

August 12, 2002

Richard J. Barohn, MD  
Medical Director  
The ALS Clinic at the University of Kansas Medical Center  
Neurology Department  
1008 Wescoe, 3901 Rainbow Boulevard  
Kansas City, KS 66160-7314

Dear Dr. Barohn:

I am delighted to inform you that the Patient Services Committee of ALSA's Board of Trustees granted approval for the ALS Clinic at the University of Kansas Medical Center to be a certified ALSA Center effective August 12, 2002. The decision of the Patient Services Committee is based on the recommendation from The ALS Association's Center Certification Committee. Congratulations on the achievement this designation reflects.

Strengths of your ALS clinic noted by the survey team include:

- 1. "We began our visit at 8:30 am by meeting the clinic staff in a conference room area. Dr. Richard J. Barohn, MD, Medical Director, April McVey, MD, ALS Clinician and Electromyographer, and Brian K. Ghafari-Naraghi, RN, BSN, Clinical Coordinator and Research Nurse gave an overview of the clinical program, which began in September 2001. In their 7 months of operation they have seen approximately 20 new patients and 40 follow-up patients. The clinic operation and flow was discussed, it's affiliation with the University of Kansas, clinic facilities, clinical consultants, and the ALSA chapter support. The University and Medical School are highly supportive. Through them, Dr. Barohn has secured the use of the Landon Center for Aging. This recently refurbished facility is very spacious and state-of-the-art, with ample clinic space, handicap parking space, clinic rooms, and clinician consult space. Clinic rooms (8-10) were available for use during the twice-monthly ALS clinic schedule. They see approximately 10 patients per week of which 2-3 are newly diagnosed. In addition, there is EMG on-site as well as a room dedicated to quantitative measurements. Classroom space is available as well."*
- 2. "One special point about the Landon Center that is rare, if not unique for an ALS Clinic facility, is the presence of a fully equipped gait laboratory. While this is funded separately from ALS activities, the facility contains all the apparatus necessary for kinetics, kinematics and surface EMG recordings affording a unique opportunity for clinical research. The Landon Center director seems very supportive of the ALS program."*
- 3. Dr. Barohn is the Chairman of Neurology as well as the ALS clinic Medical Director. In this position he consults on all newly diagnosed patients that are seen through the University neurology medical service. All referrals are seen by Dr. Barohn and directed to the ALS clinic team. Dr. McVey trained with Dr. Robert Miller at the Forbes Norris Center. As such, she is highly qualified to care for ALS patients. Mr. Ghafari came from an oncology background and has, as one might expect, adapted quickly to the ALS patient population. ALS patients are then introduced to the ALSA chapter nurses who are also dedicated and knowledgeable. They proceed with an initial education of disease and assessment of needs. Other individuals involved are a PT, and OT, social worker, Speech Language pathologist and a nutritionist. New and follow-up patients receive a phone call by the ALSA nurse and the Clinic Nurse to identify patient issues or concerns to be addressed at the clinic visit. The Clinic meets twice monthly on Monday's from 8:00 am to 4:00 pm. All new patients see all clinical specialists. Follow-up patients are scheduled for those needed specialists triaged from the pre-visit phone contact. Other specialists are added to the clinical visit as necessary. Each specialist spends 20-30 minutes with each patient. Dr. Barohn assesses patients for clinical care needs, oversees multi-disciplinary team members, refers patients to appropriate research studies and makes outside clinical specialist referrals as appropriate."*
- 4. "The patient education is centralized. A vast patient education area is designated with Video, Internet, as well as a wealth of written educational material. Patient education is ongoing at each clinic visit, during support groups, and at special patient conferences. A new patient resource notebook is given to each new patient which covers the clinic operation and staff, web sites, resources, support group meetings, etc."*

5. *“Clinic staff attends the yearly ALSA clinical conference in Washington, D.C. to update their knowledge and network with other colleagues from around the country at other ALS clinics. Some staff attends the International Alliance MND Meeting yearly as well. This ALSA Chapter is active in education of the patients, health care professionals and the community.”*
6. *“Dr. Barohn is a national expert in the field of ALS. Prior to taking the chairmanship at KU, he has developed ALS clinics at San Antonio and Dallas. This is reflected in his CV that outlines a vast number of articles relating neuromuscular diseases as well as to both ALS clinical care and ALS clinical research over the last 15 years of his career. He is a 15 year member of WALs (Western ALS Study Group). We have no doubts about continued research productivity.”*
7. *“We followed 2 patients scheduled for that day. All team members rotated through each patient’s clinic room assessing, recommending appropriate treatment options, and evaluating previous treatment recommendations. The specialists made good eye contact, gave appropriate information and initiated problem solving when appropriate. Flow sheets on the door, along with the patient’s chart, and clinical data sheets facilitated each specialist’s visit with the patient. This team varied in years of experience, although this is a young clinic staff, they have the core clinical foundation and strength of the chapter clinical team to provide excellent ALS clinical care to this region. They seemed very knowledgeable and caring, thus facilitating an environment where patients and families felt comfortable in asking questions. Dr. Barohn and Dr. April McVey both have many years of experience as neuromuscular experts and have experience in ALS patient management and research. Equipment is available to patients in the clinic; large equipment is delivered directly to the patient’s home. The wheelchair scale is located between the waiting area and the clinic rooms. The clinic flow is consistent and timely, with little wasted time, but the visits do not appear “hurried.” Specialists seemed to take adequate time to complete their assessments and recommend interventions.”*
8. *“The team conference was completed over the staff lunch hour. All patients were discussed by all clinicians and decisions made accordingly. Dr. Barohn initially presents the cases and then opened up the clinical discussion. After all clinicians reported, a brief but open exchange between team members occurred. Specific medical and psychosocial recommendations were made. The ALS Clinic nurse took notes to ensure adequate follow up. The team also provides home evaluations periodically throughout the disease course when needed.”*
9. *“The clinic has many strengths which include a large state-of-the-art rehab facility to see their patients, a financially strong ALSA chapter that has worked successfully in developing a vast support community and varied health care providers, and enthusiastic medical director, and array of team members.”*

One suggestion from the site visitors and members of the Certification Committee is included here for your information:

1. *“There are only minor limitations related to some team members’ inexperience with ALS.”*

The ALS Association is pleased to add the name of the ALS Clinic at the University of Kansas Medical Center to its list of certified ALSA Centers. This designation will be included in relevant ALSA publications and on ALSA’s web site. An ALSA Center sign is provided for display in the clinic.

The ALS Association appreciates the excellent clinical care and patient services you and the staff at the ALS Clinic at the University of Kansas Medical Center provide to people with ALS and their families. We look forward to working closely with you, your staff and ALSA’s Keith Worthington Chapter.

Sincerely,

Mary Lyon, RN, MN  
Vice President, Patient Services  
ML/blm  
Enclosure (one ALSA Center Sign)

cc: Michael Havlicek  
Laural Winston  
Terry Betzelberger  
Beckie Cooper  
Brian K. Ghafari-Naraghi  
Sally Dwyer