Under the care of GHS specialists, Carrie Smetana enjoys motherhood, music and other pursuits in spite of a congenital heart defect.

Each year, 40,000 babies in the U.S. are born with a congenital heart defect. Clemson resident Carrie Smetana, now 29, was among those infants: Physicians diagnosed her with aortic valve stenosis when she was only a few months old.

“I’m fortunate because my condition is less complex than what some kids – and their parents – deal with,” Smetana said. “The valve is narrowed and doesn’t open or close all the way. My heart has to work harder to pump blood. But I’ve never had surgery for it or had to treat it.”

Smetana was under the care of a pediatric cardiologist in Charleston for most of her life. Then 10 years ago, she transferred her care to R. Austin Raunikar, MD, a pediatric cardiologist with Children’s Hospital of Greenville Hospital System (GHS).

The majority of babies with congenital heart disease are surviving well into their adult years – an estimated 7,000 in South Carolina alone.

Heartfelt Care for Adults
Although it might seem odd for an adult to be under a pediatrician’s care, the situation isn’t unusual for patients with congenital problems, especially when heart care is concerned. “Adult cardiologists primarily work with adult-onset problems such as coronary disease rather than congenital problems,” explained Benjamin Horne, MD, medical director of Pediatric and Congenital Cardiology at GHS. “They’re very well trained, but transitioning a patient with congenital problems to an adult cardiologist isn’t always the best option.”

“It seems like there’s a different approach, depending on whether the patient is diagnosed as an adult or as a child,” Smetana said. “When an adult is diagnosed with a valve problem, the cardiologist handles it by fixing things based on the patient’s age and lifestyle. But when you’re dealing with a congenital problem, the goal usually is to do as little as possible to test the longevity of the valve.”

Fitting the Program to the Need

Although Smetana continued seeing Dr. Raunikar as she moved from her teen years into adulthood, that’s not always the case. “Lots of patients with congenital heart disease aren’t seeing a physician because they think previous surgeries cured the problem,” noted Dr. Horne. “In reality, they need lifelong follow-up to watch for residual effects of the disease or to pick up on new things they haven’t noticed themselves.”

To encourage that type of care, GHS developed the Adult Congenital Heart Disease (ACHD) clinic. The clinic opened in 2011 with the goal of helping patients transition from pediatric to adult care, so they get the attention they need.

“Many patients stop coming for follow-ups during their teen or college years,” said Manisha Patel, MD, director of the clinic. “They lose insurance coverage or are concerned about long-term complications from congenital heart disease.”

She continued, “With the clinic, we want to educate patients on their heart defects and long-term expectations. We want to anticipate and prevent medical problems and help them live long, fulfilling lives.”

As patients with congenital heart problems reach adulthood, they’re at higher risk for arrhythmias, heart failure, pulmonary hypertension, liver failure, residual cardiac defects and other problems. The ACHD clinic gives patients access to the full range of necessary cardiac tests such as CT (computed tomography) and MRI (magnetic resonance imaging), Holter monitoring, exercise stress testing and echocardiography.

Patients in the clinic also can easily connect with GHS physician specialists or other healthcare professionals who can get involved with the patient’s care as needed.

“The adult cardiologists are on board with the plan,” Dr. Horne said. “They have a good knowledge base and can refer patients to the clinic. We’re fortunate that we also have them to help with cardiac problems the patients might have in other realms.”

Smetana says she didn’t mind continuing her care through Dr. Raunikar’s office because they had built a sound doctor/patient relationship and she liked the lighter atmosphere of a pediatrician’s office. Not all patients in their 20s feel that way, however.

“We wanted the clinic to have an age-appropriate setting that seemed more appropriate for adults,” Dr. Horne explained. “I think we’ve achieved that.”

Doctor Eases Adjustment

Even with the more adult atmosphere and the targeted care, switching to a new care group still can be challenging.
“I was very happy seeing Dr. Raunikar and Dr. Horne,” Smetana commented. “They’re both very competent, and I trust them. But when Dr. Patel came on board and the ACHD clinic opened, I realized I needed to go there.”

Smetana’s transition to Dr. Patel’s care under the ACHD clinic was natural because she was pregnant with her second child. Dr. Patel was able to provide the special management Smetana needed during pregnancy. They discovered that baby Ellie also has an aortic valve defect; it hasn’t caused problems yet.

“Under other circumstances, we might not even know that she has an issue,” Smetana said. “Dr. Patel saw it because she was watching things so closely. Now we know to keep a check on things as Ellie grows.”

Smetana enjoys still seeing Dr. Raunikar for Ellie’s care, though her own relationship with Dr. Patel is developing.

“When I first met Dr. Patel, she knew my file but didn’t know me,” Smetana said. “It was hard to start over. But I’ve had fabulous care, and I like Dr. Patel more with every appointment.”

Stories such as Smetana’s have helped spread word about the ACHD clinic.

“Many ACHD patients in our region need specialized care,” Dr. Patel observed. “This is the only clinic in the Upstate specifically tailored to meet their needs. By improving access to care, we hope to save lives.”

“Until the clinic opened, there really wasn’t a good place to transition care,” Dr. Horne added. “There wasn’t anything nearby, though it was clear that the trends showed a program like this would be necessary. We’re ahead of the curve and are pleased that our patients are receiving the best possible care.”

If you or an adult you know has a congenital heart defect, make an appointment at the ACHD clinic by calling (864) 454-5120.