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## Karen Gibson

Working at the La Villa School of the Arts in Jacksonville, Fla., has taught Karen Gibson, 46, something about drama. But it didn't prepare her for the dramatic turn her own life would take one day last June.

"It began with a casual conversation I had after a routine exam at my gynecologist's office," says Gibson. "She asked me if I had any health problems I wanted to discuss. I said, 'not really, but I had noticed recently a hardness or a lump above my belly button on my left side.' It didn't cause me any pain, and it would sort of come and go, so I didn't think much of it."

Her physician ordered a computed tomography (CAT) scan and the results showed that Gibson had renal cell carcinoma (RCC), the most common form of adult [kidney cancer](#) in the United States. She was referred to Mayo Clinic in Jacksonville for surgery to remove the tumor and kidney.

Adding to the swirl of emotions that follow any cancer diagnosis, she learned that RCC remains largely a mystery. The causes of the disease are not well understood, no screening test is available to enhance early detection and treatment options are limited, as are tools for predicting the effectiveness of therapies. Although it strikes about 36,000 Americans each year, it is considered rare.

"The month between my diagnosis and surgery was the worst of my life," says Gibson. "They couldn't tell me the stage of the tumor until after the surgery, and I knew that if it was stage III and it had spread beyond the kidney, my odds of surviving five years were about 10 percent. I thought about my teenaged daughter. I realized I may only have five years, at best, with her."

As it turned out, Gibson had a stage II tumor, which has a much better prognosis. Her surgery, done by urologist [Dr. Michael Wehle](#), went well. With only one kidney, she watches her diet closely and tries to exercise more, but she is enjoying life.

Gibson also feels good about a decision she made during her treatment last year to participate in a research effort at Mayo Clinic that aims to unravel the mystery surrounding RCC. Investigators at both the Rochester and Jacksonville campuses are asking patients with RCC to enroll in a registry that will fuel several long-range studies.

"It was easy to participate, and I thought, if I can help somebody else avoid what I went through, why not," says Gibson.

Alexander Parker, Ph.D., a cancer epidemiologist leading the study at Mayo in Jacksonville, wants to solve the mystery.

"Improving treatment for patients with RCC is very important, but Mayo Clinic is also in the business of finding out why this cancer develops and how we can prevent it," Parker says. "Having people without the disease participate in our registry allows us to compare samples and lifestyle characteristics, to get clues as to why some people develop it and others don't, which then opens up the possibility of developing new and exciting prevention strategies."

Parker and his colleagues are enrolling patients with RCC, as well as a comparison group of patients who do not have the disease. From each participant they are collecting biological samples, clinical data and detailed information on lifestyle habits using a take-home questionnaire. Follow-up surveys are then done each year to update patient status.

"If in 10 years, we're still referring to RCC as 'a mystery' it would be a real tragedy," says Parker. "That's what we're trying to change with our registry effort. The valuable data and specimens we are collecting will ultimately help us examine important questions across the entire spectrum of this disease."



Launched in Jacksonville in 2004, the registry includes more than 150 RCC patients and 25 unaffected "controls." The goal is to enroll 500 in each group by 2009. Combined with the efforts in Rochester, this registry will be one of the largest RCC research databases in the country. For more information, call 904-953-8401.