Leigh Anne Tanzberger was eight when she learned she had kidney disease. Twenty-eight years later she is an advocate for better education and treatment alternatives for kidney patients.

Born in Houston but raised in New Orleans, she served as president of the New Orleans Kidney Patients Association. Now a resident of New Territory, Tanzberger is an activist with the WeKAN Kidney Advocacy Network, a grassroots patient advocacy group that ensures chronic kidney disease patients receive quality care.

Tanzberger has also earned the distinction of being the only patient invited to serve on the board of the Texas Renal Coalition. She traveled to Washington in June to rally for H.R.1298/S. 635, the Kidney Care Quality and Improvement Act of 2005. The bill's goals are to minimize financial barriers for home dialysis, educate patients in pre-endstage renal disease to delay onset of kidney failure, increase reimbursement to surgeons to encourage use of fistula implants versus grafts and provide improved training for dialysis technicians.

While in Washington, she and 18 other kidney patients affiliated with WeKAN spoke to congressmen and, with the help of lobbyist Sasha Burns, obtained nine co-sponsors for the bill, with promises of more support. A number of congressmen were more receptive this year because of a growing awareness of the impact that other conditions, like high blood pressure, diabetes and obesity, have on kidney disease.

Dealing with a chronic kidney condition has not been easy. She went into renal failure requiring a kidney transplant has been on three transplant lists, experienced significant scarring from catheters used in the treatment of her condition and battled and been cured of thyroid cancer.

In 1999, a surgical mishap involving her colon knocked her off the transplant list and forced her into hemodialysis treatments, in which an external machine functions as the kidney and cleans the blood. Prior to that, Tanzberger had been undergoing peritoneal dialysis, a daily in-home procedure that uses implants in a patient's abdominal cavity to filter and cleanse the blood, allowing patients to move about freely during treatment instead of being connected to a machine. Now, Tanzberger undergoes three hours of hemodialysis three days a week.
The procedure removes waste, salt and extra water to prevent them from building up in the body. Having grown up with the disease, she follows a strict diet to ensure her levels remain in healthy ranges, but said many diagnosed later in life are set in their ways and have more difficulty maintaining recommended dietary guidelines. That is why education is so important, as are managing such conditions as high blood pressure, diabetes and obesity, said Tanzberger. In addition to working for the passage of House and Senate bills, she and others are educating the public through a program called “Decrease the Increase” sponsored by the Texas Renal Coalition. Next to the phenomenal support she receives from her family, her greatest strength has been her inner resolve to manage her condition. “You just need to deal with what has been dealt. And you fight. You can live a normal life with kidney disease; you have to just change habits,” said Tanzberger.

By the numbers:
9 -- Rank among leading causes of death in the United States.
14,500 -- New end-stage renal disease cases in 1979.
100,359 -- New end-stage renal disease cases in 2002.
42,000 -- Americans on dialysis and with kidney transplants in 1978.
431,000 -- Americans on dialysis and with kidney transplants in 2002.
20 million -- Estimated number of Americans (one in nine) with some stage of chronic kidney disease. Most are unaware of it.
Sources: Centers for Disease Control; WeKan Kidney Advocacy Network