

1997 NN&I Quality of Life Award Winner

LORAC Tries to Make "Rehabilitation" a Household Word in Renal Care

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• **Rehabilitate** – 1. to put back in good condition 2. to bring or restore to a state of health or constructive activity.

It is assumed that all of those who treat patients with end-stage renal disease (ESRD) might have the above goal in mind with the first needle stick on dialysis, or the first visit by the social worker after a kidney transplant. Indeed, when the federal entitlement for treating ESRD patients was approved by Congress 25 years ago, the expectation was that not only would lives be saved but patients could resume a fairly normal lifestyle - including getting back to work.

Times have changed. The patient population has changed. In 1995, the mean age of ESRD incidence - start of dialysis - was 60 years old, according to the U.S. Renal Data System's 1997 report. Close to 33,000 patients who started dialysis in 1995 were 65 years or older; another 25,000 were between the ages of 45-65 years old.

Hardly a group with much potential for rehabilitation. How could the renal community expect to "restore" this patient population "to a state of health or constructive activity?"

Despite the odds - or perhaps because of them - The Life Options Rehabilitation Advisory Council (LORAC) was formed in 1993 to see what could be done. Funded solely by Amgen Inc., LORAC has spent the last five years producing a series of reports, clinical tools, guidelines, and education programs to help patients and professionals think about how quality of life can be improved. The multidisciplinary group developed the "5 E's" of rehabilitation - education, employment, exercise, encouragement, and evaluation - then defined the terms and created an annual award to recognize those who help motivate patients toward rehabilitation. Recently, Amgen agreed to fund a two-year demonstration project at sites in North Carolina and California to help determine the impact of exercise on patient functioning and well-being.

"If the results of this research are consistent with past studies, the fact that exercise has the potential to positively impact both proximal and distal outcomes, and thereby satisfy the goals of renal rehabilitation, will be affirmed," wrote Kutner

et al. in the article "Fulfilling the Promise: Linking Rehabilitation Interventions with ESRD Patient Outcomes," in the May 1997 issue of *Dialysis and Transplantation*.

Behind all of LORAC's efforts is the belief that dialysis should not simply be a means of sustaining life for patients with ESRD. Quality of life *can* be restored with the support of the provider, patient, employer, and government.

LORAC's focus on quality of life made it an appropriate recipient for *Nephrology News & Issues's* 1997 Quality of Life Award. The award has been presented annually since 1989 to individuals, organizations, or companies that have improved the quality of life of patients with ESRD. The winner is selected from a panel of NN&I's Editorial Advisory Board and receives a \$1,000 stipend, to be donated to an organization of the winner's choice. LORAC says it will donate the money to help fund a rehabilitation program at a dialysis unit.

Motivated to Make a Difference

LORAC was conceived "by a group of professionals and patients with a special interest in quality of life," says Edith Oberley, president of Medical Media Associates (MMA), a Madison, Wisconsin-based medical communications company that staffs the work of the Council. Amgen, with an interest in helping patients reach their fullest potential with erythropoietin, agreed to provide a special grant to fund the work of the Council.

Oberley's interest in organizing LORAC was partly motivated by her role as a 25-year home hemodialysis partner to husband Terry, who has maintained his career as a physician despite ESRD. She was also inspired by long-term dialysis patients - "the 25-30 year veterans who had to learn the '5 E's' to survive" long before LORAC formally identified them, says Oberley. In fact one of LORAC's research projects for 1998 is to identify clinical and social characteristics of patients who have lived with renal

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THE WORK OF LORAC

- Renal Rehabilitation Report (1st issue/1993) newsletter for patients and professionals
- Estab. the Rehabilitation Resource Center (1994)
- Renal Rehabilitation: Bridging the Barriers (1994) the report was LORAC's initial effort to define rehabilitation, barriers, and opportunities. Version also done for patients and families.
- Exercise for the Dialysis Patient: A Comprehensive Program (1995) includes instruction books and videos
- Employment: A Guide to Work, Insurance, and Finance for People on Dialysis (1996)
- New Life, New Hope: A Book for Families & Friends of Renal Patients (1997) joint publication with AAKP
- Unit Self-Assessment Manual for Renal Rehabilitation (in press)

More information on LORAC can be obtained from its worldwide website at <http://www.lifeoptions.org> or by calling the Resource Center @ 800/468-7777.

■ LORAC: Improving Q of L

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disease more than 15 years, with the hope of gaining more insight into the key to longevity.

LORAC's current 18 volunteer members are divided into workgroups on education/communication, research, and liaison activities with the renal community. Six emeritus members also provide input. LORAC members go on the road and spread the word about rehabilitation with other patient organizations and through programs to help direct rehabilitation research. "It's a group that is incredibly devoted," says LORAC program manager Marty Pipp, MPH.

But will longer, healthier lives be realized if dialysis facilities make the effort to help Educate patients about their disease, create Employment opportunities, provide an Exercise program, Encourage patients to improve, and Evaluate the results?

Oberley says the presence of rehabilitation in the dialysis and renal transplant unit is increasing gradually, and LORAC is trying to capitalize on it. "We are seeing an increase in interest on the part of dialysis chains in rehabilitation...managed care organizations see it as a valuable tool in preventive care. The Health Care Financing Administration has included rehabilitation in their Conditions of Coverage, and state surveyors ask about it when interacting with patients," says Oberley. Pipp says LORAC will approach the Renal Physicians Association about making rehabilitation part of the Scope of Practice for nephrologists.

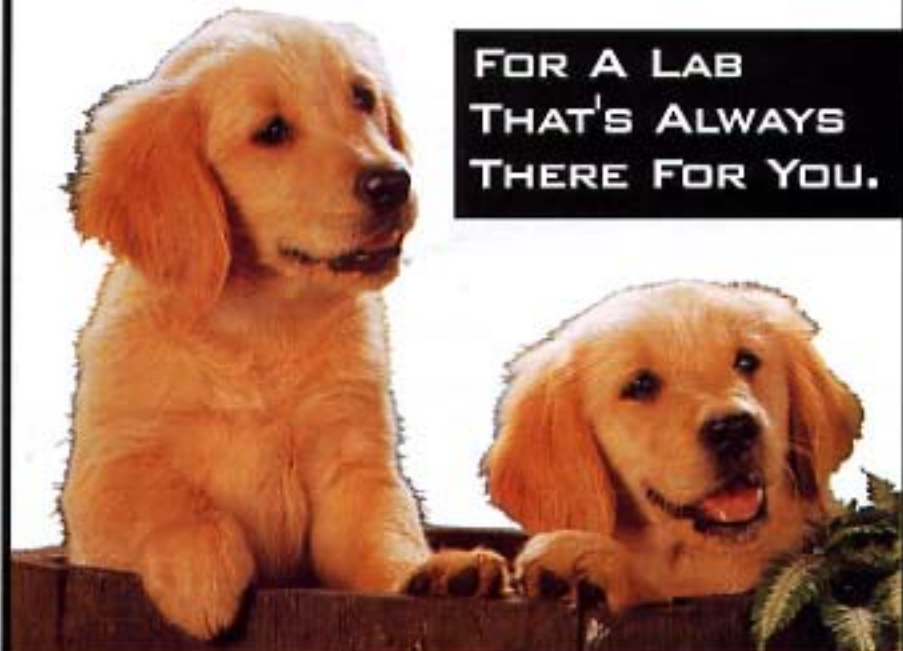
Other organizations such as the National Kidney Foundation, the American Association of Kidney Patients, and the American Kidney Fund are making very important contributions to rehabilitation, says Oberley. Not only are more people talking about rehabilitation, they are writing about it: a literature review about rehabilitation between 1992-

1996 showed a 700% increase in articles from just four years earlier.

"It will take three dynamics - education, altruism, and mandates (both government and corporate) - to make rehabilitation universally effective," says Oberley. If LORAC continues its pursuit to see all patients experience the "5 E's", the renal community will be a better one. **NNM**

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