

The Renal Support Network, 20 years later

Lori Hartwell

When I started the Renal Support Network (RSN) in 1993 I hoped to have at least a small impact at the local level. But our patient-run organization has had a national influence in helping patients with chronic kidney disease, and we are proud of our accomplishments.

RSN is based on two fundamental principles: An illness is too demanding when you don't have hope, and one friend can make the difference. My realization about the importance of hope and friendship came from many sources. I would like to highlight two interactions—one with a health care professional and one with a fellow patient—who unknowingly provided some of the inspiration that led to the development of my core beliefs and the formation of the RSN.

Hope and my nephrologist

People who have kidney disease need to believe that they have a future and that they're valued. Health care professionals can have a profound impact on providing hope and encouraging their patients. In my case, I remember a time when I was trying hard to overcome yet another medical hurdle during one of my many hospital stays when my doctor said, "Lori, someday you're going to write a book and call it *I Can*." He went on to tell me how important my attitude and strong will were to my recovery. That was perhaps the first time I started to believe I had a future, and it gave me the will to fight the many battles that lay ahead. My nephrologist, Dr. Richard Fine, was a prophet who planted the seed that led to my authoring the book *Chronically Happy: Joyful Living in Spite of Illness*. The lesson? Health care professionals should never underestimate the effect that a few personalized words can have on motivating and inspiring their patients.

Friendship through peers

Friendship has also helped lead me to where I am today. Looking back, I realize that when I was growing up I seldom got the chance to meet people my age who were living with CKD. I desperately wanted to connect, but didn't quite know how. It seemed that most of my friends were adult



Ms. Hartwell is the founder of Renal Support Network, which marks its 20th year of service to kidney patients in 2013.

medical professionals that I saw more frequently than any children my own age. Finally, when I was in my late teens, I was lying in a hospital bed having a routine blood transfusion. In the bed next to mine was a girl named Gloria, who was also being transfused. Like me, Gloria had run the gamut with her illness and, during the next couple of hours, we shared our stories with a quiet understanding, laughter, and tears. I felt connected. Finally, someone understood where I had been and, more importantly, where I was going and the challenges I would face. Gloria shared strategies, wisdom, and a joy for life attitude that helped her navigate her illness. She became my friend and confidante, and I found myself trying to emulate her attitude. She helped me learn how to process my feelings better than any trained therapist. The lesson? It wasn't long before my friendship with Gloria made me realize that one friend can make the difference.

RSN's goals

One of my goals for RSN has always been to help provide patients with a platform from which they could help fellow patients by sharing their experiences, approach to life, strengths, and hope. Examples of how we are living these values can be seen in programs such as RSN's Renal Teen Prom, Kidney Talk radio program, and Live & Give Newsletter, to name a few. Another goal has been to let health care professionals know what a profound impact they can have on their patients when they encourage them to live their lives and plan a future. To work toward this goal, we continually distribute materials to health care professionals through programs such as our annual essay contest and Communication Prescription Video for Health Care Professionals. These programs provide concrete examples of how health care professionals make a difference in the everyday life of their patients.

One final concept that I believe is important for patients and health care professionals to focus on is the need for persistence in trying to improve the lives of individuals with CKD. People who know me know I am not only chronically happy and hopeful—I am also chronically persistent. Trust me when I say that nothing matches the feeling of being able to use your own life experiences to help others. You often hear the phrase that 'giving is better than receiving,' and that is even more true when the gift that you are giving is the hope that improves someone else's life. **NN&I**