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New York
Presbyterian**

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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: Jose Ballester, Mary Ellen Blake, John Charpentier, Sarla Chugh, Robert Daley, Peter Demmerle, Anthony Franco, Rona Feuer, Brenda Jefferson, Jules Jacoby, Diana Kartsen, Jack Lamel, Kevi Mallios, Lynn Miller, Gregory McDonald, Roberta Nielsen, Clifford Rimpo, Richard Snape, Dennis Selinger, Carmine Tortorello, and Antonio Zacarias.

From the desk of Hiroshi Mitsumoto, MD

We certainly have a lot to report in this summer's newsletter! The clinical trial of high dose CoQ10 in ALS (called the QALS study), directed by my colleague, Dr. Petra Kaufmann, began stage 2 only 4 months ago. Already 80 patients have been enrolled, recruited from ALS Centers throughout the United States. It took only several weeks, which was way ahead of the enrollment goal. Next spring, after 9 months, we will get the final results. This study has a unique design consisting of two stages: the first stage determined which dose of CoQ10 is better than the other. The second stage studies the effects of the dose chosen after completion of stage 1. The higher dose was chosen based on a side effect profile. The final statistical analyses will be made in patients combined from the first and second stages of the study for a total of 185 patients. Throughout the United States, 18 centers are participating in this QALS study with the entire operation being conducted at Columbia University. The statistical Principal Investigator, Dr. Seamus Thompson, the data manager, Richard Buchsbaum, and the statistical coordinator, Anita Tierney, come from the Mailman School of Public Health. The clinical study coordinator, Alexandra I. Barsdorf, is from our ALS Center. I received praise from my colleagues at other centers for how well and professionally the QALS study has been conducted. Obviously, our Columbia site has enrolled the largest number of patients and we certainly appreciate your participation. We will have the results next spring.

In other news, the minocycline clinical trial, operated by the Western ALS Study Group and headed by Dr. Paul Gordon, the Associate Director of our ALS

Center, was completed. We regret that the patients who were on minocycline declined more when measured by the ALS functional rating scale than those who were on an inactive drug. Obviously, this is a blow, but certainly it will not stop us from continuing to try other potential medications. As everyone knows, well designed and placebo controlled clinical trials are the only way to find an effective medication for ALS. This will only strengthen our efforts to identify a second and more effective medication than riluzole.

Another study is already two thirds complete: a genetic-environmental epidemiology study funded by the Muscular Dystrophy Association. I very much appreciate the help of everyone who participated in this study. It involves either a face-to-face or telephone interview and a blood draw for DNA analyses in the future. We guarantee the confidentiality of all participating individuals. The study interviewer asks questions about family medical history, residential history, occupational history, as well as any military experience or physical activities. We also ask the same questions of their family members as the controls, which include siblings or spouses of siblings. This is a unique study to identify genetic and environmental/lifestyle factors possibly associated with ALS. We have just been notified that the Muscular Dystrophy Association will fund the next study investigating the relationship between oxidative stressors and ALS. The grant will enable us to initiate the first step of an



(continued on page 2)



The Eleanor and Lou Gehrig MDA/ALS Research Center



From the Director's Desk (from page 2)

ambitious and detailed epidemiological study involving the New York Metropolitan area. A larger grant would be necessary to conduct such a study. The overall goal of this study is to determine if genetic, environmental, lifestyle, or psychological factors are in any way associated with oxidative stress in ALS. In this study, we will compare the patients with three different controls: the spouse (sharing current environment), the siblings (sharing early life environment), and community controls (sharing environment in the same location).

There is another topic that many people may be interested in: the usefulness of exercise in ALS. When I was at the Cleveland Clinic (it feels like ages ago), I started a project investigating the effects of strengthening (resistance) exercises in patients with ALS with my former research physical therapist, Vanina Del Bello-Haas, PhD. After I moved to Columbia we asked other investigators at Washington University to join us. The results were just reported in the June 5th issue of *Neurology*. The study indicates that strengthening or resistance exercise improves ALS function based on the ALS functional rating scale and quality of life scale, and in fact, leg muscle weakness declined less in the exercise group. Although such a study must be confirmed by another study involving a larger number of patients, we believe that the right amount of strengthening exercises, if they are done carefully and properly, maybe be beneficial to those who have early ALS. Now, we are almost ready to embark on a very different type of bicycle exercise study. We are interested in investigating the physiological and biochemical effects of ramp incremental cycle aerobic exercise in patients with ALS. This exercise is in fact identical to a routine cardiac exercise stress test. We hope to begin enrolling in a pilot study this summer.

We have a number of current on-going projects. In this newsletter, Jackie Montes writes about skin biopsy protocol for developing stem cells using a nuclear transfer technique through a Harvard and Columbia collaboration. A project studying cognitive function in patients with ALS, directed by Dr. Gordon, is now half way done. An NIH-funded nutritional study to investigate how much energy patients actually consume and expend has completed enrollment. The study will be completed in the next several months. This is a multi-center study to identify

the natural history of the nutritional status in patients with ALS.

In other important news, our ALS Center and Motor Neuron Centers are closely collaborating to develop a new project to determine the cause of ALS.

I regret to report that Dr. Paul Gordon, who has done outstanding work as the Associate Director of our Center, is leaving us at the end of August to study cognitive impairment in patients with ALS at a world renowned hospital, the Hôpital de la Salpêtrière in Paris. We will miss him. To take over his work, we of course have Dr. Petra Kaufmann and will have Dr. Jinsy Andrews, who was our ALS fellow between 2005 and 2006 and completed a year as an EMG fellow. Dr. Andrews will join us as an instructor. She was the recipient of a highly prestigious award from the MDA, the MDA David A. Garner ALS Research Fellowship. This award will enable her to study the methods of clinical trials in ALS and neuromuscular diseases at the Mailman School of Public Health, Columbia University and she will work with me in studying oxidative stress in ALS. Our new ALS fellow this year is Dr. Amy Chen. She received an MD and PhD from the College of Physicians and Surgeons, Columbia University. While completing her PhD, she studied with Dr. Eric Kandel, a Nobel laureate. She completed her neurology residency at Albert Einstein College of Medicine. We also have a research fellow Dr. Woo Kyung Kim from Hallym Medical School in Seoul, Korea. We continue to put maximum effort into our patient care and clinical research.

I hope everyone has a wonderful summer!

Hiroshi Mitsumoto, M.D.





Non-invasive ventilation trial in ALS

Jaydeep M. Bhatt, M.D.

At the Eleanor and Lou Gehrig ALS/MDA Center we see a number of ALS patients that report shortness of breath with minimal exercise or at rest. After an evaluation of lung function, we may decide to start non-invasive ventilation (NIV) in the form of a bi-level positive airway pressure. Use of NIV in ALS patient populations has been associated with improved survival and quality of life. In addition the NIV device is portable, easy to use, and conserves energy in patients with daytime fatigue when used properly. Often, we will recommend starting NIV at night during sleep.

We are working with Dr. Robert Basner's pulmonary team at Columbia and actively enrolling ALS patients who use NIV devices at night to investigate oxygen levels during sleep. The goal of the study is to determine factors that affect oxygen levels of ALS patients during sleep. Enrolled patients will receive a sleep study in their home and further evaluation from the pulmonary team if inadequate oxygen levels are identified at no additional cost. There are no specific risks associated with this trial. To be eligible, patients must use NIV at least four hours per night for at least four days per week and follow up at the Columbia ALS Center regularly. This is a great opportunity for our patients to participate in current research and receive expert services at no cost. If you or someone you know or care for may be interested in participating please e-mail alscenter@columbia.edu.

Save the Date:

MDA's Wings Over Wall Street
www.wingsoverwallstreet.org
a Benefit for the Muscular Dystrophy
Association
to Fund ALS Research
September 20, 2007
5:30-9:00pm
New York, Marriott Marquis

Caregivers Seminar
October 20, 2007
For more information please
contact Jackie Puerta: jpuerta@mdausa.org
or 212-689-9040

A message from Dr. Gordon...

I regret to inform you that I will be leaving the ALS Center at the end of August. As much as I enjoy my work here, I have a rare opportunity to conduct research at the Salpêtrière Hospital in Paris. The ALS Center at the Salpêtrière, where ALS was first described, is now one of the largest in the world. Because of the number of patients seen at the Salpêtrière and its unparalleled record of research, the Center affords numerous research opportunities in areas related to ALS. The meeting of philosophies and intellectual exchange in one institution will have implications for research design and discovery that will benefit both countries. I am sorry to be leaving, but pleased and honored to be able to continue the fight against this difficult disease. I wish you all the best.

This June we were sad to see our research assistant Sheena Chew leave...Good luck, Sheena!

Dear Patients and Families,

We may have met or gotten to know each other in clinic while we took our deepest breaths and exhaled with all our might, while we chatted during minocycline trial visits, while we discussed the modafinil trial for fatigue in ALS, or while we poked at your minds during cognition visits. I would just like to say what an honor it has been to have worked with you this past year. I have been inspired by your strength and determination to live your lives fully and to contribute to our research. I am leaving to start medical school this fall, where you will continue to be the reasons why I will always work my hardest to fight ALS in my academic, personal, and professional life.

I would also like to extend my thanks to my colleagues at the center. It has been a privilege to work with such intelligent, dedicated, and caring people. I became involved with ALS because a close friend of mine has ALS, but I joined this particular center because I wanted to learn how to conduct clinical research and care for ALS patients the right way. Mission accomplished. Please be assured that you are being cared for by an incredible set of professionals that work tirelessly to advance knowledge about ALS and to improve the quality of your lives.

You all have taught me great lessons that I will take with me. Thank you. I wish you all the best.

Take care,
Sheena





SPINA GOLF OUTING

by Kat Narbonne

Every year our center volunteers to help with the Spina Golf for Life Event. The proceeds from the tournament are donated to us to help us further research in ALS. The Spina family has hosted this event for three years. It is located every year at the Rockaway River Country Club in New Jersey. The Spina family graciously plans this event every year in honor of a family member that passed away from ALS.

This event dates back to Fall 2004 when the Spina family approached our staff with the idea of creating a fundraiser for ALS research. Nancy Hirshan, our former divisional administrator, worked with them to help create the ALS Golf for Life tournament. On June 4, 2007 we had our 3rd annual ALS Golf for Life tournament which to date has raised over half a million dollars for ALS research. Each year on the first Monday of June this event, which has become a cornerstone for this center, happens despite the weather. This day the Golf for Life coincided with the remnants of Tropical Storm Barry. For those of us who attended the first year, it was hard not to forget how the thunder storms had threatened to shut down the first tournament.

Arriving at the country club on that waterlogged day I realized how seriously the Spinans take this event. I had called early to make sure that the event had not been rained out and rescheduled for a different day. I had underestimated the planning of this event and the determination of the people who plan it. The day did start with some cancellations for the golf portion but others decided to brave out the storm and come out to play. They were not disappointed. After lunch the weather cleared enough so the patrons could play golf. As one patron said, it was like Carol Spina was watching over the tournament and inserting her own personality over things. Even though the day had started on such a sour note, it ended up being one of the nicest and most successful events our center has had.

The tournament schedule goes as follows, check in between 10 and 12, lunch at 12 to 1:30, golf from 1:30 to 5:45 and cocktails and dinner from 6 to 8. During the cocktail and dinner hour, patrons of the event participate in a silent auction. This year we had a number of interesting items such as a complete spa kit, wine tasting event in the Napa Valley and Yankee tickets. In addition to the silent auction, there was a 50/50 raffle that enthusiastic patrons participated in.

(continued...)

During the dinner hour Dr. Mitsumoto and Dr. Gordon gave speeches about how events such as this tournament were a real cornerstone for our center and that half the research completed could not be done without gifts. Everyone who donates makes a difference in ALS research. To quote Dr. Gordon from last year's speech, "AIDS has changed from a fatal disease to a chronic one. Doing the same thing with ALS is possible but requires the same amount of attention and funding that makes breakthroughs that have been seen in Parkinson's Disease and AIDS." Thank you to the Spina Family for hosting the Golf for Life tournament this year and thank you to everyone who has donated to make a difference in the fight.

Special Thanks for the Spina Family for the money raised for the ALS/MDA Research Center:

This year over \$180,000 was raised.



Current Clinical Trials

Actively enrolling:

- Modafinal for Fatigue in ALS
- Genetic and Epidemiology Study
- Non-Invasive Ventilation in ALS
- Skin Biopsies for Generation of ALS- Specific Human Embryonic Stem Cells

Ongoing (closed to enrollment):

- Clinical Trial of High Dose CoQ10 in ALS-stage II
- Early Treatment of ALS with Nutrition
- Longitudinal Study in Cognitive Impairment

Enrolling Summer 2007

- Exercise and Oxidative Stress in ALS

Enrolling Fall 2007:

- Phase IIb Study Arimoclomol in ALS

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





RIDE FOR LIFE

Ride for Life began in 1998 when a small group of patients rode their electric wheelchairs over 350 miles from Yankee Stadium to Washington D.C. to raise ALS awareness. Since then, Ride for Life has raised nearly two million dollars to fund ALS research and patient services.

Ride for Life 2007 began April 28 in Montauk, Long Island and ended nine days later at Columbia University. The riders made stops at schools, parks, and businesses where they educated listeners about ALS and spoke about their valiant battles with the disease. Along the way, the riders raised money. A check was presented to Dr. Mitsumoto at the closing ceremony. The money will be used to fund crucial ALS research at the Columbia MDA/ALS Research Center.

The closing ceremony was performed amongst a bright display of 6,000 pinwheels planted on the lawn in the center of Columbia's campus. The pinwheels represented the 6,000 patients that die each year from ALS.

Four patients from the Columbia ALS Research Center showed their courage by participating in the long ride. They were Norma Steck, a member of Ride for Life's Board of Directors and Ride for Life research committee, Rich Kornak, Jack Elwood, and Stan Silver. Fern Cohen, who attends Columbia's ALS support group, also participated. They all found the event inspiring and came away with hope that a cure would eventually be found for this difficult disease.



Pinwheels that represent the 6,000 people that die from ALS each year (David Wentworth Photography)

Note from a member of Ride for Life's Board of Directors

This is my fifth year on the Ride and each year gets better. Joining Ride For Life has afforded me the opportunity to meet some of the most incredible, dynamic, caring, determined and devoted people in the fight to cure ALS. The wonderful PALS, CALS, family, friends, students, volunteers and walkers make each day of the Ride special and memorable.

All along the route from Montauk to Manhattan we are greeted and cheered. School children from kindergarten through high school greet us with music, gifts, lunches and incredible donations they collected by having ALS fund raisers. They provide me with renewed strength to fight ALS and bring hope to finding a cure. It's an event that truly enriches your life and puts it back in perspective. Experience it first hand by joining us on this journey to raise awareness and funds for ALS!

Norma Steck - PALS
<http://www.rideforlife.com/>



Dr. Mitsumoto receives the check to support ALS Research at Columbia's ALS/MDA Research Center (David Wentworth Photography)



ALSRG Group Research Meeting

by Kate Bednarz

On Monday, April 30th The ALS Research Group (ALSRG) held a meeting in conjunction with the American Academy of Neurology in Boston, Massachusetts. The ALSRG is a group of investigators aiming to advance basic and clinical ALS research, to facilitate therapy trials, to foster interactions between ALS investigators, to increase awareness of therapeutic opportunities, and to support basic scientists, young investigators and clinical investigators who are interested in ALS research. Thus far, the most successful accomplishment the group has made is the DNA Banking program, which collected more than 1700 DNA samples from both patients and controls across the United States for future research into the etiology of ALS. The DNA Banking project was very successful, and now the group plans to look at additional potential projects, such as a tissue collection. Discussion on how the ALS research group should look in five years focused around creating educational programs, young investigator programs, and involvement in clinical research or clinical trials. At this meeting Dr. Mitsumoto, who played a key role in the initiation of the ALSRG, stepped down as the chair as his term was up. Columbia's own Jackie Montes was elected to the ALSRG Board of Directors as the Allied Member and will be an integral part of the group's future endeavors.



AAN Meeting in Boston

by Mary Kilty

In early May of this year, the American Academy of Neurology held its annual meeting in Boston. Well over 10,000 neurologists from around the world attended. Dr. Mitsumoto made a poster presentation of one of his completed studies. A poster presentation is one where the goals, procedures and results of a research study are presented in poster format in a large room with many posters. The researcher is present to discuss the study results with conference participants. The topic of Dr. Mitsumoto's poster was the identification of certain 'biomarkers' from blood and urine that may be useful in assessing oxidative stress in ALS patients. Biomarkers are various chemicals that are footprints that indicating physiological processes or diseases (or both). Oxidative stress has been associated with ALS and may be an important factor in the development of ALS.

Dr. Mitsumoto and his colleagues found that certain oxidative stress biomarkers found in urine were higher in ALS patients than in healthy control patients. This finding is important because urine samples are easy to collect and relatively inexpensive to analyze for biomarkers. This makes them attractive as research tools since research studies entail enrolling large numbers of patients and healthy control subjects. In addition, further research on these biomarkers could lead to their use as diagnostic tools.

These results will be a cornerstone for measurement of oxidative stress in upcoming research by Dr. Mitsumoto and his research team. Many noted ALS researchers stopped by the poster and discussed the study results with Dr. Mitsumoto. The study generated much interest and a very positive reaction from these researchers.

Skin Biopsies for the Generation of ALS-specific Human Embryonic Stem Cells

The Eleanor and Lou Gehrig MDA/ALS Research Center and the Motor Neuron Center of Columbia University, in collaboration with the Stowers Medical Institute, the Harvard Stem Cell Institute, and Project ALS have embarked on a project to develop stem cell lines that have the genes of individuals with ALS.

Research on animals suggests it may be possible to develop special human stem cells to study diseases, including ALS, Parkinson's disease and diabetes. Stem cells may also eventually help to restore normal function to diseased organs. For instance stem cells may someday be used to replace Insulin producing cells needed to correct type1 diabetes, or brain cells to treat Parkinson's disease or motor neurons to treat ALS. Understanding stem cells is a very active area of scientific research at this time.

The specific aim of this study is to develop stem cell lines that have the genes of individuals with ALS. If you participate in this study and donate your genetic material through a skin biopsy, and if we are successful, a stem cell line we will create will have all your genes.

To date, we have collected 28 skin samples from patients with ALS and their spouses or family members. We still need more participants, specifically those with a confirmed SOD1 mutation and their family members.

If you are interested in participating, please contact Jackie Montes @ 212-305-3632 or jm598@columbia.edu.



SALIVA and ALS

by Kate Bednarz

Occasionally people with ALS report symptoms of thick, mucus-like saliva or excessive production of saliva that results in drooling. The cause is generally due to difficulty swallowing and dehydration. Treatment is important since patients may feel uncomfortable participating in social activities and therefore do not enjoy the time with their friends and family. The following interventions may help patients ease the difficulty of excess saliva:

Mucus:

- Increased fluid: Intake of fluids will help dilute the thick saliva so that it is easier to manage. If thin liquids are difficult to swallow, thicker fluids, such as milk shakes or smoothies, can provide necessary hydration needs.
- Papain, an enzyme that is found in fruit of the papaya plant, can assist in breaking down the protein element of saliva. Most health food stores sell papain in tablet form. Papain is also found in papaya nectar drinks, such as the Goya juices. These nectars are naturally thicker and more appropriate for those who have difficulty swallowing pills or thin liquids.
- To break up thick mucus try rubbing meat tenderizer inside the mouth.
- Medication: an easy remedy to try is over the counter Robitussin to help reduce thick saliva. Prescription medications are also used, including guaifenesin or a nebulizer treatment with albuterol.

Drooling:

- Medication: glycopyrrolate, amitriptyline, atropine, and scopolamine patch can be used to treat drooling.
- Botulinum Toxin: injecting the toxin into the salivary glands can help reduce the production of saliva.
- Mechanical Management: a suction machine with a Yankauer tip can be used to clear the mouth of excessive secretions. The machine is ordered through a durable medical equipment (DME) company.

Although research has not shown a direct link between dairy product consumption and increased mucus production; many patients feel that their symptoms worsen when they drink Ensure or milk. In this situation it might be beneficial to switch to a juice-based supplement such as Enlive (Ross product) or Boost Breeze (Novartis product) to increase calories in the diet.

For more information please contact the Eleanor and Lou Gehrig MDA/ALS Center's nutritionist Kate Bednarz at 212-305-1677 or kbednarz@neuro.columbia.edu

Phase III Clinical Trial of Minocycline in Amyotrophic Lateral Sclerosis

The Minocycline Trial compared minocycline to placebo for efficacy and safety. Minocycline is a tetracycline antibiotic that helps protect nerve cells in animal studies. This clinical trial, funded by the National Institute of Health, was the final important step in determining whether minocycline helps people with ALS.

Unfortunately, the results of the trial showed that minocycline did not slow the rate of disease progression in ALS. In fact, the group that took minocycline got slightly worse than the group that took placebo. The side effects associated with minocycline included neurological symptoms such as dizziness, fatigue and headache, as well as gastrointestinal symptoms such as constipation, nausea and diarrhea. If you are currently taking minocycline, please contact your physician to discuss discontinuing its use.

Despite these results, those who participated made a meaningful contribution to our common goal of identifying a treatment. The trial will yield important information for ways to improve the design of future trials and the implications will impact ALS for years to come.

Please contact Carolyn Doorish, Project Coordinator, if you have any questions at cd2141@columbia.edu, or 212-305-2027.

Look for our Newsletter on the website:

<http://www.columbiaals.org>

To save research dollars, future issues will not be sent by regular mail unless specifically requested by calling 212-305-4746.



The Eleanor & Lou Gehrig MDA/ALS Research Center
Division of Neuromuscular Diseases
Columbia University Medical Center

*Special thanks to the
**MDA/ALS Division for their
 continuing support of our
 patients and their caregivers.***

We have two new additions to our staff!

Kalli A. Voulgaris comes to the ALS/MDA Research Center from The Mount Sinai Medical Center where she worked as a Research Quality Assurance Auditor within Corporate Compliance and a Grant Manager for the Division of Cardiology. Prior to that, she worked within the Gloria and Louis Flanzer Cardiac Center as Manager of the Cardiovascular Imaging Laboratory here at New York Presbyterian Hospital/Columbia University Medical Center. She received her Master of Public Health from New York Medical College, where she studied Health Policy and Management. She is happy to be back at Columbia University Medical Center and looks forward to working with all of you!

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Olena Jennings comes to the ALS/MDA Research Center from the Department of International and Public Affairs at Columbia University's Morningside Campus. She recently completed her MFA in writing fiction at Columbia University. She looks forward to meeting all the patients and their families and to actively making a positive contribution to the Center.

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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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 Olena Jennings

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 Jackie Montes, PT, MA, NCS



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 of Columbia University Medical
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