

# Forbes Norris ALS Center

# NEWS

SUMMER | FALL 2002

## New ALS Family Fund announced at Classic Car Garden Party

Surrounded by one of the most beautiful private antique car collections in the West, nearly 100 supporters and friends of **Marshall and Nancy Mathews** and the Forbes Norris ALS Research Center gathered at the Mathews' home recently to hear about the latest ALS research and patient care programs affecting today's ALS population. After luxuriating in the elegant presence of these old automotive masterpieces, the audience listened attentively as the Norris ALS Center directors, **Robert Miller, M.D.** and **Deborah Gelinas, M.D.**, discussed the critical need for supplementing patient service clinical costs in today's difficult world of insufficient insurance reimbursements. Nancy Mathews, in a very poignant statement, joined our directors in outlining how the Center's experienced staff makes such a difference in an ALS patient's life. They also addressed some of the upcoming clinical trials, which offer great hope for the future of ALS research.

Acknowledging the help of several other organizations in putting together this elegant garden party event, Norris Center Advisory Director, **Dee Holden Norris**, recognized and thanked **Linda DeMello**, Executive Director, ALSA Bay Area Chapter; **Shannon Shryne**, Regional Director, MDA; **Jerry Mapp**, President & CEO, California Pacific Medical Center Foundation; and **Esther Quement**, Board President, ALS Research Foundation.

The afternoon ended with the exciting announcement of a \$50,000 gift to launch the Marshall Mathews Family ALS Fund for Patient Services at the Forbes Norris MDA/ALS Research Center at California



*Right: Attendees enjoy the classic cars at the Marshall Mathews family garden party.*

*Below: Dr. Deborah Gelinas with Marshall Mathews at classic car garden party.*

Pacific Medical Center. The commitment of the Mathews' family friends to the development of this fund is a testimony to the love and concern held for this special man and his family.



Join the Marshall Mathews family and the Forbes Norris MDA/ALS Research Center in developing the Marshall Mathews Family ALS Fund for Patient Services. Funding will be used to support our comprehensive patient care program.

If you are interested, please call Dee Norris at (415) 923-3608 or Mark Lachman at (415) 600-6427.



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# MEET THE NEW FORBES NORRIS ALS CENTER STAFF

## Jason Mass, R.N. and Giovanna Kushner

Jason Mass, R.N.

**Jason Mass, R.N.** recently joined the ALS Center as a Clinical Research Nurse Coordinator. Involved and working with ALS patients since 1993, Jason began his career as a staff nurse in the Neonatal Intensive Care Unit at California Pacific's California Campus prior to the merger when the facility was known as Children's Hospital of San Francisco. During this time Jason started working part time in oncology research where he developed an interest in the relationship between clinical research and patient care. He was drawn to the research projects that would attempt to solve the difficult puzzle leading to better treatments for patients. His serendipitous involvement in neurodegenerative diseases has evolved into the establishment of many meaningful relationships with patients and their families.

Jason states, "The most inspirational part of my work is the patients and families themselves; how they carry themselves with dignity and often humor despite the physical, emotional and financial burdens of living with ALS." Married, with a son soon to graduate from college, Jason spends his spare time with his family and his dog, working in his garden and on his house.

Giovanna Kushner

**Giovanna Kushner** came to the United States in 1976 from her home in the former Soviet Union and joined the Norris ALS Center in 1996 as a Clinic Coordinator. This year Giovanna accepted a position as a Research Coordinator, working closely with Jason Mass, R.N. She is able to apply her extensive administrative skills with her vast experience in the Forbes Norris ALS Clinic. Giovanna feels "fortunate to work for a clinic that emphasizes patient dignity and supports the utmost quality of life in patient care."



*Jason Mass, R.N. and Giovanna Kushner*

### Help Yourself by Learning About Your Health

Learn more about your health with the help of the California Pacific Health Care Initiative. Just go to the California Pacific Medical Center web site [www.cpmc.org](http://www.cpmc.org) and click on Learning About Your Health to find over 300 health related learning resources. Partial funding for the development of Learning About Your Health was generously provided by the Mr. and Mrs. Arthur A. Ciocca Foundation.

# RESEARCH AGENDA

The Forbes Norris Center is dedicated to finding the cure to ALS. We work in all aspects of basic science and clinical research including clinical drug trials, which are an important part of fighting and winning the war against ALS. A major factor in this research is our ALS patients and their families.

Our efforts to keep you informed on our research studies and clinical trials can help you decide whether or not you wish to become involved. Participation in research is a sometimes difficult and personal choice and a medical decision.

If you are interested in participating in any of our current research studies please contact Jason Mass at (415) 923-3967.

## Current Research Studies:

**MRS Study** — Magnetic resonance spectroscopy measuring the level of four neuro-chemicals in persons with and without ALS.

**“ALS Care” Database Study** — ALS Patient Care Database is a voluntary North American outcomes database for ALS patients. This database serves as a tool to better understand clinical practices for ALS patient care

and the relationship between medical practices and clinical outcomes.

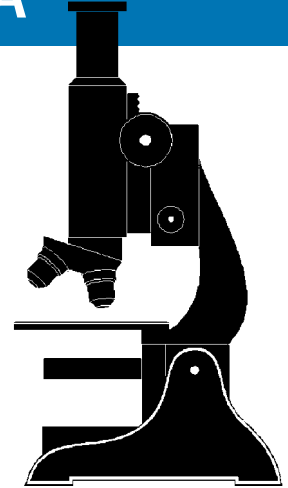
**Exercise Study** — Measures the effects of regular exercise on muscle strength and endurance in patients with ALS.

## Future Studies Scheduled to Begin in Early 2003:

**Minocycline Study** — Testing possible benefit of minocycline, an antibiotic and caspase enzyme inhibitor, in controlling programmed cell death, which is regulated by caspase enzymes.

**Myotrophin (IGF-1)** — Follow-up study testing the myotrophic and neurotrophic factor to confirm benefits for ALS patients.

**Forbes Norris database project** — The Norris MDA/ALS Research Center is forming a database to allow our clinical researchers the ability to review a large number of variables in ALS patients over an extended period of time. The data will be used in the development of future research projects and ultimately better treatments.



## News Briefs

### The ALS Association (ALSA) Advocacy Update Report

The Forbes Norris MDA/ALS Research Center collaborates with all the ALS groups around the country and the world, including the ALS Association, the only national non-profit voluntary health organization dedicated solely to the fight against ALS. We work closely with the ALSA Bay Area Chapter and are proud to have been designated the first ALSA Center of Excellence. One of its missions is to advocate politically with state and national legislatures on behalf of important patient issues and health care reform.

### ALSA Advocacy

Listed below are some of the recent ALSA accomplishments that have increased public and private support of ALS research and health care reform responding to the demands placed on those affected by ALS.

- ▶ Every May, ALSA leads a contingent of ALS patients, ALS advocates, and caregivers to Capitol Hill in Washington, D.C. for ALS Advocacy Day to raise awareness of ALS. In May 2001, over 550 people participated in this special day.
- ▶ In December 2000 ALSA advocated for Congress to pass legislation waiving the current 24-month Medicare coverage waiting period for persons

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diagnosed with ALS. This is the first ALS-specific legislation ever passed by Congress. The waiver became effective in July 2001 allowing ALS diagnosed persons access to Medicare health care benefits thereby improving the lives of thousands of people.

To find out more about ALSA, the 2003 ALSA Advocacy Day or for information on how to become an ALSA Advocate, check the ALSA Web site at [www.alsa.org](http://www.alsa.org), write to The ALS Association National Office: 27001 Agoura Road, Suite 150, Calabasas Hills, CA 91301, or telephone them at (818) 880-9007.

## MDA Helps Pay for Communicative Devices

A recent enhancement of the Muscular Dystrophy Association's Health Care Services Program has been made to authorize up to \$2,000 per individual for the one-time purchase of a communicative device. MDA saw the need and was able to add this new service earlier this year while continuing the pursuit of the Association's primary goal of developing effective treatments through the support of worldwide research.

In order to take advantage of this generous offer, a physician's prescription is required in addition to MDA registration. This is a great addition to the augmentative/communication services provided at the Forbes Norris MDA/ALS Research Center. For more information, please call the MDA Health Care Service Coordinator Rena Peek at (415) 673-7500 or Amy Roman, Speech Therapist, Forbes Norris Center (415) 923-3604.

## Medicare and ALS

### "The David Jayne Medicare Homebound Modernization Act of 2002, S2848"

David Jayne is a divorced father of two in his early forties. David also has ALS. Mr. Jayne lost his Medicare funded home health services benefits because he violated the Medicare Homebound rule by going to a University of Georgia football game. In order to maintain his benefits, David would need to become a prisoner in his home, leaving only for physician office visits, adult day care and religious services. Mr. Jayne is trying to change this rule.



David Jayne with his children

In August of this year Senator Susan Collins of Maine introduced the David Jayne (S2848) legislation to Congress. If signed by President George W. Bush, the act will amend Medicare's definition of homebound from "absence from the home" to a patient's functional limitations and clinical condition. Currently Medicare requires that a person be confined to their home in order to receive home health services. A person can only leave home for infrequent and short durations, to attend adult day care or religious services. Medicare's current "homebound rule" became effective in the 1960's prior to many of today mechanical technologies and the American's with Disabilities Act.

The David Jayne Medicare Homebound Modernization Act of 2002 will provide specific limited exception to the Medicare homebound rule directly affecting:

- ▶ Individuals who have been certified by a physician as having a permanent and severe condition that will not improve.
- ▶ Individuals who need assistance from another person with three or more of five daily living activities and require technological and/or personal assistance with the act of leaving home.
- ▶ Individuals who have received Medicare home health services during the previous 12-month period.
- ▶ Individuals who are only able to leave home because the services provided through the home health benefit makes it possible for them to do so.

## 13th Annual International ALS/MND Alliance Meeting and Scientific Symposium to be held in Australia

This year's International ALS/MND Scientific Symposium, the only international scientific meeting dedicated to clinical and basic scientific research on Motor Neuron Disease (MND), will be held this November in Melbourne, Australia. Each year this annual meeting is hosted by an alliance member organization and sponsored by the International ALS/MND Alliance, a consortium of MND groups from around the world.

This symposium brings together the world's finest ALS scientists and clinicians to discuss research results with ALS colleagues. New findings are shared including and plans for next steps in ALS research, the latest in genetics and cellular biology and pathology, and an update on clinical trials. All of which offer hope to families and people who must live with the devastation of this disease.

In addition, there are clinical sessions running concurrently with scientific sessions revealing up-to-the-minute findings on effective ALS clinical management, including quality of life, optimum respiratory techniques, and interventions for improving quality of patient care. Here the value of collegial networking is invaluable for exchanging pertinent information while learning and teaching others about current research work and achievements.

Of equal importance is the ALS/MND International Alliance meeting discussing the optimum methods of dissemination to inform and educate ALS patients and families worldwide about current research and the latest interventions for managing ALS.

Several representatives from the Forbes Norris ALS Center will be attending and presenting at the Melbourne Scientific Symposium. A report on the meeting, findings and presentations will be forthcoming in the next issue of the *Forbes Norris ALS Center News*.



*Dee Holden Norris presents the Forbes Norris Award to Dr. Lewis "Bud" Rowland with previous award recipient Dr. Hiroshi Mitsumoto (left).*

## FORBES NORRIS AWARD presented to Neurology Professor Emeritus at Columbia in New York

Each year the International ALS/MND Alliance, hosts of the International ALS/MND Symposium, presents the Annual Forbes Norris Award, at this event, to the physician/scientist nominated by his colleagues as exemplifying "care and compassion in the study and management of ALS."

The 2001 award was presented to **Dr. Lewis "Bud" Rowland**, Professor Emeritus and former Department Chair of Neurology at Columbia Presbyterian in New York City. Since Dr. Rowland was not able to attend the Symposium, **Dee Holden Norris**, Advisor Director of the Norris ALS Center and wife of the award's namesake, flew to New York in May to present this esteemed award personally to Dr. Rowland. Adding to the excitement of the day and aiding in the presentation was the current Director of the Eleanor and Lou Gehrig MDA/ALS Research Center at Columbia and the 1999 Forbes Norris Award recipient, Dr. Hiroshi Mitsumoto. We congratulate Dr. Rowland on his hard work and well-deserved recognition.



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## *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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