

Adult Congenital Heart Disease Program unique in the region

UCH PROGRAM HANDLES RESCULPTED HEARTS *By Todd Neff*

It didn't take a cardiologist to see something was amiss with the heart displayed on Dr. Robert Quaife's computer screen. Quaife, UCH's director of Cardiac Imaging, had pulled up a 3-D rendering of a 72-year-old ticker whose valves had been repaired and arteries restrung to the point that the Valentine's Day ideal had been long-since muddled.

The patient's heart showed the evidence of congenital heart disease. Such defects affect eight in 1,000 newborns in the United States every year. Many children born with profound heart defects survive – the Adult Congenital Heart Association says they

number 1.8 million nationwide.

However, the association also says such patients – particularly those whose surgeries corrected severe defects – need vigilant medical attention as they age.

UCH's Adult Congenital Heart Disease Program provides such attention to about 950 patients in Colorado and beyond, from the Dakotas to Montana, Nebraska and Kansas. It's the only such program in the region, and it has grown from around 120 patients in 2003, thanks to growing numbers of referrals, heightened awareness of UCH's skills in treating adults born with heart defects, and increasing numbers of survivors.

Difficult cases. "This is a living memorial to medical advancement," Quaife said, pointing out the elderly patient's pacemaker and scar tissue. "The challenge is not only figuring out what the original problem was, but also how it was corrected, and the corrections are very often the artwork of some surgeon."

A combination of patients living longer, increases in referrals and a growing reputation in the field have helped increase the number of patients seen by UCH's Adult Congenital Heart Disease Program.



Kathryn Richardson, family nurse practitioner for UCH's Adult Congenital Heart Defect Program.

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He proceeded to pull up image after image – two-dimensional, three-dimensional, it didn't matter – of hearts with one rather than two ventricles, with wildly distended aortas, with piping seemingly re-routed by a mischievous plumber.

Behind him stood Kathryn Richardson, FNP, nurse practitioner for UCH's Adult Congenital Heart Disease program. More and more often, Richardson said, the beneficiaries of yesterday's medical miracles require the attention of today's best cardiologists.

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Diverse treatments. Quaife said the majority of treatments for congenital heart disease involve fixing abnormal communications and/or redirecting blood flow. In some cases, Joseph Kay, MD, director of the program, intervenes in the catheterization laboratory; in others, an electrophysiologist implants pacemakers or performs catheter ablation.

The team can face delicate situations. Not infrequently, they must tell patients who believed their hearts had been fixed that they will need surgery within the next five years.

“They're totally shocked,” Richardson said.

Young survivors become adult patients. Demand for the program's services has grown since Kay's arrival at UCH in 2004, a year after it launched. Kay, who has board certifications in both pediatric and adult cardiology, in addition to pediatrics and internal medicine, treats patients whose hearts often layer nagging adult problems – arteriosclerosis, coronary blockages, high cholesterol – atop years-old repairs of far more difficult medical issues such as atrial and ventricle septal defects, tetralogies of Fallot (a combination of four distinct heart defects) and pulmonary valve stenosis, or narrowing.

“The patients are very unique in that they have had serious medical conditions since birth,” Kay said. “They have interesting complications that we are just now learning more about, and we definitely need to be in tune with other potential medical issues not previously described for these conditions.”

In addition to seeing patients in twice-weekly clinics, program nurses Richardson and Mary Brandon, RN, stay busy fielding calls and checking in with patients. Many also contact Kay directly.

“He’s the only doctor I know who hands his pager number out to all his patients,” Richardson said.

The program serves everyone from teenagers to seniors to pregnant women (child-bearing can be hard on the heart). Last year, Richardson and Kay ran the Boulder Boulder 10-kilometer road race with a dozen patients.

“What I love about this job is the variety of patients,” Richardson said. “They can be 16 years old or 72 years old, running marathons or awaiting transplants.”