

The ALS Center

NEWS

WINTER / SPRING 2002

The Forbes Norris MDA/ALS Research Center Hosts Annual International ALS/MND Symposium and Alliance Meeting

The 12th Annual International Scientific Symposium on Motor Neuron Diseases (MND) and the 9th Annual International ALS/MND Alliance meetings, hosted by the Forbes Norris MDA/ALS Research Center, were held in November at the Oakland Marriott Hotel. Nearly 450 scientists, clinicians, and health care professionals from around the world attended this annual symposium. Previous symposia have been held in Denmark, Germany, Netherlands, Canada, Britain, and the next is scheduled for Melbourne, Australia in 2002. These symposia help everyone involved with ALS keep current with the latest leading-edge scientific and clinical research, medical trends, and clinical trials, in addition to the opportunity to exchange ideas with professional colleagues to improve basic care worldwide.

This year's ALS/MND Alliance meeting inaugurated an "Ask The Experts" session. What is hoped to be an annual event for the Alliance, a world-class panel of ALS experts attending the meeting gave brief presentations on their work and answered questions from the audience. This year's "Ask The Experts" session included: Dr. Robert Brown from the Massachusetts General in Boston, Dr. Stanley Appel, from Baylor University in Houston, Dr. Jeff Rothstein, from Johns Hopkins University, in Baltimore, Dr. Nigel Leigh, from London, England, and our own Dr. Deborah Gelinas, from the Forbes Norris ALS Center. They addressed such topics as the role genetics plays in ALS, stem cell research, immune/inflammatory considerations, clinical trials, as well as practical approaches to management of ALS including alternative and nutritional supplements, giving patients and families something to take home and use immediately.



Speakers at the symposium included clinical and basic science professionals from as far away as Japan, Italy, Great Britain, Australia and Scotland. The speakers included the ALS Center's Drs. Robert Miller, Deborah Gelinas, Nancy Lee, and Mary Abood. All delivered interesting, informative and occasionally heart warming speeches to the attendees. Dr. Gelinas graciously filled in for a speaker in the clinical session, who at the last minute was unable to attend. Having only five minutes to prepare her lecture and PowerPoint presentation, Dr. Gelinas presented a wonderful lecture on the topic of "Medical and Emotional Care of the ALS Patient", a subject that is close to her heart.

The Forbes Norris ALS Center has a staff of dedicated and highly qualified ALS specialists, who strive to keep up with the latest care techniques in order to improve the lives of those affected by ALS, as well as actively participate in finding a cure for this deadly disease. We are very proud of our ALS Center scientists and physicians and wish to acknowledge their hard work to make significant contributions to the ALS Community.



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The News is Back!!!

The Forbes Norris MDA/ALS Research Center Newsletter has returned as the: *The ALS Center News*

Historically the Forbes Norris MDA/ALS Research Center has provided a newsletter to our patients, families, friends, health professionals, and donors. The newsletter reviewed what was currently happening in the world of ALS and the activities and people who supported the Forbes Norris ALS Clinic.

After a hiatus, we are back to keep you filled in on the activities and improvements of the ALS Center. Our goal is to distribute the most comprehensive news about the latest research and clinical advancements to better deliver care for our ALS patients and their families.

With this edition, we announce some of the changes that may affect you for the better!

- Our phone system is being changed to have a REAL live receptionist answer your calls during our regular business hours, Monday through Friday, 8:30 am to 5:00 pm. Our voice mail system is still available for after-hours calls.
- In February 2002, our ALS clinic day will change from Fridays to Mondays. We are changing the day to better serve you in two ways: (1) to allow you to avoid the Friday afternoon commute leaving the City, and (2) to allow us to follow through on new orders more expeditiously during the week. We hope this will also help you get better service from outside vendors for your care.
- We have some new faces at the clinic, specifically bringing in neurologists to assist Dr. Miller and Dr. Gelinas. These highly skilled physicians will have reviewed your case, and of course, Dr. Miller or Dr.

Gelinas are still available to see you as needed.

- An ongoing monthly education program of classes at the clinic for 2002 will be announced for patients and caregivers covering various ALS topics. Many of these classes will be hands-on and include information on such subjects as breathing devices, special physical therapy needs, communication issues, daily living issues and more. Please let us know your educational requests. Look for the education program questionnaire in the clinic waiting room. These classes are for you. We want and appreciate your input.

We welcome any comments regarding any of these enhancements to our ALS Clinic, and look forward to providing you with better service.

Meet the Forbes Norris ALS Center Staff

Patricia Briskin, R.N., N.P.

Patricia joins us with a strong background in varied aspects of nursing, including homecare, oncology, and medical/surgical care. She comes to us with personal experience with ALS having had a relative with the disease. After many years of nursing practice and study, she received her Masters of Science in Nursing, with an emphasis on Case Management/Long-term Care, in 1998. After which she was accepted into the Post-Graduate Adult Nurse Practitioner Program at the University of California, at San Francisco. Since receiving her Nurse Practitioner certification, she has worked at internal medicine, hematology and oncology practices.

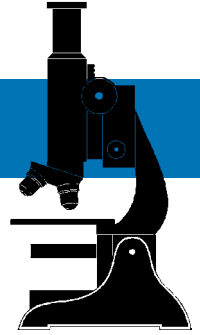
Patricia has been married to her husband Rick for 27 years and they have two children Sarah, a 21 years old

studying at Humboldt State University, and Sam, an 18 year old studying at the College of San Mateo.

“Patients who suffer from ALS require a special assistance and knowledge in adjusting their lives to the physical, emotional and mental demands of ALS. It is important that health care providers anticipate these demands and provide compassionate and effective care for patients and their families,” states Patricia. “I am honored to have the opportunity to serve patients with ALS and their families and I look forward to many enriching experiences during my time here at the Forbes Norris MDA/ALS Research Center.”



RESEARCH AGENDA



Current Research at Forbes Norris ALS Center

The ALS Center is dedicated to finding a cure for ALS and conducts various research, including clinical drug trials, which are an important part of fighting and winning the war against ALS. A major factor in this ongoing research is our ALS patients and their families. Helping us with clinical trials is our clinical research assistant, Jessica Dunne. She collects much of the needed research data and keeps patients and their families informed of the various studies needing participants.

Whether or not you participate in our research studies or clinical trials is a personal choice and a medical decision. Our efforts to keep you informed helps you make that decision. Please let us know if you are interested in participating in any of our current research studies.

Current Research Studies:

- **Minocycline drug study** — A beginning study to test the effectiveness of this drug to slow motor neuron disease progression by decreasing cellular death.
- **MRI study** — Still open, this study compares various brain chemicals in persons with and without ALS.
- **Exercise study** — Still open, this is a study to determine if exercise slows the progression of ALS.
- **Vioxx drug study** — A new drug study opening, studying the effectiveness of the anti-inflammatory drug Vioxx in slowing disease process.
- **Marinol study** — Recently completed. This trial determined the drug's effectiveness in decreasing disease advancement and spasticity that can accompany some ALS. Results will be published in early spring, 2002.

- **Post-mortem tissue study** — The "Gift of Life" study looks into cellular death through autopsy in persons who have died due to ALS. Patients can continue to help fight ALS through cadaver donation to our ALS research program.

Participation in the *North American ALS Patient Care Database* is an important component of ALS study. By simply filling out an informational form with the Forbes Norris ALS Clinic staff, you can improve the standard of care for ALS patients by disseminating information related to successful medications, medical practices and procedures that physicians are currently using.

If you haven't yet participated in this database, please do so at your next clinic visit. See our *New Briefs* for more information on this study.

News Briefs

Evidence from the ALS Patient Care Database Changes in the management of ALS since publication of the American Academy of Neurology (AAN) Practice Parameters

The North American ALS Patient Care Database reports information on the care of ALS patients. The complete publication, by Bradley et al., is available in *Neurology*, August 2000. Since May of 2001, the Patient Care Database has modified data collection forms to allow the collection of information related to adherence to the Parameters protocol.

Database Results and Patient Care Improvements:

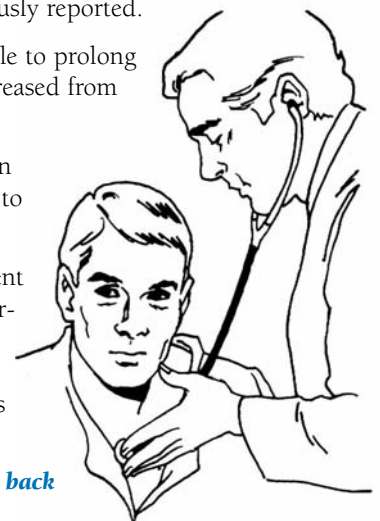
- Only 44% of patients were satisfied with how physicians presented the diagnosis of ALS. This is an area earmarked for improvement by the study.
- Marked improvement in nutrition was documented. The ALS Practice Parameter suggests that feeding tubes—percutaneous endoscopic tubes (PEG)—should be considered early in the course of ALS and begun before breathing function declines below 50% to significantly improve a person's nutritional and fluid status. Of patients with breathing muscle function (FVC)

of <50% predicted, 45% had a PEG, compared with 12% previously reported in 1999.

- Regarding symptomatic management, 88% of physicians indicated that they have discussed or implemented symptomatic management. All patients with marked drooling and marked excess of saliva received treatment, compared with 70% and 42% previously reported.
- The use of the drug Riluzole to prolong motor neuron survival increased from <50% to 62%.
- Complementary medication usage increased from 50% to 76% of patients.

Conclusions: The ALS Patient Database indicates a considerable improvement in the management quality of North America's ALS patients since the publication of the

NEWS BRIEFS continued on back





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NEWS BRIEFS continued

AAN Practice Parameter. Although performance remains sub-optimal in several areas, we have been able to identify those hotspots needing improvement for further study. This is the first North American report of outcomes improvement for ALS following publication of the AAN ALS Practice Parameters.

Family Caregiver Alliance Conference

The Family Caregiver Alliance (FCA) and the ALS Association, Bay Area Chapter, in collaboration with the Forbes Norris MDA/ALS Research Center and the ALS Center at UCSF sponsored a conference for ALS caregivers and professionals on February 9, 2002. The program included such topics as understanding VA and Medicare benefits, homecare issues, current treatment and research, and coping with family challenges.

Minocycline Pilot Study

Minocycline is an antibiotic that seems to have a powerful effect on motor neuron survival. Recent studies in the mouse model of ALS indicate significant prolongation of survival with an effect greater than that seen with Riluzole. A pilot study of Minocycline is underway at the Forbes Norris MDA/ALS Research Center at California Pacific Medical Center. Interested persons should contact Jessica Dunne at (415) 923-3938.

The Gift of Giving

The Forbes Norris MDA/ALS Research Center has been made possible in part by the support of generous donors to the California Pacific Medical Center Foundation. For more information on the Foundation or on ways you may give to the Forbes Norris MDA/ALS Research Center to support their services, please call (415) 750-4403.

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