owner brought us our bill, a small piece of paper with a single number written on it in marker. We looked at our bill and it took a second to register... 85,000 Yen. Two hundred dollars a person! That is a round trip ticket from JFK to Orlando! Our immediate reaction was to laugh hysterically and pay the bill. What else could we have done? Wash dishes for weeks or sprint out of the store? Though I’m sure those thoughts went through our minds we pulled out our wallets, paid, and laughed our entire way home. Lesson learned: make sure you check prices before entering a sushi restaurant in Japan, or you might be in for a shock. In the end, though- it was worth it, if not for the delicious food and cultural experience, but for this story we can share with you now.

Perspectives on Japan:

Home Care Increases the Need for Multi-disciplinary Clinics

by Gabriela Harrington, Clinical Nurse

Trends for managing loved ones with ALS is similar around the world as I learned from many of the presentations I heard in Japan and from some nurses I spoke with from different countries. For example, in Australia and England the government expects the family to care for the patient in their home until death. As we know, here in the United States family caregivers are not well prepared for the realities of managing the emotional and physical demands of a loved one with ALS. This trend toward homecare seems to hold worldwide, increasing the need for multidisciplinary clinics that can address the needs of both ALS patients and their families. Data from Japan set forth at the conference suggests that multidisciplinary teamwork beginning at the time of diagnosis may be most effective in helping patients and their family members understand the disease and secure help with symptom management.

Current Clinical Trials



Actively enrolling:

- Modafinil for Fatigue in ALS
- Genetic and Epidemiology Study
- Clinical Trial of High Dose CoQ10 in ALS-stage II
- Early Treatment of ALS with Nutrition
- Skin Biopsies for Generation of ALS-Specific Human Embryonic Stem Cells
- Longitudinal Study in Cognitive Impairment
- BiPap or Non-Invasive Ventilation in ALS

Enrolling Spring 2007:

- Combination Drug Selection - pool II

Please call Jackie Montes at 212-305-3632 for more information.



Perspective on Japan: ALS CARE

By Petra Kaufmann, MD

I was impressed with the excellent organization of the meeting and with Japanese hospitality. There were very good sessions on respiratory and nutritional care for ALS patients. These areas are increasingly recognized in their importance and carefully studied. While there was no major breakthrough in clinical trials, there was much encouraging news with regards to improved clinical trial methodology and new projects. Learning about the way Japanese ALS patients and their families live with this difficult disease gave reason to reflect on the way things are here in the United States. Japanese doctors told us about the way society cares for the disabled and provides comprehensive care programs in Japan.

Perspective on Japan: Rehab Research

By Jackie Montes, Physical Therapist

This year's symposium, the third that I have attended, gave evidence through many presentations, discussions and meetings that this diverse group of clinicians and scientists is working hard to fight motor neuron disease. In the future, I hope to see more work on the role of the rehabilitation specialist. Since ALS results in muscle weakness, maintaining functional mobility is often a major challenge for patients. Falls, the timing of assistive devices, and the introduction of wheelchairs are issues we face daily, but there has been little research or evidence collected to support and guide our practice. There are very few physical and occupational therapists who specialize in motor neuron disease, so we must rely on the community-based therapists to provide rehabilitation. Evidence based guidelines on management of mobility and function would help optimize patient care. So besides learning what's on the cutting edge, attending this meeting also provides an opportunity to see what needs to be done.

Ride For Life:

Join us from April 28 to May 6, 2007 for the 10th Annual Ride for Life. ALS patients will ride their electric wheelchairs more than 150 miles, from the historic lighthouse in Montauk, on the tip of Long Island, to the streets of Manhattan to raise funds for a cure and to create ALS awareness. Watch our website www.rideforlife.com for details on how you can participate or help us during the ride.



View of the Imperial Palace in Tokyo, Japan (Photo by K.Bednarz)

Perspective on Japan: Forming a Network

By Kate Bednarz, Dietitian

My experience in Japan was incredible in many ways but, I'm most grateful for the opportunity to meet other dietitians that work with motor neuron patients from all over the world. At the Allied Professionals' Forum, which took place the day before the actual conference began, I listened to Amy Ellis, a dietitian from The Carolinas Medical Center, speak about Alternative Medicine in ALS. She provided website links to help us access useful information about the safety of nutritional supplements often used by our patients.

Two days later, at the poster session, where researchers present brief summaries of their work, I spoke at length about the risks and benefits of PEG placement with a dietitian from Australia, Vanessa Brenninger. She explained that she follows the same practice of tube feed placement that we use at Columbia. We exchanged business cards so that we could bounce ideas back and forth, and confer in difficult nutritional situations caused by Motor Neuron Disease.

When I returned home, I emailed Vanessa and Amy, and we started an email list called "Dietitians in ALS." I added a few email contacts, other nutritionists that I have been in touch with during the years I've worked at Columbia. Amy returned my email with additional email addresses from ALS centers such as San Antonio, Wake Forest, Cleveland Clinic, Duke, Emory, and Forbes Norris Clinic. So now we have a list serve of twelve nutritionists working with ALS, the first of its kind!



Perspective on Japan:

One Thousand Paper Cranes

by Carolyn Doorish Clinical Coordinator:

Even though the symposium was held in Japan this year, almost all of the presentations were in English. To accommodate those who spoke only Japanese, instant translation via headset was available, at least during the major presentations. Although it was their country, the conference was held in English, not Japanese. This type of hospitality was evident throughout my stay in Japan. So was the presence of origami cranes. The paper birds were everywhere... small, large, all colors and patterns. I don't know who made them, but it was impressive to see the vast display of these intricately folded creatures, some arranged into long chains. We were continually encouraged to take them home with us. I was puzzled by this until I learned the story of a thousand cranes.

Sadako Sasaki was a Japanese girl who lived in Hiroshima, and was two years old when the atomic bomb was dropped on her city in 1945. Her home was about a mile away from the point of impact and in 1954, she became ill and was diagnosed with leukemia. Her best friend told her about an old Japanese legend that promises a wish to anyone who folds a thousand paper cranes. Sadako began making origami cranes, but not only for herself, but for all who were suffering throughout the world. Sadako folded 1300 cranes and wished for healing and peace before dying at the age of 12.

Paper cranes now have become a symbol of hope in Japan, representing the fight to overcome illness, and in this case, ALS.

Perspective on Japan:

by Paul H. Gordon, MD

Symposium Highlights, Yokohama

Advances in research usually seem to move slowly, and patients often express frustration at how long it takes for new discoveries.

It was exciting this year to see how quickly research can advance. Several projects are underway to obtain DNA samples from patients and controls. One funded by the National Institutes of Health, MDA and ALSA began collecting DNA in January 2006 and has now collected over 3400 samples. This project is being conducted at 72 Centers across the U.S. and will provide valuable resources for investigators conducting research into genetic risks for ALS.

We also learned at the meeting in Yokohama that the Translational Genomics Research Institute (TGEN), had, with the support of the MDA, Augie's Quest and the Western ALS Study Group, obtained DNA from 3200 people, conducted the first genome wide screen in ALS, and identified 50 previously unknown genetic abnormalities in people with sporadic ALS. The study, from start to finish, took just 9 months!

This breakthrough will allow researchers to study novel mechanisms of disease pathogenesis and develop assays to screen potential therapeutic agents using the newly identified genes. Revolutionary does not seem too strong a word to describe the importance of identifying 50 new genetic risks for ALS in this amount of time.



Paper cranes



Research Update:

Modafinil as a treatment for fatigue

Fatigue is common in ALS and is often reported to be one of the most disabling secondary symptoms of the diagnosis. The New York State Psychiatric Institute and the Eleanor and Lou Gehrig MDA/ALS Research Center are now recruiting for a clinical trial of Modafinil (Provigil) for the treatment of fatigue in ALS. Modafinil is an FDA approved medication to improve wakefulness in patients with excessive daytime sleepiness associated with narcolepsy. It is now being studied for its effects on fatigue in other conditions including ALS.

At study completion, the investigators hope to have a better understanding of tolerability and side effects of Modafinil as well as get a preliminary sense of efficacy.

Our research, and future patients with ALS, will benefit from your participation.

For more information on the trial, please contact:

Judith Rabkin, Ph.D: jgr1@columbia.edu or 212-543-5762

Martin McElhiney, Ph.D: mcelhin@pi.cpmc.columbia.edu or 212-543-5331



The Eleanor and Lou Gehrig MDA/ALS Research Center

Research update:

Background information regarding CoQ10 and the upcoming trial.

Research suggests that mitochondria, the powerhouses of the cell, are affected in Lou Gehrig's disease. Other data suggest that free radicals, very reactive oxygen species, contribute to the nerve cell damage. Coenzyme Q10 (CoQ10), a natural nutrient, helps mitochondrial function and scavenges free radicals. It has prolonged survival in a mouse model of Lou Gehrig's disease. Furthermore, it has helped patients with Parkinson's disease, another disease caused by nerve cell loss. We therefore believe that CoQ10 is a promising treatment for Lou Gehrig's disease. In two small studies we have given CoQ10 to patients with Lou Gehrig's disease and found that it was well absorbed by the body and also safe and well tolerated.

The clinical trial is a double-blind, randomized, placebo-controlled, multicenter phase II clinical trial. This means that there will be two groups to which subjects will be randomly assigned. Neither the treating physician nor the patient will know which treatment group they have been assigned to since both doses look and taste the same. We will be testing the safety and efficacy of a high dose of CoQ10 against a placebo (inactive substance). The trial is 9 months in duration with a total of 7 office visits. The first visit is a screening visit and then roughly 2 weeks later there is a baseline visit and then subsequent visits at months 1, 3, 5, 7, 9 and a phone call at month 10. Each visit takes about 2 hours. Muscle testing is not required for this trial but we will measure breathing.

BiPap or Non-invasive Ventilation in ALS

In this clinical trial, which is designed to determine oxygen saturation during sleep, we are currently enrolling patients with ALS who use non-invasive ventilation (BiPAP). Participation in the trial is free and involves delivery of sleep study equipment to the patient's home, also at no cost. The equipment is non-invasive and comfortable. If you or someone you know has been using BiPap for at least 4 hours a night for a month, and would like further information about how to participate in the study, please call Jackie Montes at 212-305-3632, or email her at www.columbiaals.org.

Research Techniques:

Interviewing Using the Morse Code

by Daniel Bell, Research Assistant

The Genetic and Environmental Epidemiology Study is one of the current investigations taking place at The Eleanor & Lou Gehrig Research Center. As a research assistant, it is my responsibility to conduct interviews. In most instances, these last between one and two hours, and can be done over the phone. However, if the person being interviewed has difficulty speaking, we try to meet with them in person, so we can use devices such as a dry erase board or ask for a caregiver's help to better understand the patient responses.

In December, a co-worker and I went to a patient's apartment to conduct such an interview. This particular patient had lost all ability to speak and the use his hands and arms, but still wished to participate in the study. This was my first experience interviewing someone who could not communicate verbally or write. I wasn't sure how we were going to do it.

At the start of the interview, the patient's spouse mentioned that their son would sit in during our questions because the patient was going to use the Morse code to provide his answers. The patient had served in the military and had learned Morse code there. The patient's son, who is 20 years old, realized his father was losing his ability to speak, and spent a weekend learning the Morse code

Look for our Newsletter on the website:
<http://www.columbiaals.org>
To save research dollars, future issues will be not be sent by regular mail unless specifically requested by calling 212-305-4746.

himself. Acquiring this skill allowed his dad to "talk" to him, and allowed him to become his father's interpreter.

As the questions began, the patient used a right foot tap for long and a left foot tap for short, using tapping to form letters that spelled out his answers. If an answer only required yes or no responses, the patient used one foot as yes and one foot as no. Whenever possible, my co-worker and I would ask the son and spouse questions that they might be able to answer so the patient would not have to over-exert himself during the three hours we spent with him.

It took an extraordinary amount of effort for this patient to participate in the study. He used a machine to help him breathe (BiPAP) and needed breaks to regain his strength, but his courage and determination never faltered. This is just one example of the type of commitment that we frequently see from the patients that come into our Center. Despite many trips to the hospital, this patient and his wife made an extraordinary effort to make time for our research, in the hope that the results will benefit others. Their generosity is also one example of what inspires us.



The Eleanor & Lou Gehrig MDA/ALS Research Center
Division of Neuromuscular Diseases
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Winter / Spring 2007

In this issue:

- * From the Director's Desk
- * ALS Advocacy in Action
- * Perspectives on MND Symposium
- * Wheelchair Transfer
- * Interviewing Using the Morse Code



MDA/ALS Educational Support Groups:

New York City

All Souls Unitarian Church
 1157 Lexington Avenue
 (between 79th & 80th)
 New York City
 First Floor
 Please join us
 Fourth Monday of each month
 6-8 p.m
 For more information contact
 Jacqueline Puerta: 212-689-9040

Northern New Jersey

Jewish Community Center
 on the Palisades
 411 E. Clifton Avenue
 Tenafly, NJ 07670
 Please join us
 Third Thursday of each month
 4-6 PM
 For more information contact:
 Maywood Center: 201-843-4452

Westchester

Burke Rehab Center
 (Clock Tower Bldg, Rm 202)
 785 Mamaroneck Ave
 White Plains, NY
 Please join us
 Second Thursday of each month.
 6-8pm
 For more information contact
 Gloria English: 914-345-5062

Long Island

St. Charles Hospital
 200 Belle Terre Road
 Port Jefferson, NY 11777
 Please join us
 First Friday of each month
 4:30- 6:30 PM
 For more information contact
 Deidre: 631-582-7761

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