



Chronically Motivated

Hartwell Works 24/7 to Improve the Patient-Caregiver Relationship

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“PATIENT, TEACH THYSELF.” It’s one of Lori Hartwell’s many messages to individuals doing battle with chronic illness, including renal disease. Patients can do more to improve their quality of life if they recognize the power that they have to control it—even while battling kidney failure.

But there is a message for caregivers, too. Renal professionals need to understand the challenges that patients face—challenges beyond simply getting into the dialysis chair three times a week. These other challenges are personal: grappling with the finality of a chronic illness; protecting self-esteem among peers and family; maintaining their place in the household; and dealing with changes in sexuality.

Now, Hartwell’s efforts to bridge the gap between patients and their care providers has earned her the 2003 Quality of Life Award from *Nephrology News & Issues (NN&I)*. Hartwell was selected by a panel of judges from *NN&I*’s Editorial Advisory Board. The award comes with a \$1,000 stipend to be donated to a nonprofit organization of her choice.

NN&I introduced the Quality of Life award in 1990 as a means of recognizing an individual, company, or organization that contributed to improving the quality of life for individuals with end-stage renal disease. *NN&I* presented its first award to Amgen Inc. and their team of scientists responsible for the discovery and development of human recombinant erythropoietin.

In their nomination of Hartwell, Maria Karalis, MBA, RD, LD, and Sandie Guerra Dean, LCSW, said Hartwell’s accom-

plishments “serve as a positive example for dialysis patients and health care professionals. She consistently strives to eliminate low expectations of people who have a chronic illness.”

Karalis and Dean describe Hartwell as a “successful, articulate, and funny young woman” who has “used her life experience to provide encouragement and hope to others living with chronic illness and to educate those in health care about what patients need most from them.” Further, she has helped many with chronic illness “to gain the confidence to become active participants in their health care and to set goals for themselves that bring satisfaction, purpose, and meaning to their lives.”

KEEPING BUSY

Hartwell was first diagnosed with kidney failure at age two. She has been on peritoneal dialysis, hemodialysis, and has had three kidney transplants. The last one, performed in 1990, has been successful.

Hartwell has reached out to the renal patient and caregiver community in a number of ways:

- Her latest book, *Chronically Happy—Joyful Living in Spite of Chronic Illness*, details her own path through chronic illness and dispenses helpful

thoughts and advice for patients facing the same uphill challenges.

- She understands the technical side of nephrology, having worked in the renal care industry for five years. Over the years, she has spent time in over 500 dialysis clinics.



Hartwell talks to attendees at last year’s Renal Prom, which she organizes annually. (right) Hartwell at a *Chronically Happy* book signing with American Association of Kidney Patients Palm County (Fla.) chapter members.



NN&I Quality of Life Award Winners

1990—Amgen Inc., for its development of erythropoietin

1991—Amos Hanks, a dialysis patient and informed advocate, for educating patients about their disease

1992—The Ruth Gottscho Kidney Foundation, an organization that finances and runs a camp for children

1993—Jean Kelley, a pancreas/transplant patient, who helps to educate other patients on modality options

1994—Jack Moncrief, MD, and Robert Popovich, PhD, for their pioneering work in developing continuous ambulatory peritoneal dialysis

1995—The late Susan Jaskula, MSW, for her work in helping dialysis patients lead better lives

1996—Diana and Bernie Carr, who made significant efforts to improve organ donation education after they donated the organs of their son after an automobile accident.

1997—The Life Option Rehabilitation Advisory Council

1998—Candy Wilson, RN, CPTC, a transplant coordinator who improved organ donation efforts in the Miami, Fla., area.

1999—The American Kidney Fund

2000—The late Wayne Nix, a transplant patient who spearheaded a program in Michigan to help renal patients get back to work. His efforts were later developed by the National Kidney Foundation into a national program.

2001—John Newmann, PhD, a transplant patient and advocate for patient rights

2002—Kidney Dialysis and Transplant Association

2003—Lori Hartwell

- She produced an educational video program titled *Communication Prescription for the Renal Care Professional*, created especially for renal care professionals in an effort to help them better understand and communicate with renal patients.

- She serves on the Patient Advisory Committee of ESRD Network 18 and on the California Rehabilitation Council. She has also consulted with the Centers for Medicare & Medicaid Services over vascular access issues.

- Hartwell founded the Renal Support Network, a nonprofit group, which publishes a directory of patients' names and phone numbers who wish to share their experiences of kidney disease with others.

- Each year, she organizes a prom for teenagers who have kidney disease, held at Notre Dame High School in Sherman Oaks, Calif.

This past year, she gave 45 presentations in 25 states to patient and professional groups about improving the patient-caregiver relationship. She also was a guest on 30 radio shows. She assembles the editorial content for iKidney.com, a website with articles of interest to patients

- never be threatened by a second opinion, because "a second opinion does not question a doctor's intelligence; it simply gives patients confirmation that they are on the right track"
- speak to the patient as an equal
- look the patient in the eye when he or she is speaking
- employ a staff that is professional, organized, and pleasant
- be an expert in his or her specialty
- be reliable and on time
- make the patient feel comfortable during an examination or while talking about personal or embarrassing issues
- understand that this is the patient's time to address personal health care issues, so the doctor should not take phone calls or have a hand on the doorknob while talking to him or her
- provide the patient with educational material to better understand his or her condition



Lori with husband Dean.

Chronically Happy, like Lori herself, is a dictionary of advice, aimed at bridging the relationship between the medical team and the patient. But she has plans to take the next step—to bring patients together in the same environs as renal professionals. Currently, she is organizing a companion meeting for patients at the National Renal Administrators Association's annual meeting next year in Denver, Colo., to help administrators mingle more with patients.

Hartwell told *NN&I* that her messages are for both patients and professionals. "Professionals are easier to reach," said Hartwell, who gives talks with titles like "Fostering Success in the Dialysis Facility," and "Chronically Happy, Damn It!" "If I send a message that might impact the patient, professionals need to know about it and need to feel good about it as well." *Chronically Happy*, originally aimed at patients, crosses over to professionals, she said. "I think physicians need to hear that message. Everything starts and ends with the doctor."

Getting patients involved in their care has a benefit, Hartwell believes: better outcomes. "Engaging patients as partners will lead to better outcomes. At first it might be difficult—professionals may be unsure about having patients involved in their care. But it can lead to positive results."

Hartwell learned how to take care of herself early in life: she was fighting kidney disease and alcoholism in her family. "If I didn't get control of my health, I couldn't take care of my family. This increased my self-esteem.

"It's interesting to see what a chronic illness can teach you." ■

families, and renal professionals. The site is visited monthly by over 40,000 people, Hartwell said. Her new idea is the P.E.P. Program—Patients Educating Patients. She hopes to find funding to develop an educational model to help train patients to teach and educate other patients on dialysis (see November 2003 *NN&I*).

"YOU HAVE TO LET PATIENTS IN YOUR WORLD"

In *Chronically Happy*, Hartwell walks through her anxieties and difficulties in dealing with chronic illness, identifying the phases that patients often experience in dealing with disease. In one chapter, she describes her dream doctor—ingredients that all physicians should strive for and all patients should expect. While she encourages readers to write their own lists, she suggests that good doctors should:

- treat the patient as an individual and not cookie-cut him or her into a plan that works for the doctor

Looking at "Quality" in a Different Way

After 14 years of identifying "unsung heroes" in the renal community deserving of the Quality of Life Award, *NN&I* is retiring the award this year. Since 1990, *NN&I* has made \$14,000 in donations to charitable organizations identified by Quality of Life Award winners. We are proud of our contributions and hope the renal community has benefited.

NN&I is formulating the criteria for a new award for the renal community. Look for an opportunity for nominations this spring.

Mark E. Neumann
Executive Editor