

She battles disease with support network

Woman with chronic kidney disease says the key is recognizing your value, even when seriously ill.

By Tania Chatila
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NORTHEAST GLENDALE -- Hoover High School graduate Lori Hartwell's kidneys have failed her, but that doesn't mean her brain has, she said.

"Once you become chronically ill, people feel the need to help you," she said. "The real secret to happiness is understanding you're still valuable."

Hartwell, 39, is trying to show others battling chronic kidney disease just how valuable they can be through an organization she started in 1993, the Renal Support Network.

Last week, she and about 20 others from the Renal Support Network traveled to the nation's capitol to speak with legislators about how to bring more awareness to chronic kidney disease.

"I started this because I wanted to teach other patients how to advocate themselves, how to help other patients," she said. "And I wanted to have a forum for people to meet each other."

They were also there promoting the Kidney Care Quality and Improvement act of 2005, co-authored by Rep. Adam Schiff (D-Glendale) and United States Sen. Barbara Boxer, which would provide for more chronic kidney disease education and

better access to treatment for patients, among other things.

"The two No. 1 causes of kidney disease are high blood pressure and diabetes," she said. "The problem is people won't have any signs or symptoms until their kidneys just don't work anymore. I've had friends that didn't know until they ended up in the emergency room."

More than 20 million people across the country have kidney disease, and more than 400,000 suffer from kidney failure Hartwell said.

Hartwell has had chronic kidney disease since she was 2, has been through three kidney transplants and was on dialysis -- a procedure that draws, cleans and re-inserts the blood of patients with kidney failure -- for 12 years.

Through her group -- which has about 5,000 members, 50 of whom are active nationwide -- the Glendale resident teaches others with chronic kidney disease how to present their experiences before a group, how to contact elected officials and how to speak with those in the healthcare industry about the illness.

"We really try to help patients help other patients," Hartwell said. "It will be more effective if I can teach one patient at a time what I know and then they can go out and affect their community."

Through the Renal Support Network -- which is funded

through grants and donations -- patients afflicted with the disease are not only getting the word out about the illness, but they are also helping other patients become more involved, member Shari Gilford said.

"Lori is kind of cloning herself and reproducing herself in us," said Gilford, of Portland, Ore. "That's really what we're all about. It's about helping other patients to do well and go beyond going to the clinic three times a week and sitting and doing nothing. It helps other patients become knowledgeable about our disease."

The group's newsletter, programs and scheduled events connect patients, she said.

"They are like me," Gilford said. "They care about their lives, they want to live well. They want to live their lives not known as a dialysis patient, but as a human being."

Above all, the group gives patients a voice, Hartwell said.

"An illness is too demanding when you don't have hope," she said.

"Renal Support Network tries to provide hope to other patients, so they have the drive and the desire to find the solutions they need to succeed."